



The Relationship between Marital Communication, Distress, and Intimacy for Spouses of Prostate Cancer Patients

Þóra Kristín Flygenring

2013

BSc in Psychology

Author name: Þóra Kristín Flygenring

Author ID number: 200290-2089

Department of Psychology
School of Business

Abstract

Objective: Cancer diagnosis can result in high levels of distress among spouses of cancer patients but little is known about factors that might contribute to this distress. The present study used Manne and Badr's (2008) relationship intimacy model to examine risk factors of distress among spouses of prostate cancer patients. The model suggests that marital communication affects marital intimacy, which can then determine both the patients' and the partners' psychological adaption to cancer. Only one study has used this model to examine distress in couples dealing with prostate cancer. The aim of the study was to examine whether this model can explain the variance in distress levels among spouses of prostate cancer patients in Iceland. *Method:* A questionnaire was sent to Icelandic spouses of prostate cancer patients (N=41). The relationship between intimacy, communication and distress was then examined with regression analyses. *Results:* Regression models showed that: (1) communication was positively related to intimacy and negatively related to distress levels, (2) intimacy was negatively related to distress levels, and (3) the relationship between communication and distress was mediated by intimacy. *Conclusion:* These results suggest that future interventions aimed at reducing distress among spouses of cancer patients should focus on enhancing marital intimacy and constructive communication among couples.

Útdráttur

Markmið: Krabbameinsgreining getur leitt til mikillar streitu hjá mökum sjúklinga en lítið er vitað um þættina sem stuðla að þessari streitu. Þessi rannsókn notaði sambands-nándarlíkan Manne and Badr (2008) til að kanna áhættuþætti streitu meðal maka sjúklinga með blöðruhálskirtilskrabbamein. Líkanið gefur til kynna að samskipti hafa áhrif á nánd sem ræður síðan hversu mikil sálræn áhrif greiningin hefur á sjúklingana og maka þeirra. Aðeins ein rannsókn hefur beitt þessu líkani til að skoða streitu hjá körlum með blöðruhálskirtilskrabbamein og mökum þeirra. Markmið rannsóknarinnar var að kanna hvort líkanið geti útskýrt dreifinguna í streitu meðal maka blöðruhálskirtilskrabbameinssjúklinga á Íslandi. *Aðferð:* Spurningalisti var sendur til heimila íslenskra maka blöðruhálskirtilskrabbameinssjúklinga (N=41). Sambandið milli nándar, samskipta og streitu var síðan kannað með aðhvarfsgreiningu. *Niðurstöður:* Aðhvarfsgreining leiddi í ljós að: (1) samskipti höfðu jákvæð tengsl við nánd og neikvæð tengsl við streitu, (2) nánd hafði neikvæð tengsl við streitu og (3) sambandið milli samskipta og streitu var komið til (*mediated*) vegna nándar. *Ályktarnir:* Þessar niðurstöður gefa til kynna að meðferðir sem hafa það að markmiði að draga úr streitu maka krabbameinssjúklinga ættu að einblína á að auka nánd og samskipti milli maka og sjúklings.

Foreword

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.

The Relationship between Marital Communication, Distress, and Intimacy
for Spouses of Prostate Cancer Patients

It is well established that being diagnosed with any type of cancer can be a major life stressor leading to high levels of distress (Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2010; Carmack Taylor et al., 2008; Verdonck-de Leeuw et al., 2007). Prostate cancer diagnosis, which is most common type of cancer diagnosis among men in Iceland and other western countries (Hsing, Tsao, & Devesa, 2000; Resendes & McCorkle, 2006; Krabbameinsfélagið Framför, 2011), entails some unique stressors. They include, for example, incontinence and impotence (Resendes & McCorkle, 2006), which can affect the well-being of both the patient and his spouse.

Extensive research has been devoted to examining the well-being of prostate cancer patients, which shows that over 20% experience some psychological distress (Balderson & Towell, 2003; Sharpley, Bitsika, & Christie, 2010). Additionally, increasing evidence suggests that the patients' spouses are greatly affected by the cancer diagnosis. The spouses of prostate cancer patients have similar or even higher levels of general distress than their husbands, and they report more cancer-specific distress than their husbands (Eton, Lepore, & Helgeson, 2005; Kornblith, Herr, Ofman, Scher, & Holland, 1994; Couper, Bloch, Love, Macvean, et al., 2006; Resendes & McCorkle, 2006). The distress can arise at any time after the husband's diagnosis and can last until well after treatment has been concluded (Resendes & McCorkle, 2006). A study by Couper, Bloch, Love, Duchesne, et al. (2006) indicated that around 15% of prostate cancer spouses had major depression and just less than 7% had generalized anxiety disorder. The corresponding numbers for the patients are much smaller and community prevalence is twice as small. Another study showed that 22% of spouses of prostate cancer patients had clinically relevant distress scores (Street et al., 2010), whereas up to 50% of spouses in Cliff and Macdonagh's (2000) study were anxious or depressed

(compared to 20% of the patients). Spousal caregivers of cancer patients are also at an increased risk for stroke and coronary heart disease (Ji, Zöller, Sundquist, & Sundquist, 2012), but stress in close relationships has been recognized as a risk factor for these health problems (Sarafino, 2011).

The above studies show that spouses of prostate cancer patients report high levels of distress but there is a great variability with some spouses faring worse than others (Cliff & Macdonagh, 2000). However, little is known what predicts this variability in distress among spouses. One potential model that can explain this variability is the relationship intimacy model. In 2008, Manne and Badr constructed this model which proposes that couples' communication can either promote or undermine the closeness or intimacy of the relationship, which, in turn, can determine both the patient's and the partner's psychological adaption to illness. This model proposes that intimacy is the primary force that drives communication to have its effect on psychological adaption (Manne & Badr, 2008). As described below, independent line of research suggests that the three factors (i.e., intimacy, communication, distress) in the model might indeed be linked.

First, recent literature has demonstrated a link between marital communication and distress, as well as marital communication and intimacy among couples dealing with prostate cancer. Prostate cancer patients and their wives talk very little with one another about their emotions, worries and fears regarding the cancer (Boehmer & Clark, 2001; Zakowski et al., 2003). This is a major concern since marital communication has been shown to be related to distress. A study on prostate cancer patients and their spouses by Manne, Badr, Zaider, Nelson and Kissane (2010) showed for example that couples who reported high levels of mutual constructive communication regarding cancer-related concerns were more likely to report lower levels of distress. Marital communication was also related to having greater levels of marital intimacy.

Second, research has also found a link between intimacy and distress. Studies have shown that marital intimacy can be greatly affected by cancer. Around 59% of female carers and 79% of male carers felt that the intimacy of the relationship and the frequency of sex had decreased or stopped after their partner was diagnosed with cancer (Hawkins et al., 2009). In the case of prostate cancer patients, this can be partially explained by erectile dysfunction (Zaider, Manne, Nelson, Mulhall, & Kissane, 2012). In Manne et al.'s study (2010), more marital intimacy was associated with less distress, even after controlling for marital communication.

Manne et al. (2011) also showed that an intimacy enhancing intervention can lower patients' and their spouses' cancer concerns and distress among those who had high levels of distress prior to the intervention. Thus, by fostering marital intimacy, both partners' distress levels can be decreased.

The above studies have collectively shown that communication and intimacy can independently influence distress levels. But how do these factors interrelate? The interaction between these variables has only been established fairly recently in prostate cancer studies. Currently only one study has explored the interplay between all three factors for this group (Manne, Badr, Zaider, Nelson, & Kissane, 2010). This study demonstrated that intimacy mediated the association between distress and mutual constructive communication, patient demand-partner withdraw communication, and mutual avoidance, for both the patient and his spouse.

Since currently only one study has been conducted on this subject, there is a need to replicate the findings. The aim of the study was, therefore, to extend on the model put forth by Manne and Badr (2008) by examining whether marital intimacy and communication are related to distress among spouses of prostate cancer patients in Iceland.

It is hypothesised that, in accordance with Manne and Badr's model, marital communication will have an effect on marital intimacy, which in turn will have an effect on psychological distress in spouses. Better communication will, therefore, lead to more intimacy, which will in turn lower distress levels. It is also hypothesised that marital communication has a direct effect on distress and intimacy, but that the relationship between communication and distress will, like in Manne et al.'s (2010) study, become non-significant after controlling for intimacy levels. In other words, the relationship is mediated by intimacy. Thus, marital communication only has an effect on distress by enhancing marital intimacy.

Method

Participants

The sample used in the current study was comprised of Icelandic women whose husbands had been diagnosed with prostate cancer. The current study is part of a larger longitudinal study, where some prostate cancer patients exercise expressive writing while others serve as controls. The men's wives were contacted later during the course of the study.

To be eligible for the study, the women had to be married to a prostate cancer patient, who was or had participated in the longitudinal study; and they had to be able to read and understand Icelandic. The women were recruited through their husbands.

The wife sample consisted of 42 women. Response rate was 84%, since 50 married men participated in the study. Participating in the study was completely optional and participants were informed via their consent form that they could drop out of the study anytime they wanted. Participants did not receive any payment for participating in the study.

Measures

The women completed a questionnaire which consisted of over 200 questions and took about an hour to complete. The questionnaire covered issues such as well-being, quality of life, social support, emotional expressiveness and marital satisfaction. The participants'

demographic data was also gathered, including age, residence, employment situation, and education level. The current study will however only focus on the three following variables: communication, intimacy and distress. The questions used are available in appendix 1.

This is a cross-correlation study with the use of a single administration of a questionnaire. To test the hypotheses, two predictor variables (communication and intimacy) and one outcome variable (distress) were examined.

Communication. Communication was assessed with 3 questions, taken from the Positive Feeling Questionnaire (PFQ), which was developed by O’Leary, Fincham, and Turkewitz (1983). Participants were asked how often they talked to their partner about pleasant and unpleasant issues that happen throughout their day and how often they talk about issues that they and their partner disagree on or that they think are generally difficult to talk about. Participants were asked to rate the frequency of their communication over the last month on a five point Likert scale (ranging from “very often” to “never”). The answers were then re-coded so that a higher score indicated more communication. The communication scale had high internal consistency, with $\alpha = 0.815$.

Intimacy. The questions regarding intimacy from Sternberg’s Triangular Love Scale (1988) were used to measure global relationship intimacy or affection. This scale consisted of 15 questions on e.g. how warm their relationship is and how much they can depend on their partner. Participants were asked to rate how accurately certain statements described their marital relationship. Answers were given on a five point Likert scale, ranging from “very accurate” to “very inaccurate”. The answers were re-coded so that a higher score meant greater intimacy. The intimacy scale had excellent internal consistency with $\alpha = 0.923$.

Distress. Both general and cancer-specific distress was assessed. General psychological distress (i.e. feeling anxious or depressed) was assessed with the Hospital Anxiety and Depression Scale (HADS), developed by Zigmond and Snaith (1983). This scale

includes 14 questions assessing depression and anxiety symptoms, like not enjoying things they used to enjoy, having panic attacks, or being on edge. Half of the questions measured depression symptoms and the other half measured anxiety symptoms. Scores range from zero to 21 for anxiety and depression, respectively. In the current study, anxiety and depression scores were analysed together as a general distress measure. Participants were asked to rate on a four point scale (ranging from zero to three) how much the 14 statements represented their feelings during the last week. A higher score on HADS means greater distress.

According to Snaith (2003), a depression or anxiety score between zero and seven can be considered normal, whereas a score between eight to 10 suggests that the person could be clinically depressed or anxious. A score of 11 or higher indicates that the person is most likely dealing with a clinical anxiety or a depression disorder. The cut-off score for probable depression or anxiety is therefore set at eight.

The entire HAD scale had very good internal consistency with $\alpha = 0.879$, and anxiety and depression had alpha scores of 0,821 and 0,794 respectively.

Cancer specific distress was assessed with the revised version of the Impact of Event Scale (IES-R), developed by Horowitz, Wilner, and Alvarez (1979). This scale includes 22 questions; 8 measured avoidance (e.g. trying not to think about the cancer), 7 measured hyper arousal (e.g. difficulties in falling asleep), and 7 measured intrusion (e.g. everything reminds them of the cancer). All three factors were analysed together to form one cancer-specific distress measure. Participants were asked to rate on a five point scale (ranging from zero to four) how often the statements represented their feelings on prostate cancer since their husband had been diagnosed. Answers ranged from “never” to “very often”. A higher score suggests more distress. There is no fixed cut-off score for this scale (Christianson & Marren, 2012), although some researchers have made their own cut-off scores to identify participants with symptoms in the clinical range. Creamer, Bell and Failla (2003) recommended using a

rather conservative full scale cut-off score of 33 points, whereas according to Asukai et al. (2002), a score of 24 or 25 is sensitive enough.

The IES-R had excellent internal consistency in the current study, with $\alpha = 0.943$ for the full scale. The avoidance scale had an alpha level of 0.876, and the hyper arousal and intrusion scales had alpha levels of 0.814 and 0.850 respectively.

Procedure

The current study had a cross-correlation survey design, as it consisted of a single questionnaire which was only administered once.

In early November of 2012, two packages were mailed to prostate cancer patients who were in a relationship and were already participating in the longitudinal study. The men were asked to give their spouses the package that was meant for them. This package contained questionnaires, a pre-stamped return envelope, an introduction letter describing the study (see appendix 2), and an informed consent form (see appendix 3). Interested women were asked to sign the consent form, complete the questionnaires and return them to the researchers in the pre-stamped envelope as soon as they had filled them out.

Around two weeks later, patients whose wives had not mailed back their questionnaires were called to inquire if they had given their wives the information and asked if they had any questions regarding the study.

A research application was sent to the institutional ethics committee, as is customary for all research, and was approved. The questionnaires and the consent forms were kept in separate locked cabinets at Reykjavík University. The study's researchers and supervisor were the only individuals who had access to the information, which will be destroyed in a timely manner.

All participants had to sign an informed consent form prior to participating, where they were told that they could drop out of the study whenever they wanted. As some of the

more personal questions could be distressing to the participants, they were also provided with a telephone number that they were encouraged to call if they became anxious or distressed when answering the questionnaires, or if they had any questions in general.

Data analysis

Descriptive statistics were conducted to gather information on certain characteristics like the variance in age and education. The data was also examined for any confounding variables for distress (e.g. age, education level, residence, employment, time since husband was diagnosed, etc.).

The data was also scanned for missing values, and as a result one participant was excluded from the analysis. Participants who answered 90% of the questions or higher were included and their missing values were replaced with the mean score of each scale.

The four steps to establishing mediation by Baron and Kenny (1986) were used to see whether intimacy mediated the association between communication and distress. According to Baron and Kenny, mediation occurs when (1) the causal variable is significantly related to the outcome variable (2) as well as the mediator variable, and (3) when the mediator variable is associated with the outcome variable. Finally, for a complete mediation to occur, (4) the effect of the causal variable on the outcome variable must become non-significant when the mediator variable is put into the model. Therefore, three regression analyses were performed to examine the relationship between communication and distress, communication and intimacy, and intimacy and distress. A fourth regression analysis was conducted to see whether or not intimacy mediated the association between communication and distress and to examine how much intimacy and communication can explain the variance in distress levels. These regression analyses were done for both of the distress measures, i.e. general and cancer-specific distress.

The data was analysed with a software package called SPSS, version 19.0. Results were accepted as significant if the p-value was equal to or less than 0.05.

Results

Descriptive statistics

The demographic characteristics are shown in Table 1. The participants' age ranged from 42 years to 84 years, with a mean age of 64.69 years ($SD = 9.18$). Most of the women were over 50 years old (93.7%). Over half of the sample was unemployed and a majority (73.2%) was living in Reykjavík or surrounding areas. One in four women had completed a college education and 39% had only finished compulsory education.

To examine potential covariates the relationship between the demographic characteristics and the outcome variables (two types of distress) was examined but none were found to be significant.

Since HADS has a cut-off score for "caseness", the data was examined to see whether any of the women would be considered clinically depressed or anxious. One woman had a depression score of nine so she could be classified as being clinically depressed. Three women were considered clinically anxious; they had a score of eight, 10 and 13, respectively. Five women just missed the cut-off score (three for depression and two for anxiety), since they had a score of seven instead of eight.

By using a cut-off score of 25 on the IES-R, seven women were classified as having cancer-specific distress. A more conservative cut-off score of 33 points revealed that three women had cancer-specific distress.

Table 1

Characteristics of the participants

		N (%)
Age	50 years or younger	2 (6.3%)
	51-60	8 (25%)
	61-70	12 (37.5%)
	71-80	9 (28.1%)
	81 years or older	1 (3.1%)
	Missing	9
Employment	On the employment market	16 (39%)
	Retired/other	25 (61%)
Residence	Reykjavik or surrounding areas	30 (73.2%)
	Rural areas	4 (9.8%)
	Village/town outside	7 (17.1%)
	Reykjavik's surrounding areas	
Education	Compulsory education	16 (39%)
	Secondary education or	13 (31.7%)
	vocational training	
	Vocational training following	2 (4.9%)
	secondary education	
	College	10 (24.4%)

Communication

To test whether communication was independently associated with intimacy and general distress levels, two regression analyses were done where distress and intimacy were respectively entered as the dependent variables.

The results indicated that communication had a positive relationship with intimacy ($\beta = 0.601$; $t(40) = 4.696$, $p < 0.01$) and it was negatively related to general distress levels ($\beta = -0.551$; $t(40) = -4.127$, $p < 0.01$). Greater amount of communication was therefore associated with higher levels of intimacy and lower distress levels (see figure 1). Cancer-specific distress yielded the same results, where greater amount of communication was associated with lower cancer-specific distress ($\beta = -0.336$; $t(40) = -2.228$, $p < 0.05$).

Communication explained about 30.4% of the variance in general distress levels ($F(1,39) = 17.028$, $p < 0.01$) and 11.3% in cancer-specific distress ($F(1,39) = 4.963$, $p < 0.05$). It also explained around 36.1% of the variance in intimacy levels ($F(1,39) = 22.055$, $p < 0.01$; see table 2).

Intimacy

To test whether intimacy was independently associated with distress levels, another regression analysis was conducted. Intimacy was negatively associated with general distress levels ($\beta = -0.612$; $t(40) = -4.835$, $p < 0.01$; see figure 1) and cancer-specific distress levels ($\beta = -0.442$; $t(40) = -3.076$, $p < 0.01$), where higher levels of intimacy were related to lower distress levels. Intimacy explained 37.5% of the variance in the women's general distress levels ($F(1,39) = 23.378$, $p < 0.01$) and 19.5% of cancer-specific distress levels ($F(1,39) = 9.462$, $p < 0.01$; see table 2).

Communication, intimacy and distress

To see how much intimacy and communication explained the variance in distress scores, and whether or not intimacy mediated the association between communication and

distress, a hierarchical regression analysis was conducted. Results indicated that communication and intimacy explained around 42.7% of the variance in the women's general distress scores ($F(2,38) = 14.182, p < 0.01$) and around 20.3% of the variance in their cancer-specific distress ($F(2,38) = 4.840, p < 0.05$; see table 2). The relationship between communication and general distress was no longer significant ($\beta = -0.287; t(40) = -1.869, p > 0.05$), as indicated by the broken line in figure 1, when intimacy was entered into the regression model. This suggests that the relationship between communication and distress is mediated by intimacy. The same results were found for cancer-specific distress ($\beta = -0.110; t(40) = -0.609, p > 0.05$).

Table 2: *The coefficient of determination (R^2) for various relationships between communication, intimacy and distress*

	Percentage ($R^2 \cdot 100$)
Communication → distress (general)	30.4%
Communication → distress (cancer-specific)	11,3%
Communication → intimacy	36.1%
Intimacy → distress (general)	37.5%
Intimacy → distress (cancer-specific)	19,5%
Communication + intimacy → distress (general)	42.7%
Communication + intimacy → distress (cancer specific)	20.3%

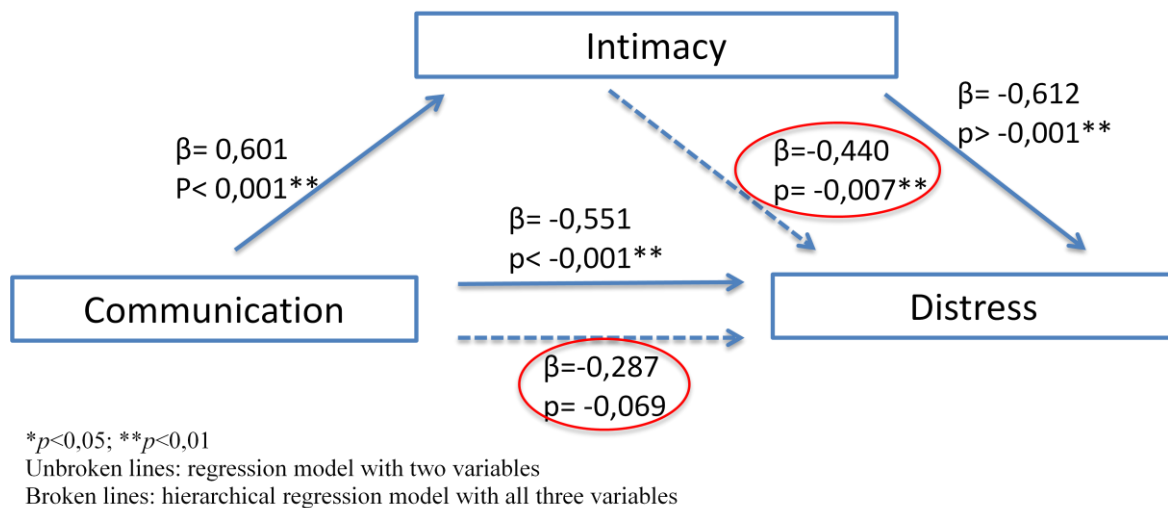


Figure 1: The relationship between marital communication, marital intimacy and general distress for spouses of prostate cancer patients

Discussion

The current study was conducted to examine the relationship between communication, intimacy and distress among spouses of prostate cancer patients. The results indicated that communication and intimacy were negatively related to women's distress levels. These results are in accordance with Manne et al.'s (2010) findings, who found that mutual constructive communication regarding cancer-related concerns and global relationship intimacy were each negatively associated with distress.

It seems that intimacy is the primary force that influences women's adaption to their husbands' prostate cancer because when controlling for intimacy, communication in itself was neither related to general distress levels, nor cancer-specific distress. This suggests that intimacy mediated the association between communication and distress. This is also consistent with Manne et al.'s (2010) study, where the effect of mutual constructive communication on distress was mediated by intimacy levels.

The intimacy mediation in the current study fulfilled the four required steps of mediation put forth by Baron and Kenny (1986). This mediation indicates that women who

talked to their husbands about positive and negative issues and issues that are generally difficult to talk about were less distressed than the women who talked less to their husbands. However, this relationship can be explained by higher levels of intimacy.

The current study's results collectively support Manne and Badr's (2008) relationship intimacy model, which declares that marital communication has an effect on marital intimacy, which then influences psychological distress. The results were also all consistent with the study's hypotheses.

When looking at how many women reached the cut-off score on HADS and IES-R, it was found that around 10% of the women could be classified as being depressed or anxious, and 7-17% had cancer-specific distress (depending on whether the cut-off score is put at 25 or 33 points). This percentage is smaller than what has been reported in the literature (e.g. Street et al., 2010; Cliff & Macdonagh, 2000). For example, Street found that 22% of spouses had relevant distress scores and Cliff and Macdonagh (2000) found that almost half of the spouses in their study were anxious or depressed. A possible explanation for this is that Iceland has a small, tight-knit community so relatives and old friends of the participants may be more likely to live a short distance away from them. They might therefore receive a larger amount of support than is possible in countries where the extended family and friends live further apart.

Previous studies have collectively shown that wives of prostate cancer patients are similarly or more distressed than their husbands (e.g. Eton, Lepore, & Helgeson, 2005) and these results were also observed in the current study. Women were significantly more anxious ($M = 3.122$, $SD = 2.92$) than men ($M = 1.60$, $SD = 1.88$; $t(79) = -2.784$, $p < 0.01$) and they also had more intrusive thoughts ($M = 4.84$, $SD = 3.62$) than the men ($M = 3.15$, $SD = 3.56$; $t(79) = -2.122$, $p < 0.05$). There was, however, no difference in depression scores, avoidance or hyper arousal (data not shown).

This study has several strengths. It focused on spouses of prostate cancer patients, but in only a fraction of this research literature the focus is either on both partners or only on the spouse. The research examining the well-being of spouses of men with prostate cancer is severely lacking, even though they have been shown to be similarly or even more distressed than the patients. Since these women are at a high risk for a diminished quality of life (for example in regards to erectile dysfunction; which affects both partners), examining their well-being to find ways to decrease their distress is very important. The current study is also the only study that the author is aware of, besides Manne et al.'s study (2010), that has examined the relationship between intimacy, communication and distress with the spouses of prostate cancer patients. This research topic has only recently been examined for this group, so more studies are needed to establish this relationship.

There were some limitations to the study. Since it was a cross-correlation study, it inhibits us from drawing causal conclusions from the results. Future studies could therefore use a longitudinal design to confirm the relationship found in the current study. The sample that was used in the study was also quite small (in the end it consisted of 41 women), which may have influenced the results. It is also important to note that the questions used to measure the communication and intimacy variables in the current study were different from the questions in previous studies (e.g. Manne et al. (2010) had six different communication variables focusing on cancer-related concerns). The current study only looked at general communication, i.e. not on cancer-specific communication. It also didn't focus on negative versus positive communication styles which might have been important variables in the relationship between the three factors. Future studies might therefore look at more sub-variables of communication.

Despite the fact that both prostate cancer patients and their spouses are vulnerable to developing high levels of distress, and that intimacy and communication is linked to distress,

there are still very few couple-focused interventions used today that focus on enhancing these factors. These kinds of couple-focused interventions have been proven to be successful for both prostate cancer patients and their wives (Manne et al., 2011). The current study has highlighted the importance of involving both the patients and their spouses in psychological care and the need to establish good communication among couples and enhance their intimacy.

According to Malcarne et al. (2002), focusing interventions on the spouses of prostate cancer patients might even be more effective than focusing on the patients, since women are more likely than their husbands to express their emotions and seek help, and are less likely to resist psychotherapy. They suggest that providing the spouses with interventions to decrease their distress may ultimately also benefit the patients since there is a positive relationship between distress levels in husbands and distress levels in wives.

It becomes clear from the results of the current study that marital intimacy is a protective factor against distress. To be able to increase the availability of couple and/or spouse based therapies that focus on increasing intimacy and communication, we need to establish a need for them. This can be done by expanding this literature and conducting prospective, longitudinal studies with intimacy and communication enhancing interventions.

References

- Asukai, N., Kato, H., Kawamura, N., Kim, Y., Yamamoto, K., Kishimoto, J., et al. (2002). Reliability and validity of the Japanese-language version of the impact of event scale-revised (IES-R-J): four studies of different traumatic events. *Journal of Nervous and Mental Disease*, 190(3), 175–182.
- Balderson, N., & Towell, T. (2003). The prevalence and predictors of psychological distress in men with prostate cancer who are seeking support. *British Journal of Health Psychology*, 8(2), 125.
- Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51(6), 1173–1182.
- Boehmer, U., & Clark, J. A. (2001). Communication about prostate cancer between men and their wives. *The Journal of Family Practice*, 50(3), 226–231.
- Carmack Taylor, C. L., Badr, H., Lee, J. H., Fossella, F., Pisters, K., Gritz, E. R., & Schover, L. (2008). Lung cancer patients and their spouses: Psychological and relationship functioning within 1 month of treatment initiation. *Annals of Behavioral Medicine*, 36(2), 129–140. doi:10.1007/s12160-008-9062-7
- Christianson, S., & Marren, J. (2012). The impact of event scale - revised (IES-R). *Medsurg Nursing: Official Journal of the Academy of Medical-Surgical Nurses*, 21(5), 321–322.
- Cliff, A. M., & Macdonagh, R. P. (2000). Psychosocial morbidity in prostate cancer: II. A comparison of patients and partners. *BJU International*, 86(7), 834–839. doi:10.1046/j.1464-410x.2000.00914.x

Couper, J., Bloch, S., Love, A., Macvean, M., Duchesne, G. M., & Kissane, D. (2006).

Psychosocial adjustment of female partners of men with prostate cancer: A review of the literature. *Psycho-Oncology*, 15(11), 937–953. doi:10.1002/pon.1031

Couper, J. W., Bloch, S., Love, A., Duchesne, G., Macvean, M., & Kissane, D. W. (2006).

The psychosocial impact of prostate cancer on patients and their partners. *The Medical Journal of Australia*, 185(8), 428–432.

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

doi:10.1016/j.brat.2003.07.010

Eton, D. T., Lepore, S. J., & Helgeson, V. S. (2005). Psychological distress in spouses of men treated for early-stage prostate carcinoma. *Cancer*, 103(11), 2412–2418.

doi:10.1002/cncr.21092

Hasson-Ohayon, I., Goldzweig, G., Braun, M., & Galinsky, D. (2010). Women with advanced breast cancer and their spouses: Diversity of support and psychological distress.

Psycho-Oncology, 19(11), 1195–1204. doi:10.1002/pon.1678

Hawkins, Y., Ussher, J., Gilbert, E., Perz, J., Sandoval, M., & Sundquist, K. (2009). Changes in sexuality and intimacy after the diagnosis and treatment of cancer. *Cancer Nursing*,

32(4), 271–280. doi:10.1097/NCC.0b013e31819b5a93

Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of event scale: a measure of subjective stress. *Psychosomatic Medicine*, 41(3), 209–218.

Hsing, A. W., Tsao, L., & Devesa, S. S. (2000). International trends and patterns of prostate cancer incidence and mortality. *International Journal of Cancer*, 85(1), 60–67.

doi:10.1002/(SICI)1097-0215(20000101)85:1<60::AID-IJC11>3.0.CO;2-B

- Ji, J., Zöller, B., Sundquist, K., & Sundquist, J. (2012). Increased risks of coronary heart disease and stroke among spousal caregivers of cancer patients. *Circulation*, 125(14), 1742–1747. doi:10.1161/CIRCULATIONAHA.111.057018
- Kornblith, A. B., Herr, H. W., Ofman, U. S., Scher, H. I., & Holland, J. C. (1994). Quality of life of patients with prostate cancer and their spouses. The value of a data base in clinical care. *Cancer*, 73(11), 2791–2802. doi:10.1002/1097-0142(19940601)73:11<2791::AID-CNCR2820731123>3.0.CO;2-9
- Krabbameinsfélagið Framför. (2011) *Hvað er blöðruhálskrabbamein?* Retrieved March 19, 2012, from <http://www.framfor.is/frettir/hva-er-bloeruhlskrabbamein/>
- Malcarne, V. L., Banthia, R., Varni, J. W., Sadler, G. R., Greenbergs, H. L., & Ko, C. M. (2002). Problem solving skills and emotional distress in spouses of men with prostate cancer. *Journal of Cancer Education*, 17(3), 150–154. doi:10.1080/08858190209528823
- Manne, S., & Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer*, 112(S11), 2541–2555. doi:10.1002/cncr.23450
- Manne, S., Badr, H., Zaider, T., Nelson, C., & Kissane, D. (2010). Cancer-related communication, relationship intimacy, and psychological distress among couples coping with localized prostate cancer. *Journal of Cancer Survivorship*, 4(1), 74–85. doi:10.1007/s11764-009-0109-y
- Manne, S. L., Kissane, D. W., Nelson, C. J., Mulhall, J. P., Winkel, G., & Zaider, T. (2011). Intimacy-enhancing psychological intervention for men diagnosed with prostate cancer and their partners: A pilot study. *The Journal of Sexual Medicine*, 8(4), 1197–1209. doi:10.1111/j.1743-6109.2010.02163.x

- O’Leary, K. D., Fincham, F., & Turkewitz, H. (1983). Assessment of positive feelings toward spouse. *Journal of Consulting and Clinical Psychology*, 51(6), 949–951.
doi:10.1037/0022-006X.51.6.949
- Resendes, L. A., & McCorkle, R. (2006). Spousal responses to prostate cancer: An integrative review. *Cancer Investigation*, 24(2), 192–198. doi:10.1080/07357900500524652
- Sarafino, E. P., & Smith, T.W. (2011). *Health Psychology: Biopsychosocial Interactions* (7th edition). New Jersey: John Wiley & Sons.
- Sharpley, C. F., Bitsika, V., & Christie, D. R. H. (2010). ‘Why I feel bad’: refinement of the effects of prostate cancer upon lifestyle questionnaire and an initial exploration of its links with anxiety and depression among prostate cancer patients. *Psycho-Oncology*, 19(8), 839–846. doi:10.1002/pon.1623
- Snaith, R. P. (2003). The hospital anxiety and depression scale. *Health and Quality of Life Outcomes*, 1(1), 29. doi:10.1186/1477-7525-1-29
- Sternberg, R. J. (1988). *The Triangle of Love: Intimacy, Passion, Commitment*. New York: Basic Books.
- Street, A. F., Couper, J. W., Love, A. W., Bloch, S., Kissane, D. W., & Street, B. C. (2010). Psychosocial adaptation in female partners of men with prostate cancer. *European Journal of Cancer Care*, 19(2), 234–242. doi:10.1111/j.1365-2354.2008.01012.x
- Verdonck-de Leeuw, I. M., Eerenstein, S. E., Van der Linden, M. H., Kuik, D. J., de Bree, R., & Leemans, C. R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *The Laryngoscope*, 117(2), 238–241.
doi:10.1097/01.mlg.0000250169.10241.58
- Zaider, T., Manne, S., Nelson, C., Mulhall, J., & Kissane, D. (2012). Loss of masculine identity, marital affection, and sexual bother in men with localized prostate cancer.

Journal of Sexual Medicine, 9(10), 2724–2732. doi:10.1111/j.1743-6109.2012.02897.x

Zakowski, S. G., Harris, C., Krueger, N., Laubmeier, K. K., Garrett, S., Flanigan, R., & Johnson, P. (2003). Social barriers to emotional expression and their relations to distress in male and female cancer patients. *British Journal of Health Psychology*, 8(3), 271–286.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361–370.

Appendix 1: The questionnaire**Intimacy (Sternberg's Triangular Love Scale)**

Hversu vel eiga eftirfarandi staðhæfingar við þig?

Á mjög vel við um mig – á frekar vel við um mig – á hvorki vel né illa við um mig – á frekar illa við um mig – á mjög illa við um mig

1. Ég styð velferð konunar minnar/mannsins míns á virkan hátt.
2. Ég á í hlýju og einlægu sambandi við konuna mína/manninn minn.
3. Ég get reitt mig á konuna mína/manninn minn þegar ég þarf á henni/honum að halda.
4. Konan mín/maðurinn minn getur reitt sig á mig þegar hún/hann þarf á mér að halda.
5. Ég vil deila lífi mínu og öllum eignum mínum með konu minni / manni mínum.
6. Ég fæ töluverðan tilfinningalegan stuðning frá konunni minni/manninum mínum.
7. Ég veiti manninum mínum/konunni minni töluverðan tilfinningalegan stuðning.
8. Ég á auðvelt með að tjá mig við konuna mína / manninn minn.
9. Konan mína / maðurinn minn er mér mikils virði.
10. Mér finnst ég vera náinn konunni minni/manninum mínum.
11. Samband mitt við konuna mína/manninn minn er þægilegt.
12. Mér finnst ég skilja konuna mína/manninn minn mjög vel.
13. Mér finnst að konan mín/maðurinn minn skilji mig mjög vel.
14. Mér finnst ég geti algjörlega treyst konunni minni/manninum mínum.
15. Ég deili mjög persónulegum upplýsingum um mig með konunni minni/manninum mínum.

General distress (the Hospital Anxiety and Depression Scale, HADS)

Vinsamlegast merktu við þann svarreit sem á við hverja staðhæfingu.

*Spurt er um líðan þína síðastliðna **VIKU**.*

1. Ég er uppspennt og taugatrekkt:

- ☐ Alls ekki
- ☐ Öðru hvoru, stundum
- ☐ Oft
- ☐ Næstum alltaf

2. Ég nýt þess sem ég var von að gera:

- ☐ Ábyggilega eins mikið
- ☐ Ekki alveg eins mikið
- ☐ Aðeins að litlu leyti
- ☐ Varla nokkuð

3. Ég fæ einhvers konar hræðslutilfinningu eins og eitthvað hræðilegt sé að fara að gerast:

- ☐ Alls ekki
- ☐ Að litlu leyti, en ég hef ekki áhyggjur af því
- ☐ Já, en ekki svo slæma
- ☐ Alveg örugglega og oft slæma

4. Ég get hlegið og séð það skoplega í kringum mig:

- ☐ Eins mikið og áður
- ☐ Ekki alveg eins mikið núna
- ☐ Ábyggilega ekki eins mikið núna
- ☐ Alls ekki

5. Áhyggjur fara í gegnum hugann:

- ☐ Aðeins stöku sinnum
- ☐ Öðru hvoru, en ekki svo oft
- ☐ Mjög oft
- ☐ Svo til stöðugt

6. Ég er kát:

- ☐ Svo til alltaf
- ☐ Stundum
- ☐ Ekki oft
- ☐ Alls ekki

7. Ég get setið róleg og slappað af:

- ☐ Alltaf
- ☐ Yfirleitt
- ☐ Ekki oft
- ☐ Alls ekki

8. Ég er sein til hugsana og verka:

- ☐ Alls ekki
- ☐ Stundum
- ☐ Mjög oft
- ☐ Næstum alltaf

9. Ég finn til hræðslukenndar, fæ óróleikatilfinningu í magann:

- ☐ Alls ekki
- ☐ Öðru hvoru
- ☐ Nokkuð oft
- ☐ Mjög oft

10. Ég hef misst áhugann á því hvernig ég lít út:

- ☐ Ég hirði jafn vel um mig og áður
- ☐ Kannski hirði ég ekki um mig eins og ég ætti að gera
- ☐ Ég hirði ekki um mig eins og ég ætti að gera
- ☐ Alveg örugglega

11. Ég er óróleg eins og ég þurfi alltaf að vera að aðhafast eitthvað:

- ☐ Alls ekki
- ☐ Ekki svo mjög
- ☐ Þó nokkuð mikið
- ☐ Mjög mikið

12. Ég hlakka til þess sem framundan er:

- ☐ Eins mikið og áður
- ☐ Eitthvað minna en áður
- ☐ Örugglega minna en áður
- ☐ Eiginlega alls ekki

13. Ég fæ skyndileg ofsahræðsluköst:

- ☐ Alls ekki
- ☐ Ekki mjög oft
- ☐ Nokkuð oft
- ☐ Mjög oft

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

- ☐ Oft
- ☐ Stundum
- ☐ Ekki oft
- ☐ Mjög sjaldan

Cancer-specific distress (the Impact of Event Scale – Revised, IES-R)

Eftirfarandi er listi yfir umsagnir fólks um streituvaldandi atburði. Skoðaðu hvert og eitt

atriði og merktu við hve oft þessar umsagnir hafa átt við þið hvað varðar

blöðruhálskirtilskrabbamein síðan maki þinn greindist.

Aldrei – sjaldan – stundum – oft – mjög oft

1. Allt sem minnti mig á það kom tilfinningunum aftur af stað.
2. Ég átti erfitt með að sofa.
3. Aðrir hlutir komu mér til að hugsa um það.
4. Ég var pirruð og reið
5. Ég reyndi að taka ekki nærri mér þegar ég hugsaði um eða var minnt á það.
6. Ég hugsaði um það þó það hafi ekki verið ætlunin.
7. Mér leið eins og það hefði ekki gerst eða það væri ekki raunverulegt.
8. Ég forðaðist allt sem minnti mig á það.
9. Myndir af því skutust upp í huga minn.
10. Ég var uppstökkt og mér brá auðveldlega.
11. Ég reyndi að hugsa ekki um það.
12. Ég vissi að ég hafði miklar tilfinningar tengdar því en ég tókst ekki á við þær.
13. Það var eins og tilfinningar mínar tengdar því væru dofnaðar.
14. Ég lét stundum eða leið eins og ég væri komin aftur til þess tíma þegar það gerðist.
15. Ég átti erfitt með að sofna.
16. Sterkar tilfinningar helltust yfir mig annað slagið.
17. Ég reyndi að þurrka það út úr minningunni.
18. Ég átti erfitt með að einbeita mér.

19. Þegar ég var minnt á það fékk ég líkamleg einkenni eins og svitaköst, öndunarerfiðleika, ógleði eða mikinn hjartslátt.
20. Mig dreymdi um það.
21. Ég var aðgætin og á verði.
22. Ég reyndi að tala ekki um það.

Communication (the Positive Feeling Questionnaire, PFQ)

Eftirfarandi er listi af 8 spurningum um mismunandi tilfinningar milli fólks í sambandi.

*Vinsamlegast svaraðu hver og einni eins og þér líður **almennt** með maka þinn síðustu mánuði. Svarið á að sýna hvernig þér **raunverulega** líður en ekki hvernig þér ætti að líða.*

*Vinsamlegast svarið hverri spurningu með því að velja þá tölu sem best lýsir tilfinningum þínum til maka þíns undanfarna mánuði. Veljið einungis **eina tölu** fyrir hverja spurningu.*

Mjög oft – oft – af og til – sjaldan - aldrei

1. Hve oft talið þið um ánægjulega hluti sem gerast yfir daginn?
2. Hve oft talið þið um óþægilega hluti sem gerast yfir daginn?
3. Talið þið út um það sem þið eruð ósammála um eða eigið erfitt með?

Appendix 2: The introduction letter

Kynningarbréf fyrir vísindarannsóknina:

„Rannsókn á líðan aðstandenda karlmanna sem hafa greinst með krabbamein í blöðruhálskirtli“

Erlendar rannsóknir benda til þess að mökum einstaklinga sem hafa greinst með krabbamein geti liðið misvel og finnist oft að ekki sé komið til móts við þarfir þeirra. Því þykir okkur mikilvægt að skoða þennan hóp svo hægt sé að fá upplýsingar um líðan þeirra og í kjölfarið hanna úræði sem gætu aðstoðað við hina ýmsu þætti sem fylgir því að eiga maka sem hefur greinst með krabbamein. Þessi rannsókn er fyrsta rannsóknin á líðan og lífsgæðum meðal maka einstaklinga sem hafa greinst með krabbamein hér á Íslandi, svo vitað sé. Við vonumst til, að með þinni hjálp getum við komist að því hvernig líðan og lífsgæðum þessa hóps er háttað hér á landi.

Ef þú hefur áhuga að vera með þá er meðfylgjandi í þessu umslagi: spurningalisti, tvö eintök af upplýstu samþykki og umslag. Þátttaka þín felst í því að svara spurningalistanum í einrúmi. En áður en þú gerir það biðjum við þig um að lesa upplýsta samþykkið vel yfir og undirrita það, þú heldur öðru eintakinu eftir sjálf(ur).fyrir þig. Það tekur síðan um rúma hálfa klukkustund að svara spurningalistanum. Þegar þú ert búin(n) að svara spurningalistanum, biðjum við þig um að senda okkur spurningalistann og undirritaða eintakið af upplýsta samþykkinu til baka í meðfylgjandi umslagi, ekki þarf að greiða póstburðargjald.

Nánari upplýsingar varðandi rannsóknina veitir Unnur Vala Guðbjartsdóttir, verkefnastjóri í síma 865-0549 eða á netfanginu uvgl@hi.is.

Ábyrgðarmaður rannsóknarinnar er Heiðdís B. Valdimarsdóttir prófessor í sálfræði við Háskólann í Reykjavík, sími 599-6200, netfang: heiddisb@ru.is.

Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til Vísindasíðanefndar, sími: 551 7100, netfang: visindasidanefnd@vsn.stjr.is

Appendix 3: The consent form

Upplýst samþykki fyrir þátttöku í vísindarannsókninni:

„Rannsókn á líðan maka karlmannna sem hafa greinst með krabbamein í blöðruhálskirtli“

Erlendar rannsóknir benda til þess að makar þeirra sem greinst hafa með krabbamein líði misvel og finnist oft að ekki sé komið til móts við þarfir þeirra. Markmið þessarar rannsóknar er að kanna lífsgæði og þarfir meðal maka einstaklinga sem hafa greinst með krabbamein hér á Íslandi, þar sem lítið sem ekkert er vitað um þennan hóp hér á landi.

Þátttakendur í þessari rannsókn eru makar karlmannna sem hafa greinst með krabbamein í blöðruhálskirtli. Þátttaka þín felst í því að svara meðfylgjandi spurningarlista og pósthleggjja hann til okkar. Það tekur einungis rúma hálfa klukkustund að svara öllum spurningunum (án hlés).

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. Þú átt rétt á því að öllum gögnum sem aflað hefur verið um þig í rannsókninni verði eytt og þau ekki notuð, ef þú hættir þátttöku.

Við metum mikils þátttöku þína í rannsókninni en ekki er hægt að tryggja að þú hafir beinan hag af þátttöku, en með þátttöku þinni hjálpar þú okkur að skoða líðan og lífsgæði hjá mökum krabbameinssjúklinga. Ekki verður greitt fyrir þátttöku í rannsókninni.

Sumar spurningar í spurningarlistanum geta kallað fram óþægilegar tilfinningar. Ef það gerist eða ef þú nú þegar finnur fyrir vanlíðan, getur þú haft samband við Sjöfn Ágústs dóttur sálfræðing (Miðstöð sálfræðinga, Bæjarhrauni 6, s.8983725).

Meðferð allra gagna og upplýsinga sem aflað verður í rannsókninni verður samkvæmt ströngum reglum um trúnað. Enginn utan rannsóknateymis mun hafa aðgang að rannsóknargögnum. Rannsóknargögn verða varðveitt á öruggum stað hjá ábyrgðarmanni rannsóknarinnar á meðan á rannsókn stendur. Rannsóknargögnum verður eytt að lokinni rannsókn. Gögnin verða ekki notuð í markaðsskyni, né af þriðja aðila, eingöngu rannsakendur munu nýta þau. Niðurstöður rannsóknarinnar verða birtar í ritrýndum tímaritum en þær verða að engu leyti persónugreinanlegar.

Ábyrgðarmaður rannsóknarinnar er Heiðdís B. Valdimarsdóttir prófessor í sálfræði við Háskólann í Reykjavík, sími 599-6200, netfang: heiddisb@ru.is.

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

Unnur Vala Guðbjartsdóttir
Verkefnastjóri

Heiðdís B. Valdimarsdóttir
Ábyrgðarmaður

*Mér hefur verið kynntur tilgangur þessarar vísindarannsóknar og í hverju þátttaka mín er
fólgin.
Ég samþykki þátttöku.*

Dags. _____ Undirskrift þátttakanda _____

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

***Nánari upplýsingar veitir Unnur Vala Guðbjartsdóttir s. 865-0549
Bestu þakkir fyrir að gefa þér tíma til að taka þátt í rannsókn okkar***

*Ef þú hefur spurningar um rétt þinn sem þátttakandi í þessari vísindarannsókn eða vilt hætta þátttöku í
rannsókninni getur þú snúið þér til Vísindasiðanefndar, sími: 551 7100, netfang: visindasidanefnd@vsn.stjr.is*