The intersecting system of patients with chronic pain and their family caregivers
Mohammadi, Somayyeh

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2016

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

Copyright
Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

Take-down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): http://www.rug.nl/research/portal. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.
Chapter 7

General Discussion
The aim of the current thesis was to examine the psychological and social factors that are associated with the pain experience. First, we investigated the existence of pain-related cognitions (i.e., attentional bias to pain) among patients and their family caregivers (chapter two and three). Second, we examined whether patients’ and caregivers’ pain-related cognitions and behaviors are associated with pain outcomes (e.g., pain behaviors, pain intensity; chapter four). We also examined whether the interactions among all family members moderate the relation between pain intensity and distress (chapter five). Finally, the pain-related cognitions and the psychological well-being of family caregivers of patients with chronic pain were investigated (chapter six). In the current chapter, the main findings of the empirical chapters will be presented briefly. We will organize the findings according to several themes, including attentional bias among patients and their family caregivers, family caregivers’ responses and patients’ well-being, family functioning and patients’ well-being, and the caregiving experiences of caregivers and their well-being. The findings regarding each theme will be discussed in the context of the existing literature. Then, at the end of each section, practical implications and potential interventions will be discussed.

The main findings of the current thesis

**Attentional bias among patients and their family caregivers**

Patients with chronic pain needed less time to detect pain-related information (i.e., pain faces), while they needed more time to detect happy-related information (i.e., happy faces) than control participants. In addition, family caregivers of patients with chronic pain showed faster detection of pain-related information in comparison to happy information. The findings demonstrated that the caregivers who did not show attentional bias to pain were in concordance with the patients in their estimation of the patients’ pain intensity. In contrast, caregivers who showed attentional bias to pain information were more likely to overestimate or underestimating the patients’ pain intensity. In addition, we found that caregivers with higher attention to pain-related information reported that their family member with chronic pain expressed more pain behaviors. Further analyses showed that higher levels of attentional bias to pain information in caregivers were not related to patients’ and caregivers’ disagreement in reporting patients’ pain behaviors.

**Family caregivers’ responses and patients’ well-being**

The findings showed that the association between pain catastrophizing and pain intensity in patients was partially mediated by patients’ expression of pain behaviors. Further analyses indicated that the link between patients’ pain intensity and patients’ pain behaviors depended on family caregivers’ responses. More specifically, patients who expressed more pain (e.g., by grimacing, distorted walking) perceived higher levels of pain, but only if caregivers showed solicitous and distracting responses.

**Family functioning and patients’ well-being**
The findings showed that higher levels of pain intensity were related to more distress among patients with pain. However, this relationship was only significant if patients were living with low functional families (e.g., families with indirect communication styles, low cohesion, and problematic affect regulation). If patients were living with highly functional families there was not any association between pain intensity and distress.

The caregiving experiences and caregivers’ well-being

The findings revealed that higher levels of caregiving demands were related to greater perceived injustice among family caregivers of patients with pain. Moreover, the results indicated that the link between caregiving demands and lower levels of caregivers’ well-being is mediated through a higher level of caregivers’ perceptions of injustice.

Implications of the findings and clinical interventions

Attentional bias among patients and their family caregivers

Attentional bias to pain information among patients. In the current section, we will focus on the potential consequences of attentional bias to pain information. Then, we will introduce an important intervention that recently has been suggested for decreasing attentional bias to pain information.

In line with the findings of other studies among patients with pain (e.g., Crombez, Van Ryckeghem, Eccleston, & Van Damme, 2013; Schoth & Liossi, 2010), the findings of the current study support the existence of attentional bias to pain-related information among patients with chronic pain. In the short-term, existence of attentional bias to pain may be beneficial because it warns a person that (s)he is facing a potential threat, and it evokes self-care and pain-avoiding responses in the person (Moore, Keogh, & Eccleston, 2013). To promote self-care responses, attentional bias to pain ceases the individual’s current plans and goals and encourages the initiation of the plans that are essential to avoid the pain and danger. However, in the long-term, specifically when the pain is chronic, consistent attention to pain-related information has no life-saving function, and might negatively affect patients’ performance (Durnez & Van Damme, 2015; Eccleston & Crombez, 1999; Van Ryckeghem et al., 2013). For example, it has been suggested that attentional bias to pain information leads patients to notice pain sensations in their body or in the environment. Pain sensations prone patients to avoid physical activities that they consider as dangerous. Subsequently, these patients may experience greater physical disability compared to patients who show relatively low levels of attentional bias (Vlaeyen & Linton, 2000; Vlaeyen & Linton, 2012). Considering the potential negative effects of attentional bias to pain on patients’ lives, applying effective ways to manage the attentional bias to pain information is important.

The notion that attending to pain information may cause interferences in patients’ daily lives has led to the interest of modifying attentional bias to pain-related information (Sharpe, Johnson, & Dear, 2014). One method that has been used to reduce attentional bias is Attention Bias Modification (ABM). In ABM, participants are trained to attend away from
pain-related information mainly by means of a dot-probe task (e.g., McGowan, Sharpe, Refshauge, & Nicholas, 2009). For example, McGowan and her colleagues (2009) used ABM among a group of participants with pain to investigate the effect of attention training on participants’ pain ratings, pain thresholds and pain tolerance levels. Box 1 provides information about the ABM that was used by McGowan and her colleagues (2009). The results of the ABM by McGowan and colleagues (2009) showed that the participants (i.e., non-pain patients university student) who were trained to attend away from pain-related information showed significant delay in reporting pain during a cold pressor task, and when they did report pain, they reported lower levels of pain intensity.

In the same line, Sharpe and her colleagues (2012) showed that patients with acute pain who had participated in a single session of attention bias modification training reported less pain and a lower frequency of pain experiences at follow-up three months later compared to the patients with acute pain who were assigned to a control group. In a separate study-on patients with chronic pain- Sharpe and colleagues (2012) showed that patients who had been assigned to a four-session attention training intervention reported lower anxiety sensitivity and pain-related disability in comparison to chronic pain patients who were assigned to a control group. Although these studies pointed to the existence of potential benefits of attentional bias modification, the mechanism of change is not clear. It is possible that the attention training interventions facilitate the efficacy of distracting strategies that are often considered as important elements of pain management programs (Sharpe et al., 2012). Since only few studies have applied ABM training and although the results are promising, the evidence based on these studies is still preliminary. Therefore, further investigations are needed to determine the applicability of ABM.

**Box 1. The Attentional Bias Modification procedure**

In Attentional Bias Modification, first a fixation point (i.e., “.”) is presented in the center of the screen. Then, the fixation point disappears and immediately a word pair (one neutral word and one pain-related word) appears on the screen. One word is presented above the previous location of the fixation point and the other word appears below the previous location of the fixation point. These two words remain on the screen for 500 milliseconds and then both disappear simultaneously. Finally, in the location of only one of the words, either the letter “p” or “q” (i.e., the probes) is presented. Participants have to press “p” if the letter p appears or they have to press “q” if they see the letter q on the screen. This procedure is similar to the procedure that is usually used for assessing attentional bias to pain information. The only difference is that in the attentional training away from pain-related information, the probes always appear in the location of the neutral words and not the pain-related words. In contrast, in the measurement of attentional bias the probe appears randomly either in the location of a neutral or a pain-related stimulus (See chapters 2 and 3 for more information about assessing attentional bias to pain).

**Attentional bias to pain information among family caregivers.** The findings of the current thesis showed that family caregivers of patients with chronic pain tend to detect pain-related information faster than other information. These findings raise several questions. First, why do these biases exist among family caregivers? Having the responsibility to take care of
an individual in pain might prone family caregivers to remain hypervigilant and sensitive to pain-related cues. This could be an adaptive process that helps family caregivers to notice pain and aids them to mobilize their resources to help their family members (Goubert et al., 2005). In line with this, we found that family caregivers with higher attentional bias to pain information reported more pain behaviors in their family members with chronic pain. However, the cross-sectional nature of the current study and other studies (e.g., Vervoort, Trost, Prkachin, & Mueller, 2013) regarding the existence of attentional bias to pain information among family caregivers does not allow us to verify this speculation since it is possible that some caregivers had been sensitive to pain information even before the commencement of the pain condition in their family member.

The second question that can be asked is: Does existence of attentional bias among family caregivers have a positive or negative role? As we already indicated, the existence of attentional bias in caregivers may help them to detect and respond to patients’ pain expressions. This might have a positive function since it can help caregivers to provide support to their family members. However, this might only be true if attentional bias to pain information helps family caregivers to gain accurate perceptions of the pain experience. The findings indicated that only the caregivers who showed no attentional bias to pain information accurately gauged the pain intensity in their family members. Therefore, caregivers with attentional bias to pain may not be able to accurately estimate the pain intensity of their family members. This is in line with other studies suggesting that the existence of attentional bias to pain is related to the perception of non-pain-related cues as pain cues (e.g., Liossi, White, Croome, & Hatira, 2012).

However, we did not confirm that caregivers’ attentional bias to pain is associated with the disagreement between patients and their main family caregivers in reporting patients’ pain behaviors. This finding is in contrast to what we have found previously, i.e., caregivers’ attentional bias to pain was related to caregivers’ inaccurate perceptions of patients’ pain intensity. Applying different analytical approaches might be one of the reasons for the inconsistency between the findings regarding attentional bias and the patient-caregiver agreement with respect to pain intensity and pain behaviors. In the second chapter, the investigation of the disagreement between patients’ reports and caregivers’ reports of pain intensity has been conducted based on the difference scores (i.e., subtracting patients’ scores of pain intensity from caregivers’ scores of pain intensity). In the third chapter to examine the disagreement between the patients’ reports and the caregivers’ reports of pain behaviors, we used hierarchical linear modeling. In hierarchical linear modeling, by not using the difference scores, we avoided losing statistical power (Cano, Johansen, & Franz, 2005). We were not able to perform the hierarchical linear modeling analyses to investigate the disagreement in patients’ and caregivers’ reports in pain intensity. The main reason is that the pain intensity scale (i.e., Visual Analogue Scale) consisted of only one item, while to perform hierarchical linear modeling, we need to develop two parallel subscales from the original scale (please see chapter three for more information). Another reason for the inconsistent results might be the type of the variable under the study. In chapter two the role of attentional bias on the patients’ and their caregivers’ reports of pain intensity was assessed and in chapter three the report of
pain behaviors was the variable of interest. Further studies are still needed to investigate whether the effect of attentional bias in patient-caregiver disagreement in perceiving a specific variable depends on the type of analyses or the type of the variables of interest. Therefore, it is not possible to draw a definite conclusion regarding the role of attentional bias among family caregivers in patient-caregiver disagreement on pain-related variables.

A final issue worth addressing is whether the existence of attentional bias among family caregivers has any association with caregivers’ well-being. As we discussed earlier, attention has a limited capacity. Therefore, caregivers’ constant attention to pain-related information may interfere with their daily activities and their current goals. Examining the effects of the existence of attentional bias among family caregivers is an interesting avenue for future research. Probably, one also is interested to study the effects of attention modification training in family caregivers or to investigate whether changes in patients’ pain conditions have an influence on caregivers’ attentional biases to pain information.

In short, it can be concluded that attentional bias to pain information among family caregivers does exist. It is plausible to assume that caregivers who show more attentional bias to pain information in general detect more pain cues in the patients. Probably these caregivers are more inclined to manifest supportive responses. However, if caregivers overestimate patients’ pain and needs, the degree of support that they show will not fit the needs of the patients. In the short-term this might be beneficial for the patients because they receive attention and support. However, in long-term, providing constant care and support might discourage patients to take responsibilities and even increase patients’ disability level. It is also possible that constant attention to family members’ pain and trying to provide support increase the perception of burden in family caregivers. Therefore, it seems plausible that in the long-term the existence of attentional bias to pain information may result in deterioration of both patients’ and their family caregivers’ well-being.

**Family caregivers’ responses and patients’ well-being**

Patients who catastrophize about pain tend to express more pain behaviors. In turn, patients who express more pain behaviors perceive their pain as more intensive, but only if caregivers’ display solicitous and distracting responses. These findings indicate that family caregivers’ responses play an important role in the pain experience. While the literature supports the importance of social and family factors (e.g., caregivers’ responses) in the physical and psychological outcomes of pain, the evidence suggests that these factors may have both positive and negative effects on pain outcomes. For example, according to the operant models of pain, patients with pain express pain behaviors to communicate their pain and to encourage others to provide supportive responses (Gatzounis, Schrooten, Crombez, & Vlaeyen, 2012). These models indicate that pain behaviors will be reinforced if they are followed by positive responses (Fordyce, 1976). For instance, caregivers’ solicitous responses are related to more pain behaviors, greater pain intensity, less physical activity and increased disability (Chambers, Craig, & Bennett, 2002; Flor, Kerns, & Turk, 1987; Kerns et al., 1991). In contrast to operant models, the stress-buffering hypothesis indicates that social support has a protective function against the negative impact of an illness (Ringdal, Ringdal, Jordhoy, &
Kaasa, 2007). In the same vein, some studies suggest that patients with chronic pain who receive supportive responses experience less distress, less intensive pain and better adjustment to the pain condition (Jensen et al., 2002; Turk, Okifuji, & Scharff, 1995).

The main difference between these two viewpoints (i.e., operant models versus stress-buffering hypothesis) is their definition of supportive responses. It seems that caregivers’ responses that entail attention to patients’ pain and patients’ pain behaviors have a reinforcing function and are related to negative outcomes of pain. However, caregivers’ responses that convey the notion that the patients’ condition is being understood and support is available are related to positive outcomes for patients (López-Martínez, Esteve-Zarazaga, & Ramírez-Maestre, 2008). Therefore, it is highly important to help caregivers to provide support without reinforcing the patients’ pain and pain behaviors.

To do so, recently, studies emphasized the role of a validating communication style (Edlund, Carlsson, Linton, Fruzzetti, & Tillfors, 2015). Validation responses consist of empathic responses. Asking questions to gain a complete understanding of the patient’s pain experience or declaring reflective statements about the patient’s internal experience are considered as validating communication. Validating communication is related to the reduction in emotional arousal, higher perception of social support and higher marital satisfaction (Cano, Barterian, & Heller, 2008; Edlund et al., 2015; Leong, Cano, & Johansen, 2011). However, so far, only one study has investigated the effect of a validating communication style as an intervention for patients with pain (i.e., Edlund et al., 2015). This study found that educating family caregivers to show validating responses decreased patients’ negative affect. However, this study only used a single session intervention and also did not compare the effect of validating communication with other treatments such as cognitive behavioral treatment. Moreover, this study did not follow patients’ and caregivers’ interactions over time. Hence, no evidence supports the long-term effects of caregivers’ validating responses. Therefore, further investigations are needed to obtain a better understanding of the effect of validating communication and its impact on patients’ physical and psychological outcomes.

**Family functioning and patients’ well-being**

In the previous section, we explained that the responses of one of the family members (i.e., the main family caregiver) are related to patients’ well-being. In the current thesis, we found that the interactions among all family members (i.e., family functioning) were also associated with patients’ well-being. More specifically, we found that the perception of more intense pain was related to the elevated levels of distress if patients were living with families with low functional interactions (i.e., dysfunctional families).

Family system theories provide a productive context to study the effects of the interactions among all family members (i.e., family functioning) on patients’ outcomes. To explain the effect of family context on the well-being of patients, Patterson, McCubbin, and Warwick (1990) indicated that patients who are encouraged by their family members to participate in the activities that enhance their self-esteem have a higher ability to manage their distress. Other studies pointed out that family members’ coping styles are associated with
patients’ adjustment (Wong & Heriot, 2008). In addition, families’ discouragement of independency is associated with externalizing behavioral symptoms in patients (Morris et al., 1997). Therefore, patients who are living with families that do not encourage them to be independent are more likely to express pain and illness behaviors. In turn, since these patients are more prone to express pain and illness behaviors, it is more likely that their family members believe that they are not able to take responsibility (Cipolletta, Marchesin, & Benini, In Press). Knowing the effect of the family system on patients’ mental and physical health has important clinical implications. To date, most of the interventions that have aimed to enhance patients’ well-being have targeted only the patients, or the relationship between patients and only one of their family members; few studies have tried to intervene into the interactions within the family system.

One of the important theories that have tried to consider the role of all family members in the patients’ illness is the Family System Theory. The studies based on the family system theory usually have considered the interactions and dynamics among family members and they have tried to change those beliefs, communication and problem solving styles that are not adaptive and are barriers to adaptation of family members to the pain condition. The results of the studies in which family therapy interventions have been applied often provide evidence to support the effectiveness of these interventions on patients’ pain condition (e.g., Grondin, Bourgault, & Bolduc, 2014; Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009). For example, Grondin, Bourgault and Bolduc (2014) showed that patients who were assigned to a family–centered educational intervention experienced less postoperative pain and less anxiety after hip arthroplasty surgery compared to those that were assigned to a control group. It should be noted that asking all family members to participate in an intervention is not always plausible or practical. Future studies are needed to examine the advantages or disadvantages of family interventions versus the interventions that only target patients’ psychological characteristics and versus the interventions that focus on the interactions between patients and only one of their family members (e.g., spouses, parent).

The caregiving experiences and caregivers’ well-being

The majority of the studies in this thesis has focused on the influence of social factors (e.g., family caregivers’ responses) on the patients’ pain and well-being. However, according to the systemic perspective, while family caregivers’ cognitions and behaviors have an influence on patients’ well-being, caregivers’ cognitions and behaviors can also be affected by the pain condition. For example, the findings of this thesis showed that the pain condition can negatively impact other aspects of caregivers’ lives such as their perceptions about the justness of their situation, their distress level, and their overall well-being.

The findings of other studies also showed that experiencing higher levels of distress, burden, and anger among family caregivers of patients with chronic illnesses are common (Fletcher et al., 2008; Given, Given, & Kozachik, 2001; Mosher, Bakas, & Champion, 2013; Osse, Vernooij-Dassen, Schadé, & Grol, 2006; Stenberg, Ruland, & Miaskowski, 2010). Observing lower well-being among family caregivers are not unexpected since family caregivers have to provide various types of care and support for their patients without any
training. As well, the changes in the caregivers’ lives that are posed by the demands of caregiving responsibilities also play a role in the deterioration of the caregivers’ well-being. In addition, in the current thesis we found that caregivers who perceive their condition as a caregiver as unjust show higher levels of burden, distress, and anger comparing to those caregivers who do not assume their condition as unjust.

Since, caregivers are the main and probably the most immediate source of support for the patients, their physical and psychological well-being has an important implication for their ability to provide support to their family members in pain. For example, it is likely that caregivers who perceive their condition as unjust show more aggressive behaviors towards patients or eventually they may show less desire to support the patients or they manifest less interest in getting involved in the psychological or physical pain management interventions, specifically if they blame their own patients for the unfairness of their condition (Martin-Cook, Remakel-Davis, Svetlik, Hynan, & Weiner, 2003; Williamson et al., 2005). Hence, it is more likely that patients with caregivers who consider their condition as unjust may also show lower physical and psychological well-being.

Therefore, considering psychological interventions to target perceptions of injustice among family caregivers might be important for the well-being of the family caregivers and subsequently for the well-being of patients with chronic pain. Several interventions have been proposed to target perceptions of injustice. For example, cognitive reappraisal techniques and anger management interventions are suggested as effective interventions in reduction of injustice-related cognitions (Bruehl, Chung, & Burns, 2006; Scott & Sullivan, 2012). In addition, Sullivan and his colleagues (2009) pointed to the beneficial aspects of pain acceptance interventions for patients with chronic pain who report high levels of perceived injustice. They suggested that pain acceptance can help patients to continue their life goals and stop pain controlling or pain avoiding activities. However, none of the above interventions have been yet applied among family caregivers. Therefore, it is important to examine whether these interventions can result in the reduction of perceived injustice among family caregivers and increase their psychological well-being.

**General conclusion**

In conclusion, this thesis emphasizes the associations between patients’ pain-related cognitions (both explicit and implicit pain-related cognition) and the outcomes of pain. Second, the thesis shows that caregivers’ responses and the support within a social context such as the communication and problem-solving styles among family members are related to patients’ behavior and well-being. Third, this thesis sheds light on the association between caregiving responsibilities and caregivers’ well-being. These findings indicate that patients’ well-being and pain-related outcomes are associated with personal, interpersonal and social factors. This confirms the role of biopsychosocial perspective in understanding the effects of pain on patients and their family caregivers.
References


Cipolletta, S., Marchesin, V., & Benini, F. (In Press). Family functioning as a constituent aspect of a child's chronic illness. *Journal of Pediatric Nursing, (0)* doi:http://dx.doi.org/10.1016/j.pedn.2015.01.024


Ringdal, G. I., Ringdal, K., Jordhoy, M., & Kaasa, S. (2007). Does social support from family and friends work as a buffer against reactions to stressful life events such as terminal cancer? *Palliative & Supportive Care, 5*(01), 61-69.


