

Couples dealing with multiple sclerosis

A diary study examining the effects of spousal interactions on well-being

Annet Kleiboer 2006

The research reported in this thesis was conducted under the auspices of the Research Institute for Psychology & Health, an Institute accredited by the Royal Netherlands Academy of Arts and Sciences.

ISBN-10: 90-393-4406-X

ISBN-13: 978-90-393-4406-4

Cover: *Two People, Madison*

Printed by Gildeprint Drukkerijen B.V., Enschedé, the Netherlands

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Couples dealing with multiple sclerosis

A diary study examining the effects of spousal interactions on well-being

Omgaan met multiple sclerose binnen je relatie

Een dagboekstudie naar de effecten van interacties tussen partners op welbevinden

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit Utrecht
op gezag van de Rector Magnificus, Prof. dr. W.H. Gispen,
ingevolge het besluit van het College voor Promoties
in het openbaar te verdedigen
op maandag 11 december 2006 des middags te 16.15 uur

door

Anna Maria Kleiboer

geboren op 2 mei 1972, te Apeldoorn

Promotoren:

Prof. dr. J.M. Bensing

Universiteit Utrecht/ NIVEL, Nederland

Prof. dr. J.J. Hox

Universiteit Utrecht, Nederland

Co-promotor:

Dr. R.G. Kuijer

Universiteit van Canterbury, Nieuw Zeeland

The research reported in this thesis was funded by the Research Institute for Psychology & Health, an Institute accredited by the Royal Dutch Academy of Arts and Sciences.

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Chapter 1

General introduction

Living with a chronic progressive disorder such as multiple sclerosis (MS) does not only present a challenge for patients, but may also produce considerable distress for their intimate partners. In addition to addressing the physical disability caused by MS, both patients and their partners must find ways to deal with the uncertainty of the disease's progression, changing role responsibilities and the psychosocial consequences (Knight, Devereux, & Godfrey, 1997; Mohr & Cox, 2001; Murray, 1995). Although most patients with MS and their partners adapt relatively well, one can imagine that this is not an easy task. The need to adjust repeatedly as circumstances continually change (most often in a downward direction) makes adaptation even more difficult and it is not surprising that higher levels of anxiety and depression have been found among MS patients (Antonak & Livneh, 1995; Mohr & Cox, 2001) and partners (McKeown, Porter-Armstrong, & Baxter, 2003; Pakenham, 2001).

Being involved in a supportive relationship is believed to play a key role in adjustment to stressful life events such as chronic illness (Sarason, Sarason, & Gurung, 2001). Ample research has shown that the global perception that support is available when it is needed is related to greater psychological and physical well-being (e.g. Monahan & Hooker, 1995; Reinhardt, Boerner, Horowitz, & Lloyd, 2006; Symister & Friend, 2003). However, results are less consistent when the effects of *actual* support or *enacted* support are studied. Some studies have documented positive effects (e.g. DeLongis, Capreol, Holtzman, O'Brien, & Campbell, 2004; Feldman, Downey, & Schaffer-Neitz, 1999), whereas others have shown neutral effects (e.g. Bolger, Foster, Vinokur, & Ng, 1996), or even negative effects (e.g. Bolger, Zuckerman, & Kessler, 2000; Newsom & Schulz, 1998). These inconsistent results suggest that the effects of spousal support are not the same for each person, or that they depend on other factors that may interact with spousal interactions to determine its effect.

This thesis is motivated by our lack of knowledge about the processes that explain how and for whom spousal interactions are beneficial or harmful in the context of chronic illness (i.e. multiple sclerosis). An important feature of the present thesis is that we examined both patients and partners as recipients and providers of support. For the most part, social support research in the context of chronic illness is focused on the patient as the support receiver and the partner as the support provider, thereby neglecting the fact that patients may also provide support to their ill partner and thus partners may also receive support. A diary method was used to examine the effects of spousal interactions because daily process designs offer unique insights into challenging questions with respect to the situational aspects of receiving and providing support and offer the opportunity to examine individual differences in reactivity.

Multiple sclerosis: clinical features

MS is a chronic and often disabling disease of the central nervous system that most commonly starts in young adulthood between the ages of 20 and 40. For a long time it was

thought that inflammation of the myelin sheath surrounding the axons in the central nervous system was the central mechanism underlying the disease process in MS (Murray, 2006). However, it is now evident that the disease is more continuous and widespread than previously thought, including diffuse changes in white and grey matter, breakdown of myelin, and damage to axons (Murray, 2006). Because damage to the nerves can occur anywhere within the central nervous system, neurological symptoms vary widely between MS patients, dependent on where the damage is located. Symptoms can include loss of function, visual problems, debilitating fatigue, loss of balance, pain, loss of cognitive function and emotional changes (Noseworthy, Lucchinetti, Rodriguez, & Weinshenker, 2000).

The course of the disease among MS patients is very diverse. The onset of the disease can be gradual or acute and in most patients exacerbations are followed by periods of remission. However, a progressive deterioration of health is possible as well (Lublin & Reingold, 1996). Four major types of MS can be distinguished. A mild course of MS (benign course) is characterized by little disease activity and is found in 10-15% of all patients. The most common course of disease is a course marked by periods of disease exacerbations and remissions (a relapse-remitting course; RRMS) in which a sudden worsening of symptoms occurs which may remit partially or fully over the course of several weeks or months. A relapse remitting course is most often followed by a secondary progressive phase (SPMS). Approximately 10-15% of the patients have a primary progressive type of MS (PPMS), which is marked by a steady worsening of symptoms with no exacerbations. The course of the disease can change at any time in the disease process and patients can gradually progress towards more severe forms of MS (Lublin & Reingold, 1996).

The cause of MS is poorly understood. However, there is strong evidence that the disease is caused by the interaction of genetic factors and environmental influences, such as viral infection (Wingerchuk, Luchinetti, & Noseworthy 2001). The prevalence of MS is highest in Northern Europe, Southern Australia and the middle part of North America (Noseworthy et al., 2000). In the Netherlands, approximately 13.000 people have been diagnosed with MS (www.rivm.nl).

So far, there has been no cure for MS, only relief of symptoms by disease modifying drugs that reduce the number and severity of attacks. However, no change in eventual deficit or disability has been shown by these drugs, nor can they reverse damage that has already occurred nor are they effective for all patients (Murray, 2006).

Multiple sclerosis: consequences for patients and partners

The distress that most MS patients experience does not only result from their physical limitations, but also from the psychosocial consequences of having a chronic condition and the uncertainty of the disease's progression (Eklund & MacDonald, 1991; Murray, 1995).

Due to the nature of MS, patients constantly have to adapt to new situations, often involving losses such as reduced physical independence, restrictions in daily activities, loss of work and social contacts (Murray, 1995). Not every patient manages to deal with these problems successfully and depression is a common symptom in MS (Siegert & Abernethy, 2005; Minden, 2000). Research has shown that MS patients have higher levels of depression than people living with other chronic illnesses (Schubert & Foliart, 1993; Patten, Beck, Williams, Barbui, & Metz, 2003). Although part of the depression may be provoked by the disease process, depression also has clear psychosocial origins (Mohr & Cox, 2001). Factors related to the experience of depression in MS patients include loss of role functioning, the perception of uncertainty, the intrusiveness of the disease as experienced by patients, and the amount of social support received (Mohr & Cox, 2001). Compared with depression, not much research has been conducted on anxiety in MS patients. This is surprising as anxiety in MS can be provoked by the perceived potential threat and the uncertainty of the disease's progression (Mohr & Cox, 2001). However, levels of anxiety appear to be higher in MS than those found among health people (Jansens, van Doorn, & de Boer, 2003; Maurelli, Marchioni, Cerretano, Bosone, Bergamaschi, Citterio, Martelli, Sibilla, & Savoldi, 1992).

A chronic illness such as MS does not only have an effect on the individual lives of patients, but is also likely to have a profound effect on the intimate partner. Because of their interdependence, both members of the couple are affected not only by their own reactions to the illness but also by the emotional distress of their partner (Kelley & Thibaut, 1978; cf. Rusbult & Van Lange, 2003). Research has shown that the well-being of patients and partners is highly related and often follows the same pattern over time (Pakenham, 1998; Segrin, Badger, Meek, Lopez, Bonham, & Sieger, 2005). Each new adjustment that patients have to deal with also affects the partner, including changing role responsibilities, sexual difficulties, financial problems and feelings of loss.

Additionally, partners experience unique stresses as a result of living with a chronically ill person. Some emanate directly from caregiving, others from restructured family roles and responsibilities as the disease progresses or presents new challenges (McKeown et al., 2003). Taking care of an ill partner may be stressful especially when it is a lifelong task, and often implies taking on additional responsibilities such as performing household tasks or assistance with self-care (Kuyper & Wester, 1998). Partners can be overwhelmed by the tasks of caregiving and their own needs can easily be overlooked. Ample research has shown that taking care of an ill partner may be burdensome (e.g. Pakenham, 2001; Ybema, Kuijer, Hagedoorn, & Buunk, 2002), which may explain the higher levels of anxiety and depression that are found among partners as compared to the general population (McKeown et al., 2003; Pakenham, 2001).

For both patients and partners receiving support may be a critical resource for dealing with the stresses imposed by the illness. For patients, support can help them deal with the practical demands and the emotional distress generated by the disease (Cutrona, 1996;

Murray, 1995). Likewise, partners may also need support from the ill partner to deal with the stressful situation (Kriegsman, Penninx, & Van Eijk, 1994). However, an increasing number of researchers suggest that actual supportive interactions may not always be beneficial and sometimes also have costs (Bolger et al., 2000; Newsom & Schulz, 1998; Gleason, Iida, Bolger, & Shrout, 2003). When and for whom supportive interactions with the partner are beneficial or harmful is not clear, however. The current thesis addresses these actual supportive interactions. In the following paragraphs we will explain our definition of supportive interactions; we address how support receipt and provision may change in the context of chronic illness and address potential costs and benefits of interactions with the partner.

What are spousal exchanges?

Spousal exchanges refer to the occurrence of supportive behaviors between intimate partners. Based on the different functions that supportive behaviors may serve, different classifications of support are described (Cutrona & Russell, 1990). Although the categories proposed by different researchers differ substantially, most distinguish between emotional support and instrumental support (Pierce, Sarason, Sarason, Joseph, & Henderson, 1996). *Emotional support* is often defined as the communication that one is cared for and loved, by showing affection, providing reassurance, and listening. *Instrumental help* or *tangible assistance* involves the provision of concrete assistance such as help with household tasks. In the context of chronic illness, instrumental support may be most important for patients with greater disabilities, whereas emotional support will be needed to deal with the emotional distress evoked by the disease (Helgeson & Cohen, 1996). Although instrumental help and emotional support are distinct classes of support events, sometimes their functions may overlap. Instrumental help, for example, may sometimes also be perceived as a sign of affection by the recipient (Wills & Shinar, 2000).

In addition, negative interactions with the partner are often considered as a crucial component of social support models (Abbey, Andrews, & Halman, 1995; Helgeson & Cohen, 1996). *Negative interactions* (also called hindrance or negative responses) are actions that cause the individual to experience distress and at least have some reservations about the relationship itself, for example providing criticism, avoiding the partner or being demanding (Rook, 1992). Negative interactions with the partner may be a source of stress to the recipient (Shinn, Lehman, & Wong, 1984), can be perceived as a sign of rejection and contain a threat to the relationship with the provider (Druley & Townsend, 1998; Rook, 1992). Although negative responses are not common, they have been reported by patients with various chronic illnesses such as cancer (Manne, Taylor, Dougherty, & Kemeny, 1997), rheumatoid arthritis (Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991) and MS (Lehman & Hemphill, 1990; Mohr & Cox, 2001). Negative responses from the patient towards the healthy partner have been largely neglected, however. Research has shown that

the relation between the occurrence of positive and negative supportive exchanges is moderate, suggesting that both may occur within the same relationship (Abbey et al., 1995).

It is important to notice that supportive interactions are conceptually different from the perceived availability of support. Although both concepts are covered by the broader term social support, supportive interactions refer to the actual occurrence of supportive behaviors whereas the perceived availability of support refers to the perception of support that is believed to be available when needed (Dunkel-Schetter & Bennett, 1990). It is argued that the stress protective effects of the perceived availability of support do not involve actual support transactions but reflect more general evaluations of the relationship with the provider instead of actual exchanges (Kaul & Lakey, 2003; Lakey & Drew, 1997). The fact that several studies have shown that the perceived availability of support and actual support exchanges are only moderately related supports the idea that these are different concepts (Dunkel-Schetter & Bennett, 1990; Lakey & Drew, 1997).

The term actual supportive interactions suggests that someone truly provided the support. It is important to notice that actual support is generally measured by a person's perspective of whether supportive behaviors occurred (Helgeson, 2003). Supportive behaviors can be viewed from the recipient's perspective or the provider's perspective. These are subjective perceptions and recipients and providers of support may not always agree on the amount of support they report receiving or providing (Abbey et al 1995; Coriell & Cohen, 1995). For example, sometimes providers make statements that are intended to be supportive but are received by the recipient as critical or demanding (Dakof & Taylor, 1990). Consistent with many researchers, we argue that supportive interactions cannot be determined by outsiders to be supportive, they must be perceived that way by recipients (Cohen & Wills, 1985; McCaskill & Lakey, 2000; Lakey, Adams, & Neely, 2002).

Receiving and providing support in the context of illness

A chronic illness such as MS changes the context in which supportive interactions are given and received. In order to deal with the disease, patients often need increasing amounts of support and help from the partner, however, their physical limitations or emotional distress may prevent them from providing support to the healthy partner in return (Cutrona, 1996; Thompson & Pitts, 1992). Hence, the healthy partner often has to take over many tasks that the ill partner can no longer perform (e.g. help with household chores or assistance with self-care), providing an increasing amount of support to the ill partner without receiving much in return. Thus, supportive exchanges may become more unidirectional when one partner is diagnosed with chronic illness and partners are considered to provide a larger share than patients (Cutrona, 1996; Thompson & Pitts, 1992). Although this may apply to both emotional and instrumental support, this may be most pronounced in instrumental support since it will be easier for patients to provide emotional support to partners.

The balance between the give-and-take of support in intimate relationships has most often been studied from the perspective of equity theory (Walster, Walster, & Berscheid, 1978). According to equity theory, a relationship is out of balance or inequitable when the ratio of contributions and rewards of one partner deviates from the ratio of contributions and rewards of the other partner. In the context of chronic illness, the relationship may become inequitable in such a way that patients may feel overbenefited (i.e. they receive more support than they provide) and partners may feel underbenefited (i.e. they receive less support than they provide). Research among couples dealing with cancer (e.g., Kuijer, Buunk, & Ybema, 2001; Kuijer, Buunk, Ybema, & Wobbes, 2002) and partners of cardiac patients (Thompson, Medvene, & Freedman, 1995), showed that patients generally felt that their partner was doing more for them than the other way around, whereas partners generally felt that the relationship was balanced in terms of give-and-take.

Not much attention has been given to if and how negative interactions with the partner may change in response to chronic illness. Some studies suggest that caregiving distress is related to an increase in negative responses from the partner to the patient (Manne, Alfieri, Taylor, & Dougherty, 1999; Revenson & Majerovitz, 1990; Thompson, Gailbraith, Thomas, Swan, & Vrungos, 2002), especially when the partner believes that the patient is not dealing very well with the disease (Manne, Taylor, Dougherty, & Kemeny, 1997; Thompson et al., 2002). In contrast, in a study by Druley and Townsend (1998), rheumatoid arthritis patients did not report receiving more negative responses from their partner than healthy controls. In addition, little attention has been given to negative responses that patients may provide to the healthy partner. One study by Lane and Hobfoll (1992) in pulmonary disease patients showed that patients were angrier when they had more severe symptoms and expressed their anger towards the partner, suggesting that patients may also respond negatively towards the healthy partner.

The costs and benefits of support

For a long time, the social support literature has focused primarily on the positive aspects of supportive relationships. However, there's a growing awareness that intimate relationships come with costs (Abbey et al., 1995; Bolger et al., 2000; Newsome & Schulz, 1998; Manne et al., 1999; Rook, 1992). These costs most obviously concern negative interactions with the partner. The detrimental effects of negative interactions with the partner are well-described and have shown to exceed the beneficial effects of positive interactions (Newsom, Nishishiba, Morgan, & Rook, 2003; Manne et al., 1997; Schuster, Kessler, & Aseltine, 1990). Individuals dealing with stressful life events such as chronic illness may be especially vulnerable to negative responses they receive from their partner (Druley & Townsend, 1998; Ingersoll-Dayton, Morgan, & Antonucci, 1997; Kiecolt-Glaser, Dyer, & Shuttlesworth, 1988; Rook, 1992). Due to the stress of living with a chronic illness, personal resources are often taxed and negative responses received from the partner may add to the

burden that is already experienced. This will probably apply to both patients and partners. However, this may apply especially to patients, who often become more dependent on their partner and may have heightened concerns about abandonment (Cutrona, 1996; Druley & Townsend, 1998).

More counterintuitive is the observation that supportive interactions may also come with costs (e.g. Bolger et al., 1996; Newsome & Schulz, 1998). Several researchers have suggested that positive supportive interactions may contain health enhancing and health threatening elements (Gleason et al., 2003; Shrout, Herman, & Bolger, 2006; Bolger, et al., 2000). On the one hand, receiving support may communicate that one is loved and cared for which increases a sense of social connection and enhances feelings of self-esteem (Sarason et al., 2001). This may be especially important for patients, because of their increased dependency on their partner, not only for practical help, but also with respect to their self-esteem. Additionally, receiving support may buffer the detrimental effects of stress such as negative interactions (Cohen, Gottlieb, & Underwood, 2000) and distract the recipient from worries associated with stressful events (Rook, 2001).

On the other hand, receiving support may signal that one has failed, is dependent, or is incompetent (Fisher, Nadler & Whitcher-Alagna, 1982; Gleason et al., 2003; Liang, Krause, & Bennett, 2001). In couples dealing with a chronic illness this may apply to both partners, although these feelings may be more pronounced among patients. Further, support may draw attention to the problem the support was intended to resolve, leading to cognitive appraisal costs (Lazarus, 1991). In addition, for patients, support may emphasize their status as an 'impaired person' (DiMatteo & Hays, 1981). As a result social support may undermine the recipient's self-esteem, well-being, and feelings of autonomy. Finally, receiving support may make the recipient feel indebted to the provider (Walster et al., 1978).

The same mixture of beneficial and harmful elements may apply to providing support. On the one hand providing support allows one to display positive attributes such as concern, love, and commitment (Rusbult & Van Lange, 1996), it may draw attention away from one's own problems and it communicates independence (Gleason et al., 2003). The latter may be especially important for individuals with a chronic disease as they are often placed in a position of dependence. Additionally, helping someone in need may be a fulfilling experience and may boost self-esteem (Williamson & Clark, 1989). Research that pays attention to the positive effects of caregiving, showed that caregiving may improve peoples' sense of self-worth and confidence in meeting challenges (Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt, & Van den Bos, 1998; Ybema, Kuijer, Hagedoorn, & Buunk, 2002).

On the other hand there may be considerable costs to providing ongoing support and help to others as well. In fact, in the literature on caregiving the positive aspects have received far less attention than the negative aspects (Martire & Schulz, 2001). Ample research has shown that the provision of ongoing care and support to an individual with a

chronic illness is often a stressful experience and partners may become overburdened by the amount of support and help that needs to be provided (Martire & Schulz, 2001).

In sum, interactions with the partner may have both costs and benefits. Although the theoretical explanations for the costs and benefits of supportive interactions are clear, empirical evidence of the underlying processes is inconsistent so far, and does not shed light on the basic mechanisms involved. A diary method is an appropriate instrument to unravel these processes because they offer the opportunity to examine under which conditions supportive interactions are beneficial or harmful and more or less potent in patients and partners. As outlined above, in the context of chronic illness the effects of supportive interactions may be different than when both partners are healthy due to changing role responsibilities and an imbalance of give-and-take in the relationship. Additionally perceiving your relationship as imbalanced (both overbenefited and underbenefited) may also have costs. Many studies showed that perceptions of inequity are associated with more distress and lower relationship outcomes among healthy couples (e.g. Grote & Clark, 2001; Sprecher, 2001) as well as couples dealing with chronic illness (Kuijer et al., 2001; Thompson et al., 1995; Ybema, Kuijer, Hagedoorn, & Buunk, 2001; Ybema et al., 2002).

Diary methods

Diary methods are used with increased frequency in health psychology and other social and behavioral disciplines to examine ongoing experience as it occurs within the context of everyday life. The designation 'diary method' refers to a class of methodologies that examine detailed descriptions of daily experience and reactivity (e.g. Bolger, Davis, & Rafaeli, 2003; Reis & Gable, 2000). In some forms of diary methods participants provide assessments each time a certain event occurs (e.g. a conflict) which is called an *event contingent* method. Other diary designs use an electronic device that prompt participants to provide diary reports at random intervals (*signal contingent*) or use assessments that are reported at the end-of-each day or week (*interval contingent*) (Reis & Gable, 2000).

Which form of diary is most appropriate for what study depends on the frequency with which the variables occur, on recall bias, reactivity or whether the event is concrete or not (Stone, Kessler, & Haythornthwaite, 1991). For example, when an event can be recalled quite well over the span of a day (such as the occurrence of events like interactions with the partner or daily stressors) than an interval contingent design assessing variables at the end-of-each day is appropriate. However, when a variable is believed to fluctuate from moment to moment, such as mood, it is best assessed at that moment. In this thesis, an interval contingent method was used. At the end of each day, participants were asked to report supportive interactions that occurred during the day and their well-being at that moment.

The primary benefit of diary studies is that they permit an examination of within-person processes over time making it possible to determine antecedents, correlates and consequences of daily experience and reactivity (Bolger et al., 2003). Within-person designs

differ from between-person designs that are typically used in social and behavioral research. Between-person designs examine for example whether individuals who in general receive high levels of negative responses from their partner are less affected by these responses if the partner in general provides much positive support as well. However, a within-person design provides information on the effects of negative responses *when* they occur or about *conditions* under which they have a larger effect (e.g., when emotional support is provided as well on the same day). For example, it may be that patients and partners do not differ with respect to the amount of negative responses they receive in general, but that patients are more strongly affected by them when they occur.

In addition, a diary method has some statistical advantages as opposed to single point self-report questionnaires. Participant's limited ability to recall their experiences often results in retrospective aggregated responses that reflect faulty reconstruction of the phenomena of interest (Bolger et al., 2003). One advantage of a diary method lies in the reduction of retrospective bias by assessing behaviors near the time they occur (Bolger et al., 2003). Second, by examining the temporal precedence of events within individuals, participants can be used as their own controls, thereby reducing the influence of confounding variables (West & Hepworth, 1991). Moreover, diary studies can be considered as short term longitudinal studies and have the same methodological features as longitudinal studies.

However, diary methods are not without difficulties. The greatest difficulty is that they impose substantial demands on participants and the burden experienced by the frequent self-reports may have negative effects on compliance (Gable & Reis, 1999). Because of these demands it is important to keep the diary as short as possible to limit the burden experienced by participants.

The current study

The present thesis aimed to examine 1) the amount of support received and provided by MS patients and their partners, 2) the costs and benefits of supportive interactions with the partner.

With respect to the *first issue* we expected that supportive interactions would change in response to chronic illness in such a way that partners would provide more support and help and receive less in return. However, the extent to which supportive interactions are affected by the disease may depend on the type of support (i.e. instrumental support, emotional support or negative responses). Additionally, the amount of supportive interactions that patients and partners provide to one another may depend on the patient's physical disability and emotional distress. As a result of the shift in supportive interactions from the patient to the partner, patients and partners may perceive their relationship as imbalanced. Patients may feel overbenefited in their relationship and partners may feel underbenefited. These issues were examined by the following research questions: Do patients and partners receive

and provide more or less support as compared to the other partner in the context of chronic illness? Is the amount of support provided by patients and partners related to the patient's physical disability and emotional distress? Do patients and partners perceive their relationship as imbalanced?

Regarding the *second issue*, the costs and benefits of daily received and provided support were examined within-persons over time with a diary method and between persons prospectively over a period of seven months. Using a within-person design, we first asked to what extent reciprocal exchanges of received and provided emotional and instrumental support are related to end-of-day well-being? Second, we asked whether the relation between negative responses received and end-of-day mood is moderated by emotional support received on the same day. Additionally, the following questions were examined with a prospective design: What is the effect of emotional support and negative responses received on anxiety and depression seven months later in patients and partners? What is the impact of perceptions of inequity on depression seven months later in patients and partners.

Sixty-one couples dealing with MS participated in the study. All couples completed diaries for fourteen days and filled out questionnaires prior to completing the diaries and at seven months follow-up. Supportive interactions with the partner were assessed daily using a diary method, whereas perceptions of inequity were assessed with a self-report questionnaire at baseline. One important feature of this study is that we distinguished between emotional and instrumental support because different types of support may have different effects on well-being. Thus far, the studies on the effects of actual support examined either only emotional or instrumental support (e.g. Gleason et al., 2003; Newsom & Schulz, 1998) or did not distinguish between the two (e.g. Liang et al., 2001). A final important feature of the present study is that we examined whether the processes underlying support effects are different for patients and their intimate partners. Due to the imbalance in support transactions that is provoked by the illness, support provision and receipt may have different effects for patients, who are often placed in a position of dependence, than for partners, who are often forced to take on the role of caregivers.

Outline of the thesis

To conclude, this thesis concerns a study on supportive interactions among couples dealing with multiple sclerosis (MS). Within this context we focused on two main issues: the amount of support received and given by MS patients and their partners and the costs and benefits of supportive interactions for emotional well-being. These issues are addressed in the five chapters of this thesis.

In Chapter 2 it was examined whether patient's physical disability and emotional distress were related to the amount of support that patients and partners provided to one another. We postulated that it may be difficult for patients and partners to maintain a supportive relationship in the context of chronic illness, due to the patient's physical disability

combined with the distress of living with the disease. To answer this question, both partners of couples dealing with MS completed questionnaires and subsequently filled out a diary for fourteen days to examine provided emotional support, instrumental help and negative responses.

Chapter 3 was guided by equity theory and addressed the imbalance between daily received and provided support and the extent to which reciprocal exchanges of received and provided support were associated with end-of-day well being. An additional aim was to examine whether these effects were different for patients and partners. A diary method was used to assess both patient's and partner's received and provided emotional and instrumental support and their end-of-day positive and negative mood and self-esteem. It was examined whether a change in end-of-day mood or self-esteem between day one and day two was related to the occurrence of receiving support, providing support or an interaction between both (reciprocal exchanges of support) in both patients and partners.

In Chapter 4, the association between daily received negative responses from the partner and end-of-day positive and negative mood was examined in both patients and their intimate partners. Additionally, the moderating role of receiving emotional support on the same day was examined. The same design was used as in Chapter 3. It was examined whether a change in end-of-day mood between day one and day two was related to the occurrence of negative responses, whether this effect was dependent on received emotional support and whether this was different for patients and partners.

Chapter 5, extends Chapter 4 and examined the effects of emotional support and negative responses received from the partner on anxiety and depression prospectively in both patients and partners. In this study both partners completed questionnaires with respect to their levels of anxiety and depression at baseline and at seven months follow-up. Additionally, emotional support and negative responses received from the partner were assessed using a diary method.

In Chapter 6 the association between perceptions of inequity in patients and partners on the one hand and patient's physical disability on the other was examined, as well as the impact of perceived inequity on depression in patients and partners. This was tested using a prospective design that examined the impact of perceived inequity on depression at seven months follow-up.

Finally, in the concluding chapter of this dissertation, the main results of all studies are summarized and discussed (Chapter 7).

Chapter 2

Maintaining a supportive relationship when one partner is diagnosed with multiple sclerosis (MS): the role of patient's distress and disability

Abstract

For couples dealing with chronic illness it may be difficult to maintain a supportive relationship. The current study addressed this issue by examining the relation between patient's disability and distress (anxiety and depression) and the amount of emotional, instrumental and negative support that patients and partners provided to one another among couples dealing with multiple sclerosis (MS). Sixty-one patients and partners dealing with MS completed questionnaires and kept a diary for fourteen days to assess their support provision. The results showed that patient's disability was related to both patients' and partners' provision of instrumental support, but not to the provision of emotional support. Contrary to our expectations, patient's distress was not related to a decrease in the provision of emotional or instrumental support. Further, patients and partners provided more negative responses to one another when the patient was more disabled or more anxious. In contrast, both patients and partners reported providing less negative responses when the patient was more depressed.

Introduction

MS is a chronic and often disabling disease of the central nervous system, starting in young adulthood (i.e. between the ages of 20 to 40). The disease may start gradually or acute and the course of the disease among MS patients varies widely (Lublin & Reingold, 1996). In most patients, periods of relapse are followed by periods of remission. However, a progressive decline in health is also possible (Lublin & Reingold, 1996). Clinical symptoms in MS patients are very diverse and include loss of function, debilitating fatigue, visual problems, or loss of balance (Mohr & Dick, 1998). Given the nature of MS, both patients as well as their intimate partners must learn to live with the uncertainty of the disease's progression, increasing physical disability and the psychosocial consequences (Antonak & Livneh, 1995; McKeown, Porter-Armstrong, & Baxter, 2003; Mohr & Cox, 2001). Not all couples manage to deal successfully with the stressful demands of the disease which can be inferred from the high levels of depression and anxiety in patients (Minden, 2000) and partners (McKeown et al., 2003; Pakenham, 2001).

One factor that may play an important role in patient's and partner's adjustment to chronic illness is being involved in a supportive relationship (Sarason, Sarason, & Gurung, 2001). For patients, support from the partner can help them deal with the practical demands and the emotional distress generated by the disease (Cutrona, 1996; Murray, 1995). Likewise, partners may also need support from their ill partner to deal with the situation. Research suggests that the amount of support that healthy partners receive from their ill partner is an important predictor of the healthy partner's well-being (Kriegsman, Penninx, & van Eijk, 1994). However, for couples dealing with chronic illness, it may be difficult to maintain a supportive relationship. Living with a chronic illness can be stressful, both for patients and for partners (Martire & Schulz, 2001; Mohr & Cox, 2001). This may affect the ability to provide support to one another. Considering the critical role of spousal support for well-being, it is

important to examine factors that interfere with the continuance of a supportive relationship during the course of chronic illness. The current study focused on two possible factors that may affect support provision, that is, the patient's physical disability and the patient's emotional distress.

A supportive relationship can be characterized by high levels of emotional support (i.e., the communication that one is valued and cared for), high levels of instrumental help, (i.e., the provision of aid or assistance), and the absence of negative interactions (i.e., actions that cause the individual to experience distress and at least have some reservations about the relationship itself (Rook, 1992). In the context of chronic illness, instrumental support may be most important for patients with greater disabilities whereas emotional support will be needed to deal with the emotional distress provoked by the disease (Helgeson & Cohen, 1996). The absence of negative interactions, however, is important regardless of the nature of the stressor. Although negative interactions generally occur less often than does positive support, its effect is detrimental and more potent than the impact of positive interactions (Manne, Taylor, Dougherty, & Kemeny, 1997; Rook, 2001). In this study, we were interested in the relation between the patient's level of disability and distress and these three different types of support provision: emotional support, instrumental support and negative responses.

The patient's level of disability is likely to be related to the amount of support that the healthy partner provides (Cutrona, 1996). Taking care of a chronically ill partner often involves taking on new responsibilities, which includes providing support and help with several tasks that the ill partner can no longer perform (Martire & Schulz, 2001). Several studies have shown that significant others provide higher levels of support in response to increased physical disability (e.g. Bolger, Foster, Vinokur, & Ng, 1996; Revenson & Majerovitz, 1990; Moyer & Salovey, 1999). However, most studies do not distinguish between emotional support and instrumental support. Patient's with higher levels of disability will probably have higher needs for practical help, but do not necessarily need more emotional support. For example, in a study among patients dealing with myocardial infarction, Bennett and Connell (1999) documented that the patient's physical limitations were related to higher perceived availability of instrumental support, but were unrelated to the perceived availability of affective support. At the same time, the additional caregiving responsibilities may generate distress in partners. This may result in an increase in negative responses provided by the partner to the patient (e.g. Revenson & Majerovitz, 1990; Manne, Alfieri, Taylor, & Dougherty, 1999; Thompson, Galbraith, Thomas, Swan, & Vrungos, 2002).

Most research that considers the impact of one partner's distress on the other partner's support provision is based on Coyne's interpersonal model of depression (Coyne, 1976). This theory infers that it is difficult to respond empathically to individuals who are depressed. The distress of depressed people can induce a negative mood in the support provider, and over time, they may reduce their support (Coyne, Burchill, & Stiles, 1991). In the context of illness, studies have found that significant others of distressed patients with cancer reduced

their support in response to the patient's distress (Bolger et al., 1996; Moyer & Salovey, 1999). However, other studies showed an increase in support from the spouse in response to the distress of chronically ill patients (Revenson & Majerovitz, 1990) or observed no effect (Helgeson, 1993). Again these studies did not differentiate between emotional and instrumental support. It is possible that the effects of the patient's distress on the partner's support provision may be different for emotional and instrumental support. If the partner believes that the patient is not dealing very well with the illness, partners may reduce their emotional support because they perceive their efforts as ineffective, while they may maintain their instrumental support. Additionally, they may criticize the patient for not dealing very well with the illness, or they may behave in an unkind manner and as such negative responses may increase in response to the patient's distress (Manne et al., 1997; Thompson et al., 2002).

Not much attention has been given to the relation between the patient's disability and distress and the patient's ability to be supportive. For the most part, social support research in the context of chronic illness is focused on the patient as the support receiver and the partner as the support provider, thereby neglecting the fact that patients may also provide support to their partner (Martire & Schulz, 2001). Although it is highly likely that patient's disability may impede the patient from providing practical help to their partner, it may not necessarily affect the patient's ability to provide emotional support (Thompson & Pitts, 1992). Additionally, being disabled often implies being dependent on the spouse for help (Pistrang & Barker, 1995). Not being able to manage on your own and accomplish all the activities you used to do may be frustrating for patients. Indeed, individuals who were experiencing more physical symptoms expressed more irritability towards their partner (Lane & Hobfoll, 1992). In addition, a patient who is experiencing high levels of distress may be so preoccupied with their own difficulties in dealing with the disease, that it can be difficult for them to provide support (Coyne, Wortman, & Lehman, 1988). This may apply especially to emotional support. Further, not being able to deal with the disease effectively may be frustrating which may be expressed to the partner through an increase in negative responses.

In the present study, we were interested in the relation between patient's disability and distress and actual support exchanges and not the perceived availability of support. The latter refers to the perception that support is available when needed and is highly related to concepts such as relationship satisfaction (Kaul & Lakey, 2003). Actual support refers to the occurrence of supportive behaviors. However, actual support is difficult to assess. So far, most studies used self-report questionnaires that measure someone's perception of the support they received. However, these instruments are sensitive to retrospective bias and it is not known how these self-report questionnaires relate to actual support. The only true way to measure actual support is by observing couples (Helgeson, 2003). However, observational studies are most of the time performed in laboratories, which raises questions about their generalizability (Helgeson, 2003). The present study used a daily diary method to assess spousal interactions. Although this method relies on self-report as well, it partly overcomes

the retrospective bias of self-report questionnaires by assessing behaviors near the time they occur (Bolger, Davis, & Rafaeli, 2003).

The present study examined the relation between patient's disability and emotional distress and support provision by both patients and partners. First, with respect to patient's disability, we expected that the amount of emotional support that patients and partners reported providing would not be related to patient's level of disability. Further, we expected that partners would provide more instrumental support to patients with greater disability and that patients would provide less instrumental support when they were more disabled. Finally, we expected that both patients and partners would provide more negative responses when the patient was more severely disabled. Second, with regard to the patient's distress, we expected that both patients and partners would provide less emotional support to the other partner when the patient had a higher level of emotional distress. Additionally, we expected that the amount of instrumental support that patients and partners reported providing would not be related to the patient's level of emotional distress. Finally, when the patient was more emotionally distressed, we expected that both patients and partners would provide more negative responses.

Method

Participants

MS patients and their intimate partners were recruited via one MS Centre and the neurology department of one hospital in the Netherlands. MS patients who were registered in the patient files of these clinics received a letter including information about the study and a description of the inclusion criteria. As information on inclusion criteria were not available from the patient files (e.g. we do not know how many of these patients were involved in an intimate relationship), we distributed letters to all 390 patients that were registered. This means that the number of couples who responded to the information letter cannot be used to calculate response rates. Couples were eligible for inclusion if: a) one partner was diagnosed with MS, (b) patients were currently involved in a heterosexual relationship with minimum relationship duration of one year, (c) patients were living together with their intimate partner, and (d) both partners were willing to participate in the study. Couples were excluded when they had insufficient understanding of the Dutch language or when one or both partners suffered from serious psychiatric problems or medical problems other than MS.

Seventy couples were eligible for inclusion, responded to the information letter and signed informed consent. Of the 70 couples, a final sample of 61 couples completed all the materials. Reasons mentioned for drop out were MS related health problems ($n=3$) and personal reasons ($n=3$). Three couples did not give a reason for drop-out. Of the patients with MS, 87% ($n=53$) were female and 13% ($n=8$) were male. Compared to the distribution of MS in the community (2 to 3:1, Zwanikken, 1997) female patients were slightly overrepresented in the present study. The mean age of patients was 47 years (range= 27-64, $SD = 8.5$). On average they had

been diagnosed with MS 8 years previously (range = 1-33, $SD = 6.0$). Thirty-one percent of the patients were employed (12% full-time and 20 % part-time), the other patients received a disability benefit (51%), performed household duties (10%) or were unemployed for other reasons (8%). The partners of these patients were, on average 49 years (range = 29-69, $SD = 9.4$). Most partners (80%) were employed (61% full-time and 19% part-time), the other partners were retired (11%) or were unemployed for other reasons (9%). Twenty-three percent of the patients and 27% of the partners had completed the lowest level of secondary (vocational) education only, 41% of the patients and 40% of the partners had completed middle to higher levels of secondary (vocational) education, and 36% of the patients and 33% of the partners had a college degree or higher. The couples had been married (92 %) or cohabiting (8 %) for an average of 23 years (range= 2-41 years, $SD = 10.0$) and most couples had children (77%).

Procedure

Prior to the diary part of the study, patients and partners completed questionnaires concerning demographics, physical disability, psychological distress and relationship satisfaction at home. Next, the couples were visited at home by the first author or a research assistant (1-4 weeks after the questionnaires had been returned) to provide additional information and instructions about the diary part of the study and to install an electronic diary on the couple's computer. Participants who did not own a computer were provided with a computer from the university. Computer software was developed especially for this study. The electronic diary was user friendly and easy to complete. Even participants who had little or no experience with computers were able to use the program after they were given clear instructions. Participants were instructed to complete the electronic diary every evening before going to bed, starting the following day, for fourteen days. Participants were explicitly asked not to exchange the answers with their partner while completing the diaries. The diary was designed to be completed in 5-10 minutes. Recordings were saved on a floppy disk each night and the participants did not have access to their reports after they were saved on the floppy disk. After two weeks, the couples returned the floppy disk containing each night's responses by mail.

To verify compliance, the date and time of recordings were saved on the floppy disk. Participants were allowed to fill out the diary the next morning if they did not manage to do it at night. 2.6 % of the diaries were completed the next morning. Diaries that were completed too early (before 2 pm) or too late (after 2 pm the next morning) were considered unreliable and were excluded from further analysis. This was the case for 1.6 % of the recordings. Additionally, participants who completed less than 10 days during the fourteen day period were excluded from further analyses. For this reason, we excluded two healthy partners who completed 6 and 9 days of recordings, respectively. Across the fourteen day period, participants reported an average of 13.1 days of recordings.

Instruments

Questionnaire measures

Patient's *psychological distress* was assessed with the Hospital Anxiety and Depression Scales (HADS; Zigmond & Snaith, 1983). This scale measures symptoms of anxiety and depression which can be considered an indicator of psychological distress. Fourteen items make up this questionnaire and each item can be scored on a four-point scale, with higher scores indicating higher levels of anxiety and depression. Scores between 8 and 10 are considered clinically borderline and scores of 11 and higher are considered clinically definite levels of anxiety and depression. The HADS is relatively free of criterion contamination by somatic items and is therefore appropriate for use in patients suffering from chronic illness. The instrument has proven to be valid and reliable in Dutch patient samples (Spinoven, Ormel, Sloekers, Kempen, Speckens, & van Hemert, 1997). Cronbach's alpha was .85 for the anxiety scale and .74 for the depression scale.

Patient's level of *physical disability* was assessed with the incapacity status scale (ISS; Kurtzke, 1981). The ISS provides a measure of severity of the physical disability caused by MS. For this study, the structured interview was adapted to a self-report questionnaire format, to be completed by patients. The sixteen items were rated on a five point scale ranging from 0 (normal functioning) to 4 (complete inability). The summated items indicate the amount of impairment MS patients experience. 'Healthy' individuals have scores of 0 and MS patients with a score up to 16 can be considered as affected but unimpaired. A score higher than 16 suggests impairment. The reliability of the scale, Cronbach's alpha, in this study was .85.

Patient's and partner's *relationship satisfaction* was included in the study as a control variable because ample research has shown that relationship satisfaction is correlated with support provision in intimate relationships (e.g. Kaul & Lakey, 2003; Revenson & Majerovitz, 1990). Relationship satisfaction was assessed with the relational interaction satisfaction scale (RISS; Buunk & Nijskens, 1980). This scale consists of eight summated items that assess the satisfaction with the interaction with the intimate partner. Items were scored on a five point scale ranging from never (1) to very often (5). The reliability of the scale, Cronbach's alpha, in this study was .80 for patients and .85 for partners. The correlation between the scores of patients and their intimate partners was .76.

Daily measures

Spousal interactions were assessed using a daily diary method. Both partners of the couples facing MS reported the amount of support they provided to their partner, on fourteen consecutive days. We distinguished between patients' and partners' provided emotional support, instrumental support and negative responses. *Emotional support provided* was assessed with three items: "I gave my partner a compliment", "I listened to my partner", and "I showed affection towards my partner". The answers were given on a 4-point scale (0 = not at all, 3 = very much). The items were averaged to form a scale for daily emotional

support provided. Internal consistency of the scales was calculated based on the aggregated scores over the 14 days; Cronbach's alpha was .79 for patients and .81 for partners. *Instrumental support* was assessed with one item "I gave my partner practical help", which was scored on a 4-point scale (0 = not at all, 3 = very much). *Negative reactions* were assessed with four items: "I criticized my partner", "I avoided my partner", "I hurt my partners' feelings", "I demanded a lot of my partner". The answers were given on a 4-point scale (0 = not at all, 3 = very much). The four items were averaged to form a scale that assessed daily negative provided support. However, the occurrence of negative responses was rare and the participants almost never used the higher scores of the scale which resulted in strongly skewed distributions. Therefore, the scale was dichotomized into one variable that indicated the absence or presence of a negative response on a certain day. Consequently, we did not distinguish between the effects of the different support items, nor did we differentiate between the strength of the responses that were reported.

Statistical Analyses

Multi-level regression modeling, as implemented in the program MLWin (Rasbash, Browne, Goldstein, & Yang, 2000) was used to determine the relationship between the predictors and the dependent variables. Multilevel modeling was used because our data was hierarchically nested with days (level 1) nested within persons (level 2), and persons nested within couples (level 3).

Multilevel modeling can be considered as a sophisticated regression analysis for data with a nested design (Hox, 2002). Separate regression analyses were performed for the three outcome variables, emotional support provided, instrumental support provided and negative responses provided. Provided support was predicted by patient's disability, anxiety and depression, while controlling for relationship satisfaction. In preliminary analyses we included several other potential covariates (relationship length, year since diagnosis, education). Although these variables sometimes showed significant effects on the dependent variables, the results remained the same. Therefore the analyses were presented with relationship satisfaction as a control variable only. Further, to examine whether the relations between patient's anxiety, depression and disability and provided support were different for patients and partners, we included interactions between role (patient or partner) and the predictor variables (disability, anxiety and depression) in the model.

All outcome variables were assessed at the lowest level, that is day. There were no predictor variables at the diary level. Patient's disability, anxiety and depression were assessed at the between couple level, that is, they vary between couples but not within couples. Relationship satisfaction and role were assessed at the between person level, that is, they may vary between and within couples. Because there were no predictor variables at the diary level, these analyses involve very basic level 1 models in which the outcome is simply

specified to be a function of an intercept and an error. In essence we are simply computing the person's average outcome over the fourteen days.

Linear regression analyses were performed for the equation predicting emotional support and instrumental support¹. However, the variable negative responses provided was treated as a dichotomous variable. Therefore, multilevel logistic regression analysis was performed to predict this outcome measure. In MLWin we used logit transformation and the estimation procedure that we used was penalised quasiliikelihood (PQL), 2nd order approximation (Hox, 2002). All predictor variables were grand mean centered (i.e. the overall mean was subtracted from the values of a variable), thus the regression intercept represents provided support when all variables are at their average level. The role variable (patient or partner) is effect coded with patients coded as -.5 and partners as .5. An alpha level of .05 was used for all statistical tests. The predictors were entered in the regression equation hierarchically, starting with the control variable, followed by role, the main effects and the interaction effect between role and the main effects. When significant interaction effects were found, regression equations were estimated for persons scoring 1 *SD* below and 1 *SD* above the mean of the interaction variables.

Results

Descriptive analyses of determinants and dependent variables

Descriptive statistics of the key study variables are presented in Table 1. Patients scored 14.2 on average (*SD* = 9.5) on the measure of physical disability, suggesting that the present sample of MS patients showed large variance in disability. All patients had a score higher than 0, which implies that all patients were at least mildly affected by the disease. Thirty-six percent of the patients had a score higher than 16 which indicates impairment. Patient's physical disability was positively related to patient's level of depression, but not to patient's level of anxiety (see Table 1). MS patients had higher levels of depression than did controls from a Dutch population sample (Spinoven et al., 1997), although this difference was only marginally significant. MS patients mean score of depression was 4.2 (*SD* = 2.7), whereas mean scores of depression in the healthy population was 3.4 (*SD* = 3.3) ($p = .08$) (Spinoven et al., 1997). Ten percent of the MS patients had clinically relevant levels of depression (score ≥ 8). Patients did not differ from controls from a Dutch population sample with respect to their levels of anxiety. Mean score of anxiety in MS patients was 5.5 (*SD* = 4.0), whereas

¹ We treated provided instrumental support as a continuous variable, rather than an ordinal variable. Strictly speaking this is not correct. We therefore also conducted logistic regression analyses using dummy coding to predict instrumental support. As the logistic analyses using dummy coding are more difficult to interpret, we decided to report the linear regression analyses.

Table 1 Correlation matrix and descriptive statistics of *patient's* anxiety, depression, physical disability and provided support

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---------------------------------|--------|--------|-------|--------|-------|-------|-------|-----|-----|
| 1. Patient's anxiety | - | | | | | | | | |
| 2. Patient's depression | .52*** | - | | | | | | | |
| 3. Patient's disability | .14 | .36** | - | | | | | | |
| 4. Emotional support patient | -.04 | -.25** | -.18 | - | | | | | |
| 5. Instrumental support patient | .14 | -.09 | -.30* | .65*** | - | | | | |
| 6. Negative responses patient | .08 | -.02 | .26* | .31* | .22 | - | | | |
| 7. Emotional support partner | -.04 | -.26* | -.14 | .77** | .64** | .16 | - | | |
| 8. Instrumental support partner | .05 | .20 | .41** | .32** | .22 | .26* | .46** | - | |
| 9. Negative responses partner | .12 | -.21 | .02 | .31* | .47** | .38** | .12 | .11 | - |
| Mean | 5.5 | 4.2 | 14.2 | 1.9 | 1.2 | 4.3 | 1.7 | 1.7 | 3.7 |
| SD | 4.0 | 2.7 | 9.5 | .7 | .8 | 4.1 | .7 | .9 | 3.5 |

Note Correlations are pearson's correlations. Correlations are based on the aggregated score of emotional support provided, instrumental support provided and negative responses provided. Mean score for emotional and instrumental support indicate the average amount of support that patients or partners reported providing per day (on a 0-3 scale). Mean scores for negative responses indicate the average number of days that patients or partners provided negative responses. * $p < .05$, ** $p < .01$, *** $p < .001$

controls scored 5.1 ($SD = 3.6$) on average ($p = .49$) (Spinhoven, et al., 1997). Twenty-one percent of the MS patients had clinically relevant levels of anxiety (score ≥ 8). Patient's levels of anxiety were related to their levels of depression, but not to other predictors (see Table 1).

Consistent with previous studies (e.g. Rook, 2001) negative interactions occurred not very often (see Table 1) and 30% ($n=18$) of the patients and 20 % ($n=12$) of the partners did not report having provided negative responses during the fourteen day period. All patients and partners reported having provided emotional support. Finally, one patient (2%) reported not having provided instrumental help to his or her partner.

Table 2 Emotional support provided predicted by patient's disability, anxiety and depression.

| | Support provision | | | |
|----------------------------------|-------------------|-----|------|-----|
| | B | SE | Beta | P |
| Intercept | 1.79*** | .08 | | .00 |
| Step 1 Relationship satisfaction | .04** | .01 | .23 | .00 |
| Step 2 Role (patient or partner) | -.11 | .07 | -.06 | .09 |
| Step 3 Disability | -.01 | .01 | -.08 | .19 |
| Depression | -.04 | .04 | -.11 | .36 |
| Anxiety | .02 | .02 | .07 | .52 |
| Step 4 Role*disability | <i>ns</i> | | | |
| Role*depression | <i>ns</i> | | | |
| Role*anxiety | <i>ns</i> | | | |

Note * $p < .05$, ** $p < .01$, *** $p < .001$

Beta's for interaction variables are only shown when significant.

Emotional support

Table 2 shows the results of the final model of the multilevel analysis predicting emotional support provided by patients and partners as a function of patient's level of disability, anxiety and depression. The intercept indicates that the average amount of emotional support that was provided by a patient or partner on a day was 1.8 (on a 0-3 scale). Additionally, relationship satisfaction contributed significantly to the regression equation in the first step of the analysis. Patients or partners with a higher relationship satisfaction reported providing more emotional support. In step 2, role (patient or partner) was entered but did not contribute significantly to the equation, indicating that patients and partners did not differ with respect to the amount of emotional support that they reported providing. In step 3, the main effects of patient's disability, anxiety and depression were entered. As expected, patient's level of disability was not related to the amount of emotional support that patients and partners provided. However, contrary to our expectations, a relation between patient's levels of anxiety and depression on

one hand and the amount of support that patients and partners provided on the other hand was absent. Finally, there were no interaction effects of role and the main effects, that is, the relation between patient's level of disability, anxiety and depression and the amount of emotional support that was provided was not different for patients and partners.

In sum, the amount of emotional support that patients and partners provided to the other partner was not related to the patient's disability, anxiety or depression.

Table 3 Instrumental support provided predicted by patient's disability, anxiety and depression.

| | Support provision | | | |
|----------------------------------|-------------------|-----|------|-----|
| | B | SE | beta | p |
| Intercept | 1.48*** | .08 | | .00 |
| Step 1 Relationship satisfaction | .05** | .02 | .19 | .01 |
| Step 2 Role (patient or partner) | .58*** | .11 | .24 | .00 |
| Step 3 Disability | .00 | .01 | .15 | .82 |
| Depression | .04 | .04 | .10 | .29 |
| Anxiety | .01 | .03 | .03 | .69 |
| Step 4 Role*disability | .06*** | .01 | .23 | .00 |
| Role*depression | .09 | .05 | .10 | .11 |
| Role*anxiety | -.08* | .03 | .12 | .03 |

Note * $p < .05$, ** $p < .01$, *** $p < .001$

Beta's for interaction variables are only shown when significant.

Instrumental support

The model to predict instrumental support provided by patients and partners as a function of patient's disability, anxiety and depression, is shown in Table 3. The intercept indicates that the average amount of instrumental support that was provided by patients or partners on a certain day was 1.5 (on a 0-3 scale). In the first step, relationship satisfaction contributed significantly to the regression equation. Patients or partners with higher relationship satisfaction reported providing more instrumental support. In step 2, role (patient or partner) was significantly and positively related to the amount of instrumental support that was reported providing. Partners reported providing more instrumental support than patients. Additionally, in step 3, the main effects of patient's disability, anxiety and depression did not contribute significantly to the regression equation. Finally, the interactions between role and the main effects were entered in the regression equation to examine whether the relation between patient's disability, anxiety and depression and the amount of instrumental support that was reported providing was different for patients and partners. With respect to the patient's level of disability, the interaction was significant and in line with our expectations.

As shown in Figure 1, patient's who were more severely disabled provided less instrumental support ($b = -.03, p < .01$). The opposite was observed for partners: partners of patients who were more severely disabled reported providing more instrumental support ($b = .03, p < .01$). With respect to the patient's level of anxiety, the interaction proved significant as well. As Figure 2 shows, more anxious patients reported providing more instrumental support, although the simple slope was only marginally significant ($b = .05, p < .10$). In contrast, patient's level of anxiety was unrelated to their partner's provision of instrumental support ($b = -.03 ns$). Finally, the interaction between patient's level of depression and role (patient or partner) was not significant.

In sum, more severely disabled patients reported providing less instrumental support to their partner and the healthy partner provided more instrumental support to the ill partner, which was in line with our expectations. Unexpectedly, patients with higher levels of anxiety reported providing more instrumental support to their partner. Further, in line with our expectations, patient's level of depression was unrelated to the amount of instrumental support that was provided by patients or partners.

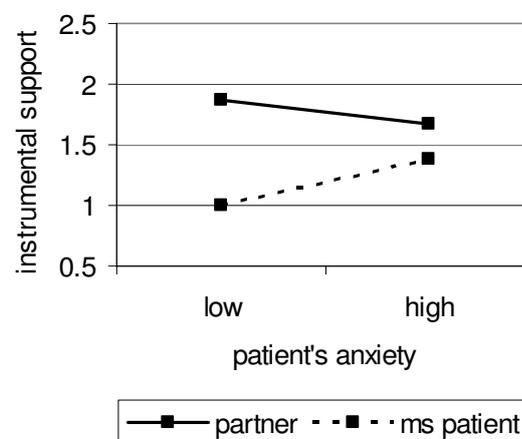
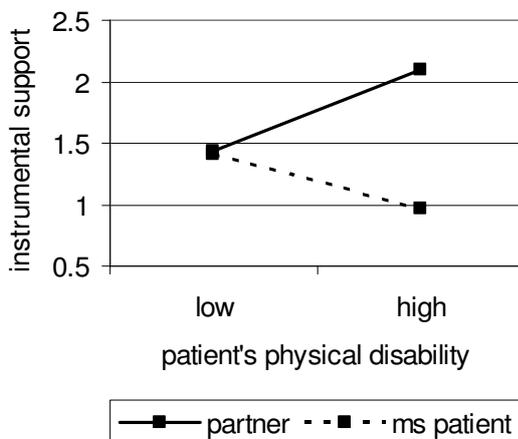


Figure 1 Instrumental support provided as a function of patient's level of disability for MS patients and their partners.

Figure 2 Instrumental support provided as a function of patient's level of anxiety for MS patients and their partners.

Table 4 Negative responses provided predicted by patient's disability, anxiety and depression.

| | Support provision | | |
|----------------------------------|-------------------|-------------|-----|
| | Odd's ratio | CI 95% | P |
| Intercept | .30 | | .00 |
| Step 1 Relationship satisfaction | .94 | .88 - 1.01 | .10 |
| Step 2 Role (patient or partner) | .72 | .44 - 1.16 | .18 |
| Step 3 Disability | 1.04* | 1.01 - 1.08 | .02 |
| Depression | .78*** | .66 - .92 | .00 |
| Anxiety | 1.12* | 1.01 - 1.22 | .03 |
| Step 4 Role * disability | <i>ns</i> | | |
| Role * depression | <i>ns</i> | | |
| Role * anxiety | <i>ns</i> | | |

Note * $p < .05$, ** $p < .01$, *** $p < .001$

Odd's ratio and *CI 95%* for interaction variables are only shown when significant.

Negative interactions

Multilevel logistic regression analysis was performed to predict the likelihood that patients or partners provided negative responses on a day. The results are shown in Table 4. The intercept indicates that the odd's ratio of providing negative responses to the partner on a day is .30. That is, a patient or partner is likely to report having provided negative responses to the other partner on approximately one in three days, on average. In step 1, relationship satisfaction was entered, but this did not contribute significantly to the regression equation. Additionally, role was entered in the regression equation in step 2, but did not contribute significantly. Thus, the likelihood of providing negative responses to the partner did not differ between patients and partners. In step 4, the main effects were entered and all contributed significantly to the regression equation. In line with our expectations, the likelihood of providing negative responses to the other partner was higher when the patient was more severely disabled. Also in line with our expectations, the likelihood of providing negative responses was higher when the patient had higher levels of anxiety. Further, contrary to our expectations, the likelihood of providing negative responses to the partner was lower when the patient was more depressed. Finally, there were no interaction effects of role and the main effects indicating that the relation between patient's disability, anxiety and depression and the amount of negative responses that were reported providing, did not differ between patients and partners.

In sum, when the patient was more severely disabled, both patients and partners reported providing more negative responses to the other partner. Additionally, when the patient was more anxious, both patients and partners reported providing more negative responses to the other partner, as well. However, in contrast, when the patient was more depressed, both patients as well as their healthy partners provided less negative responses.

Discussion

The present study examined the relation between patient's levels of disability and emotional distress (anxiety and depression) and the amount of emotional support, instrumental support and negative responses that patients and their intimate partners reported providing to one another. An important feature of the study was that we focused on both patients and their intimate partners as support providers and that we distinguished between emotional and instrumental support.

As expected, partners of more severely disabled patients reported providing more instrumental help to their partner, however, they did not report providing more emotional support. Most studies that investigated the relation between the patient's disability and the amount of support that partners provided showed an increase in support in response to the patient's disability (Bolger et al., 1996; Moyer & Salovey, 1999; Revenson & Majerovitz, 1990). However, these studies did not differentiate between emotional and instrumental support. The results of our study suggest that the mobilization of support in response to the patient's disability was limited to instrumental support and did not affect the amount of emotional support that partner's provided. Additionally, as we predicted, more severely disabled patients reported providing less instrumental support to their partner, however they did not provide less emotional support. This supports the notion that patient's disability may affect the patient's ability to provide instrumental support, however, that it not necessarily affect the amount of emotional support provided (Thompson & Pitts, 1992).

In line with other studies (e.g. Revenson & Majerovitz, 1990; Manne et al., 1999) we found that partners provided more negative responses to their ill partner, when the patient was more disabled. Additionally, more severely disabled patients provided more negative responses as well. Our study does not indicate why patients and partners reported providing more negative responses when the patient was more disabled. Due to the patient's disability, patients and partners are often forced to take on new roles and responsibilities. For partners, it is possible that the help needed by patients may conflict with their own needs. Manne and colleagues (1999), for example, found in a sample of cancer patients that a restriction in partner's activities mediated the relationship between the patient's disability and the amount of negative responses that was provided by partners. Additionally, as a care recipient, the patient is often being placed in a position of dependence (Cutrona, 1996). Not being able to manage on your own may be frustrating, and this frustration may be expressed to partners (Lane & Hobfoll, 1992).

With respect to the patient's level of anxiety and depression, we did not find support for the notion that partners reduce their provision of emotional support in response to the patient's anxiety or depression as was found in some other studies (Bolger et al. 1996; Moyer & Salovey, 1999). Additionally, patients with higher levels of anxiety or depression did not report providing less emotional or instrumental support. In contrast, patients who were more anxious reported providing more instrumental support to their partner. This result was

unexpected and we do not know why more anxious patients reported providing more instrumental support. In the context of chronic illness, anxiety often includes fear of the future and involves loss of control. Although highly tentative, it may be that patients provide more instrumental support to their partner to compensate for the loss of control. Further, it is important to notice that our sample was not very distressed, that is, they did not experience high levels of anxiety or depression (although the patients were more depressed than the general population). It is possible that higher levels of distress in patients do affect their ability to provide emotional support, for example. Additionally, we postulated that the partner's willingness to provide support may depend on the extent to which they blamed the patient for not dealing effectively with the illness. It is possible that partners perceived the patient's distress as a normal reaction to the illness, therefore they did not attribute the distress to the patient's incompetence, and they did not reduce support.

The results with respect to the relation between the patient's distress and the amount of negative support that was provided by patients and partners were different with regard to the patient's depression and anxiety. The results for depression showed that patients and partners provided less negative responses to the other partner when the patient was more depressed, which was in contrast with our expectations. Depression in the context of chronic illness typically reflects the loss of one's physical well-being (Antonak & Livneh, 1995). It has been argued that, providers of support are more willing to provide support in situations that include loss, are conceivable or controllable (Dunkel-Schetter & Skokan, 1990; Revenson, 1994). It is possible that in the context of chronic illness, depression may be seen as an appropriate reaction to the disease by the healthy partner. Therefore partners may not respond with criticism, avoidance or demand too much.

In contrast with the results for depression, patients and partners provided more negative responses to the other partner when the patient was more anxious. An important difference between depression and anxiety is that depression reflects loss, whereas anxiety may include fear for the future (Antonak & Livneh, 1995). This implies that anxiety is uncontrollable and offers little options for the partner to be helpful. Therefore, patient's anxiety may be more difficult for the partner to deal with. Moreover, anxiety may remind partners of their own fear for the future with the ill partner and emphasizes their own distress. It has been documented that patient's level of anxiety is highly related to the partner's level of anxiety (Pakenham, 1998). When both patient and partner are anxious they may both criticize the other for not dealing very well.

Apart from the relation between patient's level of disability and the amount of instrumental support that was provided, the relation between disability and distress and support was similar for patients and partners. Apparently, the patient's disability and distress has comparable consequences for the amount of support that patients and partners report providing. Many researchers suggest that patients and partners react to chronic illness as a unit, that is, the reaction of one partner to the illness is highly related to the reaction of the

other partner (Pakenham, 1998). This may explain why the patient's distress and disability may have comparable effects on the patient's and the partner's support provision.

Some limitations of the present study have to be noted. First, given that the majority of our sample consisted of female patients and male partners, we were unable to address gender differences. There is evidence that women and men attach different meanings to supportive behaviors and that women are more attentive to others and more aware of spousal interactions (Acitelli & Antonucci, 1994). Some of our findings may have been different if we had considered male patients and female partners, which may limit the generalizability of the present results. Second, we do not know whether the pattern of findings is specific to couples facing MS or whether the findings can be generalized to other chronic diseases. We assume that our findings apply to other resembling diseases as well, such as rheumatoid arthritis. Finally, our results are based on self-report and we cannot tell whether the behaviors actually occurred. Although our design precludes causal interpretation, we protected against many methodological flaws, such as retrospective bias, by using a diary method, and mood related bias, by conducting the questionnaire assessment prior to the support measures.

To conclude, the current study examined how the patient's disability and distress (anxiety and depression) may interfere with the maintenance of a supportive relationship when one partner is diagnosed with a chronic illness. An important finding was that patient's disability may affect the amount of instrumental support that is provided, however, it does not necessarily affect the amount of emotional support provided. Further, patients and partners reported providing more negative responses to one another when the patient was more disabled or more anxious. In contrast, when the patient was more depressed, both patients and partners reported providing less negative responses. The results provide valuable insight into the conditions under which patients or partners provide more or less support.

Chapter 3

Receiving and providing support in couples dealing with multiple sclerosis (MS): A diary study using an equity perspective

Abstract

This study examined the effects of daily support exchanges in couples facing multiple sclerosis (MS). Two issues were examined: the imbalance between received and provided support, and the extent to which reciprocal exchanges of received and provided support are associated with end-of-day well-being (positive and negative mood and self-esteem). Guided by equity theory we expected that one-sided support provision or receipt would be harmful for well-being for both patients and partners. We argued that these negative outcomes could be offset by reciprocating support, that is, when both partners receive and provide support. Sixty-one patients and their partners filled out questionnaires on demographics and disease related characteristics and subsequently completed computerized daily diaries for fourteen days. At the end of each day both partners completed diaries on end-of-day mood, self-esteem, received and provided emotional and instrumental support, and several control variables (daily hassles, and MS related symptoms for patients). Reciprocity in instrumental support transactions was associated with higher levels of self-esteem among both patients and partners. However, the other results all showed independent effects of support received and provided. Patients' well-being was related to providing emotional support and instrumental support, whereas partners' well-being was related to receiving emotional support from patients.

Introduction

Many studies have described the beneficial effects of spousal supportive behaviors on well-being in general (e.g. Burman & Margolin, 1992), as well as on adjustment to chronic illness (e.g. Cutrona, 1996). In the literature, a conceptual distinction has been made between the perceived availability of support and actual received support or enacted support (Dunkel-Schetter & Bennett, 1990). It is now generally acknowledged that the global perception that support is available when it is needed is related to greater psychological and physical well-being (e.g. Lindorff, 2000; Sarason, Sarason, & Gurung, 2001). However, results are less consistent when the effects of actual received support are studied. Some studies have documented positive effects (e.g. Manne & Zautra, 1989; Riemsma, Taal, Wiegman, Rasker, Bruijn, & van Paassen, 2000), whereas others have shown neutral effects (e.g. Bolger, Foster, Vinokur, & Ng, 1996), or even negative effects (e.g. Bolger, Zuckerman, & Kessler, 2000; Newsom & Schulz, 1998).

One explanation that has been offered for these negative findings is that the receipt of social support and help may only contribute to well-being when it is given within a relationship that is characterized by reciprocal patterns of exchange (Antonucci & Jackson, 1990; Buunk & Schaufeli, 1999). A recent study by Gleason and colleagues (Gleason, Iida, Bolger, & Shrout, 2003), for example, showed that receiving support had a negative impact on mood only when the recipient failed to provide support in return. Moreover, the fact that providing support may be rewarding in itself and thus may have a positive impact on well-

being has often been overlooked (Liang, Krause, & Bennett, 2001). The present study aimed to further our understanding of the association between reciprocal exchanges of social support and well-being among couples in which one partner is diagnosed with a chronic illness (i.e. multiple sclerosis). An important feature of the study was that both patients and partners were considered as providers as well as receivers of social support. For the most part, social support research in the context of adaptation to illness is focused on the patient as the support receiver and the partner as the support provider, thereby neglecting the fact that patients may also provide support and thus partners may also receive support from their ill partner.

Providing and receiving support in the context of illness

Multiple sclerosis (MS) is a chronic and often disabling disease of the central nervous system, most commonly diagnosed in young adulthood (i.e. between ages 20-40). The prevalence among women is about two to three times higher than in men (Zwanikken, 1997). The etiology of the illness is still unknown and the onset of the disease may be gradual or acute. Relapses may be followed by periods of remission, or there may be a progressive decline in health (Lublin & Reingold, 1996). Depending on the location of the lesions in the central nervous system, the illness can produce a wide variety of symptoms including loss of function, debilitating fatigue, visual problems and emotional changes (e.g. Mohr & Dick, 1998). The severity of the disease, the unpredictability of its course and the moderate effectiveness of medical treatment makes MS a very difficult disease to adjust to, not only for the patient, but also for the partner. In order to deal with the MS, patients may need increasing amounts of both instrumental help and emotional support from their partners. However, the healthy partner is also likely to experience distress (Knight, Devereux, & Godfrey, 1997; Pakenham, 1998) and may also need support from his or her partner.

Several researchers have suggested that social support exchanges may become more unidirectional when one partner has a chronic illness (Cutrona, 1996; Thompson & Pitts, 1992). That is, patients may receive more support and help from their partners and provide less in return. Research among couples coping with cancer (e.g. Kuijer, Buunk, & Ybema, 2001) and partners of cardiac patients (Thompson, Medvene, & Freedman, 1995) showed that when patients and partners were asked to provide a global appraisal of the balance of give-and-take in their relationship, patients generally felt that their partner was doing more for them than the other way around, whereas partners generally felt that the relationship was balanced in terms of give-and-take. In the present study we did not ask participants to make global judgments of support exchanges, rather we asked them to report the extent to which they received and provided emotional and instrumental support from and to their partner on fourteen consecutive days. Due to the physical disability associated with the MS it is likely that patients receive more instrumental help than they provide. Thus, we expected that

compared to their partners, patients would report receiving more and providing less instrumental support. We hypothesized that the imbalance between providing and receiving emotional support would be less pronounced, since it would be easier for patients to reciprocate emotional support.

Social support exchanges and well-being

Although spousal support is believed to be a critical resource for dealing with chronic illness (Cutrona, 1996), there is now accumulating evidence that spousal support does not always have positive outcomes for patients (e.g. Bolger et al., 1996; Newsom & Schulz, 1998). Several researchers have suggested that support and help from others often contains a mixture of enhancing and threatening elements. On the one hand, support may communicate that one is loved and cared for. On the other hand, it may signal that one has failed, is dependent, or is incompetent (Fisher, Nadler, & Witcher-Alagna, 1982; Gleason et al., 2003; Liang et al., 2001). In couples dealing with a chronic illness this may apply to both partners, although these feelings may be more pronounced among patients. In addition, for patients, support may emphasize their status as an 'impaired person' (DiMatteo & Hays, 1981). As a result social support may undermine the recipient's self-esteem, well-being, and feelings of autonomy. Another explanation for the negative effects of social support is that it might make the recipient feel indebted to his or her partner (Walster, Walster, & Berscheid, 1978). This may result in feelings of guilt.

One way in which the adverse effects of receiving support may be offset is by providing support in return. Providing support allows one to display positive attributes such as concern, love, and commitment (Rusbult & Van Lange, 1996), it may draw attention away from one's own problems and it communicates independence (Gleason et al., 2003). The latter may be especially important for individuals with a chronic disease as they are often placed in a position of dependence. Although few studies have paid attention to the impact of giving support, research suggests that, in general, it is associated with greater well-being (Brown, Nesse, Vinokur, & Smith, 2003; Silverstein, Chen, & Heller, 1996). Helping someone in need may be a fulfilling experience and may boost self-esteem. In an experiment, Williamson and Clark (1989) showed that individuals who thought they would be helping someone with whom they would like to have a communal relationship experienced increased positive mood and self-esteem. Research that pays attention to the positive effects of caregiving, suggests that caregiving may improve people's sense of self-worth and confidence in meeting challenges (Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt, & Van den Bos, 1998; Ybema, Kuijer, Hagedoorn, & Buunk, 2002).

However, there may also be considerable costs to providing ongoing support and help to others. In fact, in the literature on caregiving the positive aspects have received far less attention than the negative aspects (Martire & Schulz, 2001). Ample research has shown that the provision of ongoing care and support to an individual with a chronic illness is often

a stressful experience and partners may become overburdened by the amount of support and help that needs to be provided (Martire & Schulz, 2001). Several studies have shown that support received from the care recipient may buffer the negative consequences of caregiving. For example, Wright and Aquilino (1998) found that reciprocity of emotional support between caregiving wives and husbands who received care was linked to lower levels of burden among these wives.

In sum, we expected that reciprocity in receiving and providing support would be important for patients as well as their partners. Receiving support without providing support in return may have negative consequences. The same is true for providing support without receiving any in return. Reciprocity in social exchanges has most often been studied from the perspective of equity theory (Walster et al., 1978). According to equity theory, feeling overbenefited as well as underbenefited is stressful. However, in the present study, we did not ask whether the participants felt equitably treated or not. We defined inequity as a situation in which a participant reported providing and receiving unequal amounts of support. This means that participants in inequitable situations may not have actually felt inequitably treated. Clark and Mills (1979) have suggested that depending on the nature of a relationship different distributive justice norms apply. They argued that inequities do not tend to matter in intimate relationships because partners have a concern for the welfare of the other and respond to each other's needs without keeping track of contributions and rewards. Many studies have shown that perceptions of inequity are associated with more distress and lower relationship outcomes among healthy couples (e.g. Grote & Clark, 2001; Sprecher, 2001) as well as among couples coping with illness (Kuijer et al., 2001; Thompson et al., 1995; Ybema, Kuijer, Buunk, DeJong, & Sanderman, 2001; Ybema et al., 2002). However, these studies were generally based on global perceptions of inequity. To the best of our knowledge, the study by Gleason and colleagues (2003) is the only study that examined daily reciprocity in support transactions among healthy couples, thus far. They showed that the negative effects of inequitable emotional support transactions occurred during a short time span, that is, within a day. It is important to examine whether this is also the case among couples facing illness and whether this applies to the exchange of instrumental support.

The current study

The current study used a diary method to examine the exchange of emotional and instrumental support during an average 2-week period among couples in which one partner was diagnosed with MS. We distinguished between instrumental and emotional support because research has shown that different dimensions of social support may have different relations with well-being (Helgeson & Cohen, 1996), even though they are highly correlated. The perceptions of each partner as a recipient and as a provider of support were considered. Note that when we say that support was received or provided we always mean

the recipient's perception of received support or the provider's perception of given support. Thus, patients and partners may not agree on the amount of support they reported receiving or providing. As far as we know this is the first study that examined support transactions with a diary method among couples dealing with illness.

This study examined two issues. First, we examined the balance of provided and received support. It was expected that patients would report receiving more instrumental support than they provided. The reverse was expected for partners. The imbalance was expected to be less pronounced for the exchange of emotional support. Second, and more central to our concerns, we investigated the relation between reciprocity of provision and receipt of emotional and instrumental support and daily mood and self-esteem among both patients and their partners. Although self-esteem is related to aspects of well-being, such as mood, it is conceptually different from these measures (Heatherton & Polivy, 1991). Self-esteem can be considered an evaluative component of the self that may vary as a function of daily events (Butler, Hokanson, Flynn, 1994). In the context of adjustment to chronic illness, self-esteem is a particularly relevant outcome measure because maintaining a sense of self-esteem is often mentioned as a challenge for patients (Bensing, Schreurs, de Ridder, & Hulsman, 2002). Also for partners, self-esteem may be an important outcome of the support process (Nijboer et al., 1998). Further, one explanation for the importance of reciprocity of daily support exchanges that was offered by Gleason et al. (2003) was that it increases feelings of self-esteem. We hypothesized that, both for patients and partners, receiving and providing support would be beneficial only when the support was returned. In other words we expected to find an interaction between received and provided support in such a way that for both patients and partners a situation in which support was reciprocated would be related to higher levels of positive mood and self-esteem, and lower levels of negative mood.

Method

Participants

Patients with MS and their partners were contacted through one MS Centre and the neurology department of one hospital in the Netherlands. MS patients registered in the patient files of these clinics received a letter with information about the study and a description of the inclusion criteria. As information on inclusion criteria were not available from the patient files (e.g. we do not know how many of these patients had a partner), we distributed letters to all 390 patients that were registered. This means that the number of couples who responded to the information letter cannot be used to calculate response rates. The selection criteria for participation were that (a) patients were diagnosed with MS, (b) patients were currently involved in a heterosexual relationship (with minimum relationship duration of one year), (c) patients were living together with their partner, and (d) both partners were willing to participate in the study. Couples were excluded if their ability to

read or understand Dutch was insufficient, or when one or both partners suffered from serious psychiatric problems or medical problems other than MS.

A total of 70 couples, who met the inclusion criteria, responded to the information letter and signed informed consent. Of the 70 couples, a final sample of 61 couples completed all the materials. Reasons for drop out were MS related health problems ($n=3$) and personal reasons ($n=3$). Three couples did not specify a reason for drop-out. Of the patients with MS, 87% ($n = 53$) were female and 13% ($n = 8$) were male. Compared to the distribution of MS in the community (2 to 3:1, Zwanikken, 1997) female patients were slightly overrepresented in the present study. The mean age of patients was 47 years (range: 27 to 64, $SD = 8.5$), and on average they had been diagnosed with MS 8 years previously (range: 1 to 33, $SD = 6.0$). Fifty-seven percent of the patients described their MS as having a relapse remitting course, 43 % as having a progressive course. Thirty-one percent of the patients were employed (12% full-time and 20 % part-time); the other patients received a disability benefit (51%), performed household duties (10%) or were unemployed for other reasons (8%). The partners of these patients were, on average 49 years (range: 29 to 69, $SD = 9.4$). Most partners (80%) were employed (61% full-time and 19% part-time), the other partners were retired (11%) or were unemployed for other reasons (9%). Twenty-three percent of the patients and 27% of the partners had completed the lowest level of secondary (vocational) education only, 41% of the patients and 40% of the partners had completed middle to higher levels of secondary (vocational) education, and 36% of the patients and 33% of the partners had a college degree or higher. The couples had been married (92 %) or cohabiting (8 %) for an average of 23 years (range: 2 to 41 years, $SD = 10.0$) and most couples had children (77%).

Procedure

Prior to the diary part of the study, patients and partners completed background questionnaires on demographic and disease related characteristics at home. Next, the first author or a research assistant visited all couples at home (1-4 weeks after sending the questionnaires) to provide additional information and instructions about the diary part of the study and to install an electronic diary on the couple's computer. Participants who did not own a computer were provided with a computer from the university. Computer software was developed especially for this study. The electronic diary was user friendly and easy to complete. Even participants who had little or no experience with computers were able to use the program after they were given clear instructions. Participants were instructed to complete the electronic diary every evening before going to bed for two weeks, starting the following day. Participants were explicitly asked not to exchange the answers with their partner until both partners had completed that day's recordings. The diary was designed to be completed in 5-10 minutes. Recordings were saved on a floppy disk each night and the participants did not have access to their reports after they were saved on the floppy disk.

After two weeks, the couples returned the floppy disk containing each night's responses by mail.

To verify compliance, the date and time of recordings were saved on the floppy disk. Participants were allowed to fill out the diary the next morning if they did not manage to do it at night. 2.6 % of the diaries were completed the next morning. If the diaries were completed after 2 pm on the next day, they were excluded from further analyses because they were considered to be too late and therefore unreliable. This was the case for 0.6 % of the recordings. If the diaries were completed too early (before 2 pm), they were excluded from further analyses as well for the same reason. This was the case in 1.0 % of the recordings. Additionally, participants who completed less than 10 days during the fourteen day period were excluded from further analyses. For this reason, we excluded two healthy partners who completed 6 and 9 days of recordings, respectively. Across the fourteen day period, participants reported an average of 13.1 days of recordings.

Measures

Received and provided support. Each evening, both patients and partners reported if and to what extent they had received and provided emotional and instrumental support on that day. Three items were used to measure received and provided emotional support, respectively. All answers were given on a 4-point scale (0 = not at all, 3 = very much). The items were: "My partner gave me a compliment" / "I gave my partner a compliment", "My partner listened to me" / "I listened to my partner", and "My partner showed affection towards me" / "I showed affection towards my partner". The items were averaged to form a scale for emotional support received and emotional support provided. Internal consistency of the scales was calculated based on the daily recordings; Cronbach's alpha was 0.75 for emotional support received and 0.70 for emotional support provided. One item was used to measure the receipt and provision of instrumental support, that is, "My partner gave me practical help" / "I gave my partner practical help".

End-of-day mood was measured with the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). The instrument consists of 10 positive and 10 negative adjectives that describe possible feelings and emotions. The items were scored on a 5-point scale ranging from (1) very slightly or not at all to (5) extremely. Scores on the positive items and the negative items were summed per day to form two scales, one scale for positive mood and one scale for negative mood. Both scales had a possible range from 10-50 indicating more positive or negative mood. Internal consistency of the scales was calculated based on the daily recordings; Cronbach's alpha was 0.88 for the positive scale and 0.86 for the negative scale. The PANAS has proven to be internally consistent and valid and when used with short-term instructions (right now or today), it is sensitive to fluctuations in mood (Watson et al, 1988). In this study we used the following instructions: "Indicate to what extent you experience these feelings and emotions *right now*". The

correlation between positive and negative mood over days within individuals was close to zero ($r = .09, p < .01$).

Self-esteem was assessed with a single item, asking to what extent participants valued themselves that day. The item was measured on a 7-point scale ranging from (1) not at all to (7) very much. According to Robins, Hendin, and Trzesniewski (2001), a single self-report item to assess self-esteem is adequate because the concept of self-esteem is: 1) highly schematized for most individuals, 2) conceptually unidimensional in content, and 3) primarily reflects subjective experience. Further, in this study, the correlation between our measure for state self-esteem and the Rosenberg scale for trait self-esteem (Rosenberg, 1965) was .58 for patients and .61 for partners. Although state and trait self-esteem are conceptually different, these correlations provide some support for the validity of our instrument. Self-esteem correlated positively with positive mood ($r = .41, p < .001$) and negatively with negative mood ($r = -.31, p < .001$) over days within individuals.

The number of *daily hassles* experienced each day was included as a control variable since hassles may influence the receipt of negative responses and emotional support. A checklist was used based on the Revised Hassle and Uplift Scale (DeLongis, Folkman, & Lazarus, 1988). However, we considered the original 53 item scale too long to be used on a daily basis, so we shortened the scale by conjoining several items. One item referring to the occurrence of special incidents (e.g. accident) was added. This resulted in a 22 item scale that represented all the areas that were included in the original scale. Note that the uplifts part of the scale was not used in the present study.

Patients were asked each evening to indicate to what extent they had experienced *MS related symptoms or complaints* that day. The answer was given on a 10-point scale ranging from (1) no symptoms or complaints to (10) many symptoms and complaints.

Analyses

To compare the amount of received and provided emotional and instrumental support that patients and partners reported, we computed individual mean scores by aggregating the data across the fourteen day period. Paired sample t-tests were used to test whether the differences between patients and partners were significant, and whether differences between the amount of received and provided support within patients and partners were significant. Additionally, to test the agreement between the patient's and partner's perceptions of the amount of support received and provided, we compared the amount of support that one partner reported receiving with the other partner's support provision. To adjust for multiple comparisons, the bonferroni-holm step down procedure was used (Holm, 1979).

Multi-level regression modeling, as implemented in the program MLWin (Rasbash, Browne, Goldstein, & Yang, 2000) was used to determine the relationship between the predictors and the dependent variables. Each model had three levels, a between-couple level (level 3), a between-person level (level 2) and a within-person level (level 1). A between-

couple level was included to take account of dependency within couples. A between-person level was included to take account of dependency within persons. The within-person level of the analyses allowed each individual's evening mood or self-esteem on a given day to be modeled as a function of that individual's received or provided support. We predicted end-of-day mood and self-esteem while controlling for previous day mood or self-esteem, daily hassles and patients' daily symptoms and complaints. The regression equation was as follows:

$$M_{ijk} = b_0 ijk + b_1 M-1 ijk + b_2 symptoms ijk + b_3 hassles ijk + b_4 role jk + b_5 R ijk + b_6 Pr ijk + b_7 R ijk * Pr ijk + b_8 role jk * R ijk + b_9 role jk * Pr ijk + b_{10} role jk * Pr ijk * R ijk + e ijk.$$

Note that in this regression equation, the subscripts *ijk* indicate a variable that varies within persons across time and the subscripts *jk* refer to a time-invariant between person variable. *M_{ijk}* = End-of-day mood or self-esteem in person *j* in couple *k*, on day *i*; *b₀ ijk* = the regression intercept in individual *j* in couple *k* on day *i*; *M-1_{ijk}* = Mood or self-esteem on day *t-1* in person *j* in couple *k*, on day *i*; *Symptoms ijk* = ms related symptoms of patient *j* in couple *k* on day *i*; *Hassles ijk* = daily hassles in person *j* in couple *k*, on day *i*; *role jk* = indicates whether person *j* in couple *k* is a patient or partner; *R ijk* = received support in person *j* in couple *k*, on day *i*; *Pr ijk* = provided support in person *j* in couple *k*, on day *i*; *Pr ijk * R ijk* = interaction effect between received and provided support in person *j* in couple *k*, on day *i*; *e ijk* = residual effect in individual *j* in couple *k* on day *i*.

All predictor variables were grand mean centered (i.e. the overall mean was subtracted from the values of a variable), thus the coefficient *b₀ ijk* was the regression intercept for individual *j* in couple *k* on day *i* and represented mood or self-esteem when all variables were at their average level. The role variable (patient or partner) was effect coded with patients coded as *-0.5* and partners as *0.5*. The significance of the effects was determined with the Wald test: $Z = (\text{estimate}) / (\text{standard error of estimate})$, where *Z* referred to the standard normal distribution (Hox, 2002). An alpha level of *.05* was used for all statistical tests.

The dependent variables in our model were end-of-day positive and negative mood and self-esteem. The predictors were entered in the regression equation hierarchically, starting with the covariates (previous day mood or self-esteem, hassles and patient's symptoms), followed by role (patient or partner), the main effects (received and provided support), the interaction effect between the main effects, and finally the interaction effects between role and the main effects were entered in the regression equation. Predictors that did not contribute to the dependent variable were removed from the model. However, we included all main effects in the model even when they were not significant because in the presence of a significant interaction, the effect of the interaction variable and the direct effects of the explanatory variables that make up the interaction, must be interpreted together as a system

(Aiken & West, 1991). When significant interaction effects were found, regression equations were estimated for persons scoring 1 *SD* below and 1 *SD* above the mean of the interaction variables. Separate analyses were performed for instrumental support and emotional support and the dependent variables, self-esteem, positive mood and negative mood¹.

Table 1 Average amount of received and provided emotional and instrumental support in MS patients and their partners across the 14-day period.

| | | Received | Given |
|----------------------|----------|---------------------------|---------------------------|
| Emotional support | patients | 1.83 (.75) ^{axp} | 1.87 (.72) ^{axq} |
| | Partners | 1.54 (.79) ^{ayp} | 1.69 (.71) ^{byp} |
| Instrumental support | patients | 1.78 (.83) ^{axp} | 1.22 (.82) ^{byp} |
| | Partners | 1.06 (.80) ^{ayp} | 1.73 (.89) ^{byp} |

Note Values are means (*SD*). Means with a different superscript in a row (letters a and b) differ significantly from each other at least at $p < .05$ based. Means with a different superscript in a column (letters x and y) differ significantly from each other at least at $p < .05$. Means with a different superscript in a diagonal (letters p and q), differ significantly from each other at least at $p < .05$. Bonferroni-Holm step down procedure was used to adjust for multiple comparisons (Holm, 1979).

Results

Exchange of social support: descriptive analyses

Aggregated means and standard deviations for received and provided emotional and instrumental support are presented in Table 1. First, Table 1 shows that on average patients reported providing and receiving equal amounts of emotional support. As expected, patients reported providing less instrumental support than they received. Partners reported providing more support (both emotional and instrumental) than they received. Second, when compared to their partners, patients reported receiving more emotional and instrumental support and provided less instrumental support. However, patients and partners did not differ from each other with respect to the amount of emotional support they each said they provided. As expected, these results suggest an imbalance in received and provided instrumental support. That is, both partners agree that patients received more and provided less instrumental

¹The three-way-interactions between role and received and provided support were insignificant in all of the analysis and were therefore not included in the final regression equations.

support compared to their partners. Both partners did not agree on the imbalance of the exchange of emotional support, however. Although partners reported having received less emotional support than provided, patients reported having provided as much support as they received. Finally, we compared the amount of support that one partner reported receiving with the other partner's report of the amount of support provided. The results showed that patients reported providing more emotional support than partners reported receiving. No other differences between the amount of support that one partner reported receiving and the other partner reported providing were found.

Positive mood and social support

Table 2 presents the final models of the multilevel analyses predicting end-of-day positive mood as a function of receiving and providing emotional support and receiving and providing instrumental support, respectively. The first two steps are the same in both analyses (the b-effects differ slightly as a result of the inclusion of other predictors later on in the analyses). The intercept indicates that the predicted amount of end-of-day positive mood (on a 10-50 scale) was 25.0 for a hypothetical person with an average level of previous day mood, daily hassles, received and provided support, and an average number of symptoms and complaints. In the first step, the control variables 'previous day mood', 'symptoms and complaints' and 'hassles' were entered into the regression equations. The number of daily hassles did not significantly contribute to end-of-day positive mood and was excluded from further analysis. In the second step, role (MS patient or partner) was entered into the regression equation. Role did not significantly predict end-of-day positive mood indicating that patients and partners did not differ in their positive end-of-day mood. In the third step, the main effects of received and provided emotional support and received and provided instrumental support, respectively, were entered in the regression equation. As Table 2 shows, both received and provided emotional support contributed significantly to end-of-day positive mood, indicating that individuals reported better end-of-day mood when they received and provided more emotional support. In the analysis with instrumental support, only provided support contributed significantly to the regression equation (see Table 2), indicating that individuals reported better end-of-day mood when they provided more instrumental support. In the fourth step, the interaction between received and provided support was entered in the regression equation to examine whether the effects of receiving support differed as a function of providing support. In both analyses no interaction effect was found. Finally, the interactions between receiving and providing support on the one hand and role on the other hand were entered in the regression in order to examine whether the effects of received and provided support differed as a function of role (patient or partner). Table 2 shows that in the analysis with emotional support an interaction between role and support provided was found. As Figure 1 shows, providing more emotional support

was related to higher positive mood in patients ($b=1.34, p<.01$), but not in partners ($b=.05, ns$).

In sum, both patients' and partners' mood benefited from receiving emotional support from their partner and providing instrumental support to their partner. In addition, patients' positive mood benefited from providing emotional support to their partner as well. No support was found for a moderator effect between providing and receiving support over and above the main effects.

Table 2 Effects of emotional and practical support received from and provided to the partner on end-of-day positive mood

| | Emotional support | | | | Practical support | | | |
|-------------------------|-------------------|-----|------|---------|-------------------|-----|------|---------|
| | Effect | SE | Z | p-value | Effect | SE | Z | p-value |
| Intercept | 25.00*** | .53 | 47.3 | .00 | 24.91*** | .56 | 44.5 | .00 |
| Previous day mood | .16*** | .03 | 6.1 | .00 | .16*** | .03 | 6.0 | .00 |
| Symptoms/ complaints | -.53*** | .10 | 5.3 | .00 | -.59*** | .10 | 5.8 | .00 |
| Role (patient/ partner) | .99 | .70 | 1.4 | .15 | .38 | .70 | .6 | .59 |
| Support receipt | .97** | .33 | 2.9 | .00 | .15 | .17 | .8 | .40 |
| Support given | .81* | .34 | 2.4 | .02 | .76*** | .17 | 4.4 | .00 |
| Receipt*given | -.19 | .24 | .8 | .43 | .14 | .13 | 1.1 | .29 |
| Role*received | .31 | .65 | .5 | .64 | .03 | .36 | .1 | .93 |
| Role*given | -1.38* | .68 | 2.0 | .04 | -.16 | .37 | .4 | .67 |

Note * $p < .05$, ** $p < .01$, *** $p < .001$

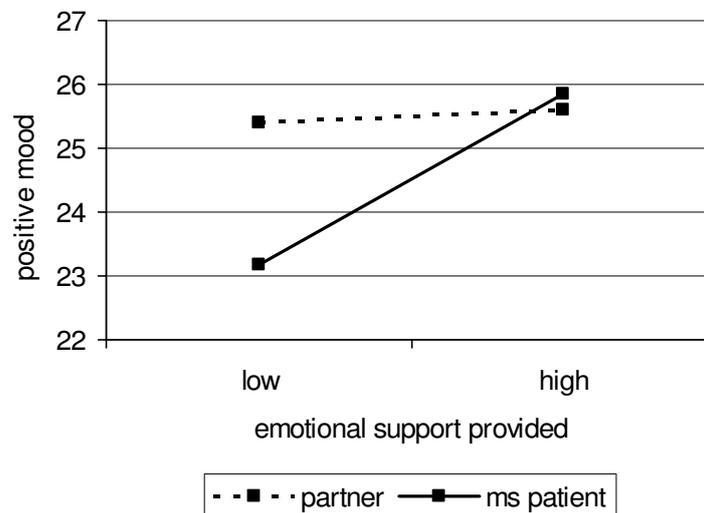


Figure 1 Positive mood as a function of emotional support provided for MS patients and their partner

Negative mood and social support

The same analyses were executed to model end-of-day negative mood as a function of receiving and providing emotional and instrumental support. The results are presented in

Table 3. The intercept indicates that the predicted amount of end-of-day negative mood (on a 10-50 scale) in the evening was 14.3 for a hypothetical person with an average level of previous day mood, daily hassles, received and provided support, and an average number of symptoms and complaints. All control variables contributed significantly to end-of-day negative mood in the first step of the analyses. Role (patient or partner) did not significantly predict end-of-day negative mood, indicating that patients and partners did not differ in their end-of-day negative mood. Table 3 further shows that neither receiving nor providing emotional or instrumental support contributed to end-of-day negative mood. The same was true for the interaction between receiving and providing support. In a final step, the interactions between role on the one hand and receiving and providing support were significant for emotional support but not for instrumental support. As Figure 2 shows, receiving more emotional support was related to lower levels of negative mood in partners ($b = -.94, p < .01$). Among patients, receiving emotional support was unrelated to negative mood ($b = .09, ns$). With respect to providing support, Figure 3 shows that among partners providing more emotional support was not related to levels of negative mood ($b = .36, ns$), whereas patients' end-of-day mood was less negative as they provided more emotional support ($b = -.87, p < .01$).

In sum, providing emotional support was beneficial for patients, whereas receiving emotional support was unrelated to negative mood. For partners the reverse was true: providing emotional support was not related to negative mood and receiving emotional support was related to less negative mood. Neither receiving nor providing instrumental support was related to negative mood. This was found for patients and for partners. Like the results for positive mood, no interaction effects were found between receiving and providing support.

Table 3 Effects of emotional and practical support received from and provided to the partner on end-of-day negative mood

| | Emotional support | | | | Practical support | | | |
|------------------------|-------------------|-----|------|---------|-------------------|-----|------|---------|
| | Effect | SE | Z | p-value | Effect | SE | Z | p-value |
| Intercept | 14.28*** | .30 | 47.6 | .00 | 14.28*** | .29 | 49.8 | .00 |
| Previous day mood | .22*** | .03 | 8.6 | .00 | .22*** | .03 | 8.6 | .00 |
| Symptoms/complaints | .52*** | .07 | 7.9 | .00 | .53*** | .07 | 8.0 | .00 |
| Hassles | .44*** | .05 | 9.9 | .00 | .46*** | .05 | 10.3 | .00 |
| Role (patient/partner) | -.29 | .49 | .6 | .55 | -.07 | .49 | .1 | .89 |
| Support receipt | -.37 | .22 | 1.7 | .10 | .02 | .12 | .1 | .90 |
| Support given | -.29 | .24 | 1.2 | .22 | -.10 | .12 | .9 | .39 |
| Receipt*given | -.04 | .16 | .2 | .82 | -.07 | .08 | .8 | .43 |
| Role*received | -1.01* | .45 | 2.3 | .02 | .03 | .33 | .1 | .94 |
| Role*given | 1.38** | .46 | 3.0 | .00 | .09 | .25 | .4 | .72 |

Note * $p < .05$. ** $p < .01$, *** $p < .001$

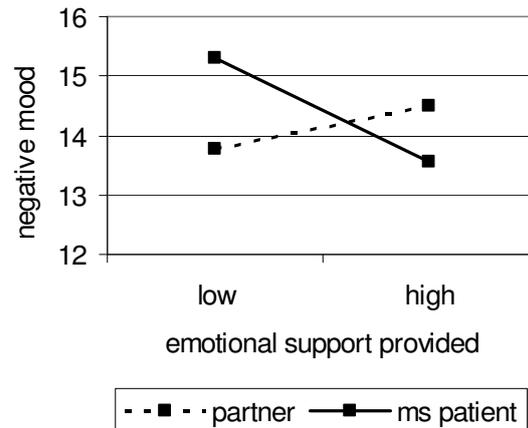
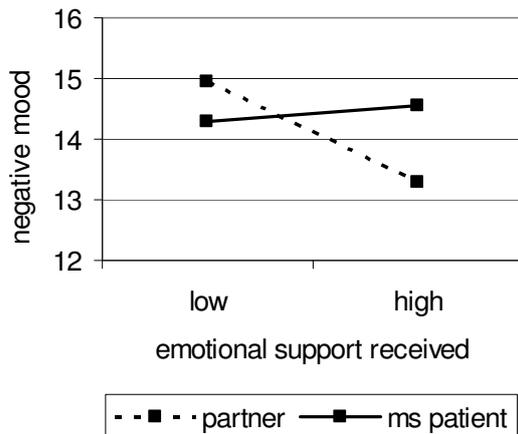


Figure 2 Negative mood as a function of emotional support received for MS patients and their partner

Figure 3 Negative mood as a function of emotional support provided for MS patients and their partner

Self-esteem and social support

Finally, self-esteem was modeled as a function of receiving and providing emotional and instrumental support. The results are shown in Table 4. The intercept indicated that the predicted amount of self-esteem (on a 1-7 scale) was 5.2 for a hypothetical person with an average level of previous day self-esteem, daily hassles, received and provided support, and an average number of symptoms and complaints. All control variables contributed significantly to self-esteem in the first step of the analyses. Role (patient or partner) significantly predicted self-esteem. On average, patients reported lower self-esteem than did their partners (in the analysis with instrumental support the b-weight in the final equation was no longer significant after inclusion of the other predictors). In the third step, emotional support provided and instrumental support provided contributed significantly to the regression, respectively. Thus, providing more emotional support and instrumental support was associated with higher self-esteem. In the following step, the interaction between providing and receiving support was significant for instrumental support, but not for emotional support. As Figure 4 shows, providing support was not related to higher self-esteem when low instrumental support was received in return ($b = .04$, ns). In contrast, receiving instrumental support was related to lower self-esteem when little or no instrumental support was provided in return ($b = .15$, $p < .001$). Thus, reciprocating instrumental support was beneficial for self-esteem. In the final step of the analyses, the interaction between role and emotional support provided proved significant. Figure 5 shows that patients reported higher self-esteem when they provided more emotional support to their intimate partner ($b = .28$, $p < .001$). For partners the relationship between self-esteem and support provision was close to zero ($b = -.04$, ns).

In sum, with respect to emotional support the results showed that providing emotional support was related to higher self-esteem among patients, but not among their partners. The receipt of emotional support was unrelated to self-esteem. With respect to instrumental support, the predicted interaction between providing and receiving support was significant: receiving instrumental support was only beneficial for self-esteem when instrumental support was reciprocated. When little or no instrumental support was provided, receiving instrumental support was harmful. This was true for both patients and partners².

Table 4. Effects of emotional and practical support received from and provided to the partner on self-esteem

| | Emotional support | | | | Practical support | | | |
|--------------------------|-------------------|-----|------|---------|-------------------|-----|------|---------|
| | Effect | SE | Z | p-value | Effect | SE | Z | p-value |
| Intercept | 5.18*** | .07 | 70.0 | .00 | 5.18*** | .08 | 68.2 | .00 |
| Previous day self-esteem | .15*** | .03 | 5.9 | .00 | .15*** | .03 | 5.9 | .00 |
| Symptoms/complaints | -.09*** | .02 | 5.4 | .00 | -.09*** | .02 | 5.7 | .00 |
| Hassles | -.05*** | .01 | 4.5 | .00 | -.06*** | .01 | 5.1 | .00 |
| Role (patient/partner) | .19* | .10 | 1.9 | .03 | .10 | .10 | 1.0 | .16 |
| Support receipt | .06 | .05 | 1.1 | .13 | -.01 | .03 | .5 | .32 |
| Support given | .13** | .06 | 2.4 | .01 | .10*** | .03 | 3.4 | .00 |
| Receipt*given | -.00 | .04 | .1 | .47 | .04* | .02 | 2.0 | .02 |
| Role*received | .03 | .11 | .3 | .39 | -.02 | .06 | .4 | .35 |
| Role*given | -.32** | .11 | 2.9 | .00 | -.07 | .06 | 1.2 | .12 |

Note * $p < .05$. ** $p < .01$, *** $p < .001$

² Our sample included primarily couples with female patients and male partners. Therefore we were not able to examine gender differences in a reliable way. However, in explorative analyses we looked at potential gender differences. With respect to our first research question, the results were virtually the same with the exception that male partners reported providing more instrumental support and in accordance female patients reported receiving more instrumental support. To explore potential gender differences in the association between spousal exchanges and well-being, we conducted all analyses for patients and partners separately and included gender as a potential moderator in the background. Twelve regression analyses were employed, six for patients and six for partners. Two analyses (one for patients and one for partners) revealed significant gender differences. First, the results showed that only for male patients, providing emotional support was significantly associated with positive mood. Second, only for female partners, providing instrumental support was significantly related to higher levels of self-esteem.

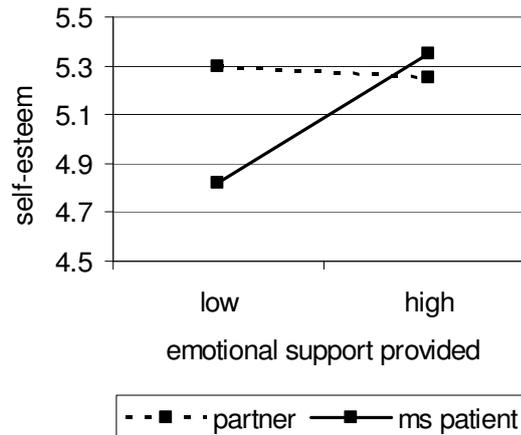
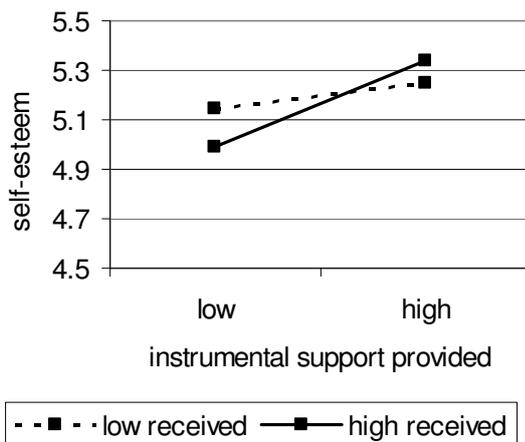


Figure 4 Self-esteem as a function of instrumental support provided to the partner and received from the partner.

Figure 5 Self-esteem as a function of emotional support provided for ms patients and their partner.

Discussion

The present study examined support exchanges among couples in which one partner was diagnosed with MS. First, the imbalance between patients' and partners' reports of support receipt and provision was examined. Second, the extent to which reciprocal exchanges of received and provided support were related to end-of-day well-being was examined.

Imbalance in support exchanges

As expected, both patients and partners reported an imbalance in the exchange of instrumental support over a two-week period. That is, both partners agreed that patients received more and provided less instrumental support compared to the healthy partner. With respect to emotional support, only partners perceived an imbalance in the predicted direction and in line with the expectations the imbalance was less pronounced than for instrumental support. Patients did not report an imbalance; they reported providing on average as much emotional support as they received from their partners. Note that we examined individual's subjective perceptions of received and provided support. Apparently, not all the emotional support that was provided according to the patient was perceived as such by the partner. Emotional support is less visible compared to instrumental support and is therefore more difficult to notice. Partners have more distractions in their lives than do patients. Not only do partners provide much practical help and care, the majority of them in the present study were employed outside the home. It is possible that partners are less aware of the emotional support that is provided to them, because they have so many other things to do. Another

possibility is that due to their own needs, patients may be less attuned to the needs of their partners; therefore, patients may not provide as much emotional support as they report.

Reciprocal exchanges of support

In line with equity theory, receiving instrumental help was associated with lower levels of self-esteem when it was not reciprocated, both for patients and partners. Apparently, receiving instrumental support without providing instrumental support in return (overbenefit in equity terms) has negative consequences for the recipient's self-esteem. For patients, the inability to reciprocate instrumental help may emphasize their status as an impaired person and may stress their dependency (DiMatteo & Hays, 1981; Liang et al., 2001). For partners, not being able to reciprocate instrumental help may threaten their competence as a caregiver. Ybema et al. (2002) found that partners of patients with cancer or MS who felt that they invested too little in their relationship in terms of help and support experienced lower levels of personal accomplishment about their caregiving role. Reciprocity of instrumental help was not important with respect to end-of-day mood. One explanation may be that self-esteem is more susceptible to reciprocal exchanges of instrumental support than mood. Self-esteem and mood are believed to be different concepts. However, it is not well-known if and to what extent they are affected by daily occurrences in a different way. A series of experiments by Heatherton and Polivy (1991) showed that mild ego distress was related to a change in self-esteem but not to a change in mood. It may be that when patients or partners were not able to return instrumental help on a certain day, they evaluated themselves less positively, however, that it did not affect their mood.

In contrast with equity theory, underbenefit (providing much instrumental support without receiving in return) was not related to self-esteem. In addition, providing instrumental support was related to positive mood among both patients and their partners regardless of whether support was reciprocated. Apparently, being able to provide practical assistance may be rewarding in itself both for patients and partners (c.f. Williamson & Clark, 1989; Nijboer et al., 1998). Also in contrast with our expectations, no support was found for the importance of reciprocating emotional support. Interestingly, the effects of received and provided emotional support were uniquely related to the patient or partner role. Patients reported better well-being when they provided higher levels of emotional support, whereas partners reported better mood when they received more emotional support. Providing emotional support may be particularly important for patients because it gives them the opportunity to show appreciation for the help and care they receive from their partner (Thompson & Pitts, 1992). For partners, receiving emotional support may be especially valuable because it communicates appreciation and love.

Apart from the relation between instrumental support and self-esteem, the present study did not provide support for the idea that support needs to be reciprocated immediately to be beneficial. Most studies that have showed the negative effects of inequity among couples

dealing with chronic illness used global appraisals of each partners' contributions and rewards to the relationship (e.g. Kuijer et al., 2001; Thompson et al., 1995; Ybema, et al., 2001). In this study we asked participants to report the amount of support they had received or provided at the end-of-day, we did not ask them whether they felt equitably treated or not. As was mentioned before, this means that participants in inequitable situations may not have actually felt inequitably treated. Several researchers have argued that in intimate relationships a need based rule is the typical rule and that equity is less important (e.g. Clark & Mills, 1979). The present study suggests that at least on a day to day basis prompt repayment in kind after receiving emotional support is not necessary in the context of illness. The results regarding emotional support are not in line with findings from Gleason et al. (2003) who found that reciprocity in emotional support transactions on a given day was associated with better end-of-day mood on that day among healthy couples. It is possible that in the context of illness the exchange of emotional interactions has a different meaning than when both partners are healthy.

The current study showed that it is important to distinguish between instrumental and emotional support. Most studies looking at the effects of enacted support either examine only emotional or instrumental support (e.g. Gleason et al., 2003; Newsom & Schulz, 1998) or do not distinguish between the two (e.g. Liang et al., 2001). This may contribute to the inconsistent effects of enacted support on well-being simply because different types of support may have different effects on well-being. A disadvantage of separately analyzing the effects of emotional and instrumental support, however, is that we were unable to examine whether, for example, instrumental support could be reciprocated by providing emotional support. Support expectations may change in the context of chronic illness. For example, patients may expect to receive more instrumental support. Therefore providing emotional support may be one way to compensate for the instrumental help they receive. Partners on the other hand, may expect to receive less instrumental support. For them, receiving emotional support from their partner may be one way to compensate for the instrumental help they provide. Future research is needed to examine this issue.

Limitations

A first limitation of the present study is that the majority of our sample consisted of couples with a female patient and a male partner. It is possible that the differences between patients and partners that we found may reflect gender differences. There is evidence that women and men attach different meanings to supportive behaviors and that women are generally more sensitive to support transactions than are men (Acitelli & Antonucci, 1994). We did explore gender differences (see note 2) and few gender differences emerged. However, the results of these analyses are highly tentative because the gender imbalance in our sample did not allow us to examine gender differences in a reliable way. We did not find support for the idea that women were more sensitive to supportive behaviors than men. In contrast, only

male patients benefited from providing emotional support with respect to their positive mood. Further, only female partners reported higher levels of self-esteem on days that they provided more instrumental support. The latter is in line with a study by Hagedoorn and colleagues (Hagedoorn, Sanderman, Buunk, & Wobbles, 2002) that showed that women's distress was related to their feelings of competence as a caregiver, but not to men's. Future research is needed to examine this issue more thoroughly.

Second, the diary method that we used in this study provides the opportunity to examine the effects of support processes over time. However, the non-experimental nature of the data precludes causal statements. Further, recordings of support and well-being have been assessed on the same moment (end-of-day). It is possible that patients or partners who were in a better mood or had higher self-esteem were inclined to report more or less received or provided support, which can be considered a limitation of the present study. We controlled for important confounding variables, that is, previous day well-being, daily hassles and MS related complaints. Thus, we protected to some extent against the problem of well-being simply predicting perceptions of spousal exchanges. However, other unknown factors could have influenced both well-being and support exchanges. Furthermore, there may be complex patterns between support received and provided that exceed over days or even months and are cumulative. For example, one-sided received support on day one may be compensated by providing support on day two. More research is needed to examine these processes.

Additionally, we did not investigate whether the effects of giving and receiving support were dependent on the person or the couple. Although we did find evidence that the effects of support exchanges varied as a function of between-person and between-couple differences, we did not examine this any further because it was beyond the scope of this study. Variance explained by between-person or couple differences means that certain aspects of the couple or the individual moderate the effects of receiving and providing support. The effects of spousal exchanges may, for example, depend on the patient's physical disability. For example, the costs and benefits of receiving and providing support may be different for a patient who is seriously disabled compared to a patient who is less disabled (Wright & Aquilino, 1998). Further, when a patient is seriously disabled and needs lots of help, equity may no longer be important and needs may prevail over equity rules (Kuijer et al., 2001).

Finally, the fact that both MS patients and their partners had to complete diaries may have led to an underrepresentation of distressed couples. It is possible that distressed couples were less willing to participate in a study like this as a couple. Additionally, our sample varied widely with respect to age and relationship length, however, on average the couples had been together for a very long time. The fact that these couples are still together after such a long time suggests that they somehow managed to deal with the MS in their relationship, successfully.

Conclusion

To conclude, this study showed that daily support exchanges in couples facing chronic illness may become imbalanced when one partner is diagnosed with multiple sclerosis, most pronounced in instrumental support. Our results indicated that the consequences of support exchanges were for a large part dependent on the type of support and the patient or partner role. Our findings have important implications. Most studies and interventions on support in chronic illness focus on the patient as the support recipient and the partner as the support provider. However, this study showed the importance of providing support to the partner for the patient's well-being and receiving emotional support from the ill partner for the partner's well-being. Future interventions should not only concentrate on the patient's needs for support, however, they should also encourage patients to explore their opportunities as a supportive partner. Additionally, for partners it is important that more attention will be given to their potential role as support recipients.

Chapter 4

Daily negative interactions and mood among patients and partners dealing with multiple sclerosis (MS): the moderating effects of emotional support.

Abstract

Negative interactions with the partner may have adverse consequences for well-being, especially for individuals dealing with chronic illness. However, it is not clear whether negative interactions affect both dimensions of positive and negative well-being and factors that may moderate this effect have not been well described. The aim of the present study was to examine the association between daily received negative responses from the partner and end-of-day positive and negative mood in patients with multiple sclerosis (MS) and their intimate partners. Further, the moderating role of receiving emotional support from the partner on the same day was examined. Sixty-one MS patients and their intimate partners completed computerized diaries for fourteen days. Both partners filled out diaries at the end of each day, recording received negative responses, emotional support and end-of-day positive and negative mood. In line with a domain specific model, patients or partners who reported receiving negative responses on a day had higher end-of-day negative mood, whereas received negative responses were unrelated to end-of-day positive mood. Further, for both patients and partners, the adverse effect of received negative responses on end-of day mood was moderated by receiving emotional support on the same day.

Introduction

The beneficial effects of being involved in a supportive relationship for well-being in general (e.g. Burman & Margolin, 1992) as well as for adjustment to chronic illness (e.g. Cutrona, 1996) have been well documented. Unfortunately, besides being supportive, interactions with the partner can also be problematic and the detrimental effects of problematic or negative interactions are believed to be more important than the beneficial effects of supportive interactions (Newsom, Nishishiba, Morgan, & Rook, 2003; Manne, Taylor, Dougherty, & Kemeny, 1997; Schuster, Kessler, & Aseltine, 1990). The aim of the present study was to examine the association between negative responses received from the partner and end-of-day mood in patients with multiple sclerosis (MS) and their intimate partners. Additionally it was examined whether this relation was moderated by receiving emotional support from the partner that same day.

By and large, the literature examining the impact of negative interactions in the context of chronic illness has focused on the patient. Negative partner interactions may involve well- intended support attempts, such as minimizing or maximizing the consequences of the illness (Lehman & Hemphill, 1990) or being overprotective (Cutrona, 1996; Kuijer, Ybema, Buunk, DeJong, Thijs-Boer, & Sanderman, 2000), but they may also include more overtly negative interactions, such as being critical, avoidant or demanding (Rook, 1992; Rook & Pietromonaco, 1987). Although these overtly negative responses are not common, they have been reported by patients with various chronic illnesses, such as cancer (Manne et al., 1997), rheumatoid arthritis (Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991) and MS (Lehman & Hemphill, 1990), with adverse effects on well-being. Negative responses from

the patient towards the healthy partner and the effects on the healthy partner's well-being have largely been neglected, however. The present study focused on the more overt negative responses that both partners may display towards each other.

One explanation for the strong impact of negative interactions on well-being is that they may be a source of stress themselves (Shinn, Lehman, & Wong, 1984). In a diary study examining several daily stressors, Bolger, DeLongis, Kessler, & Schilling (1989) found that daily interpersonal stressors (i.e. conflicts, demands) were the most distressing events. Negative interactions may be interpreted as a sign of rejection by the recipient and are believed to have such great impact because they entail a threat both to the relationship with the provider and to psychological resources such as self-esteem (Rook, 1992). Individuals whose psychological resources to deal with stressful events are already depleted, such as in individuals dealing with chronic illness and their intimate partners, may be particularly vulnerable to negative responses they receive from the partner (Druley & Townsend, 1998; Ingersoll-Dayton, Morgan & Antonucci, 1997).

MS is a chronic and often disabling disease of the central nervous system, characterized by an unpredictable and variable course. MS is most commonly diagnosed in young adulthood. The onset can be gradual or acute and in most patients relapses are followed by periods of remission. However, a progressive decline in health is possible as well (Lublin & Reingold, 1996). Due to the nature of MS, patients constantly have to adapt to new situations, often involving losses such as reduced physical independence, and restrictions in daily activities and social relationships. Compared to patients with other illnesses, higher levels of depression and lower levels of self-esteem have been documented in MS patients (Murray, 1995).

The severity of the disease, the unpredictability of its course and the lack of specific treatment not only present a considerable challenge to the patient, but also to the intimate partner (Pakenham, 1998). Because of their interdependence, both members of the couple are affected not only by their own reactions to the illness but also by the emotional distress of their partner (Kelley & Thibaut, 1978; cf. Rusbult & Van Lange, 2003). Research has shown that the well-being of patients and partners is highly related and often follows the same pattern over time (Pakenham, 1998; Segrin, Badger, Meek, Lopez, Bonham, & Sieger, 2005). Additionally, for partners, taking care of an ill partner often implies taking on additional responsibilities such as performing household tasks or assistance with self-care. Ample research has shown that taking care of an ill partner may be burdensome (e.g. Pakenham, 1998; Ybema, Kuijer, Hagedoorn, & Buunk, 2002).

Thus, both patients and their intimate partners may have depleted resources to deal with stressful events and may therefore be psychologically vulnerable to negative responses they receive from the partner. Support for this notion was found in a study by Druley and Townsend (1998). Negative responses received from the partner were related to depression through self-esteem in rheumatoid arthritis patients, but not in healthy controls.

Additionally, a study by Kiecolt-Glaser, Dyer, & Shuttlesworth (1988) showed that upsetting interactions with others were related to higher levels of depression in caregivers of Alzheimer patients, but not in healthy controls. Although this study was not limited to partner caregivers and did not address negative responses from the partner specifically, it suggests that healthy partners caring for an ill partner may have increased vulnerability for negative responses as well.

With respect to effects on well-being, different association patterns have been suggested between negative responses received from others and positive and negative dimensions of well-being. Some researchers suggest a domain specific effect, that is, negative responses impact on dimensions of negative well-being but not on dimensions of positive well-being (e.g. Ingersoll-Dayton et al., 1997). However, other researchers argue that the effects of negative responses are so potent that they affect both positive and negative well-being, which is termed a cross-over effect (e.g. Finch, Okun, Barrera, Zautra, & Reich, 1989). Empirical support for both models has been found (Finch et al., 1989; 1999, Ingersoll-Dayton et al., 1997; Manne et al., 1997; Rook, 2001). If a cross-over effect is engendered by the potency of negative responses, as some researchers suggest, one might expect that this model applies especially to individuals who are vulnerable to negative responses, that is, those who are dealing with chronic illness and their intimate partners.

However, although both patients and partners may be vulnerable to negative interactions with the partner, this may be more pronounced among patients. When one partner is diagnosed with chronic illness, the relationship is likely to change in such a way that the ill partner becomes more reliant on the healthy partner, not only for practical assistance but also with respect to their self-esteem (Cutrona, 1996; Druley & Townsend, 1998). For patients, other sources of esteem (such as work) are often lost and the partner may compensate for these losses by communicating that the patient is still valued and cared for. Because of this higher dependency on the partner, patients may be particularly vulnerable to negative responses received from their partner (Rusbult & Van Lange, 2003).

Whereas most studies so far used global self-report questionnaires to examine the impact of negative responses on well-being, this study used a diary method as we were specifically interested in the impact of negative interactions on daily mood. A diary method is an appropriate instrument to address the emotional reaction elicited by negative responses received from the partner during the course of daily life (Bolger, 2003). Mood was taken as an outcome measure because it has been found to be sensitive to distress provoked by daily occurrences such as support interactions (Stone, 1997; Stone, Neale, & Shiffman, 1993). The distress that is experienced as a consequence of negative interactions is believed to aggregate to influence broader dimensions of health (Rook, 2001). Moreover, for MS patients, investigating negative interactions is particularly important as it is suggested that stress (e.g. negative interactions) is related to periods of disease activity in MS (Schwartz, Foley, Rao, Bernardin, Lee, & Genderson, 1999).

A diary method permits a description of day-to-day fluctuations in mood and compares end-of-day mood on days that individuals did or did not report receiving negative responses. With this method a fine-grained analysis of the effects of negative interactions is possible. Additionally, a diary method has some methodological advantages as compared to single-point self-report questionnaires. First, the problem of retrospection is minimized by reducing the time between actual occurrence and report (West & Hepworth, 1991). Second, by examining the temporal precedence of events within individuals, participants can be used as their own controls, thereby reducing the influence of confounding variables (West & Hepworth, 1991).

Considering the profound effects of negative responses on well-being, it is important to explore conditions that moderate this effect. The present study examined whether the effects of negative responses received from the partner were reduced when participants received emotional support from their partner on the same day. Receiving negative responses from the partner does not preclude that one receives emotional support from the partner (Revenson et al., 1991; Vinokur & van Rijn, 1993; Schuster et al., 1990; Druley & Townsend, 1998). Emotional support involves the expression of love and care by communicating affection, value and interest (Helgeson, 1996). As was mentioned previously, receiving negative responses from the partner may be viewed as a sign of rejection by the recipient. It is reasonable to assume that the impact of negative responses will be less threatening to the relationship and to psychological resources (i.e. participants feel less rejected) when it is given by a partner who communicates love and care on the same day.

Thus far, most studies that considered the joint effects of positive and negative support in the partner relationship did not find a buffering effect of emotional support on the association between received negative responses and well-being (Schuster et al., 1990; Manne et al., 1997). However, these studies were typically based on between-person designs, that is, they examined whether individuals who in general receive high levels of negative responses from their partner are less affected by these negative responses if the partner in general provides much positive support as well (here, we use the term emotional support to refer to positive support and the term negative response to refer to negative support). Such a between-person design is different from the within-person design that was used in the current study. A within-person design provides information on the effects of negative responses *when* they occur or about *conditions* under which they have a larger effect (e.g., when emotional support is provided as well on the same day). For example, it may be that patients and partners do not differ with respect to the amount of negative responses they receive in general, but that patients are more strongly affected by them when they occur. Additionally, it may be that the effects of receiving negative responses are dependent on other things that happen on the same day (i.e. receiving emotional support).

In sum, this study examined the impact of negative responses received from the partner on end-of-day positive and negative mood in MS patients and their intimate partners. Further, the moderating role of receiving emotional support on the same day was examined. Both for patients and partners, we expected that negative responses received from the partner would have a negative effect on both positive and negative dimensions of mood, however, we expected that the effects were more pronounced for patients. Additionally, both for patients and partners, we expected that the effects of received negative responses would be moderated by receiving emotional support as well on the same day.

Method

Participants

MS patients and their intimate partners were approached via one MS Centre and the neurology department of one hospital in the Netherlands. MS patients who were registered in the patient files of these clinics received a letter including information about the study and a description of the inclusion criteria. As information on inclusion criteria were not available from the patient files (e.g. we did not know how many of these patients had a partner), we distributed letters to all 390 patients that were registered. This means that the number of couples who responded to the information letter could not be used to calculate response rates. Couples were eligible for inclusion if a) one partner was diagnosed with MS, (b) patients were currently involved in a heterosexual relationship with minimum relationship duration of one year, (c) patients were living together with their intimate partner, and (d) both partners were willing to participate in the study. Exclusion criteria were insufficient understanding of the Dutch language or when one or both partners suffered from serious psychiatric or medical problems other than MS.

Seventy couples, who were eligible for inclusion, responded to the information letter and signed informed consent. Of the 70 couples, a final sample of 61 couples completed all the materials. Reasons mentioned for drop-out were MS related health problems ($n=3$) and personal reasons ($n=3$). Three couples dropped-out without additional comments. Descriptive characteristics of the sample are detailed in Table 1 (second and fifth column). The sample showed wide variance in age, year since diagnosis and relationship length. Additionally, more female patients participated in the study which reflects the distribution of gender in the population. Further, 31 percent of the patients were employed (12% full-time and 20 % part-time); the other patients received a disability benefit (51%), performed household duties (10%) or were unemployed for other reasons (8%). Additionally, most partners (80%) were employed (61% full-time and 19% part-time), the other partners were retired (11%) or were unemployed for other reasons (9%). Twenty-three percent of the patients and 27% of the partners had completed the lowest level of secondary (vocational) education only, 41% of the patients and 40% of the partners had completed middle to higher levels of secondary

(vocational) education, and 36% of the patients and 33% of the partners had a college degree or higher.

Patients reported their actual disability by means of a self-report checklist (Kurtzke, 1989). Problems mentioned by patients included, amongst others, fatigue (95%), limited walking ability (56 %), bladder problems (72%), bowel problems (42 %), visual problems (25 %) and speech problems (15%). In general, the sample varied widely considering their functional disability, some patients were only mildly affected whereas others were severely impaired (mean 14, range 1-40, on a 0 to 64 scale, with higher scores indicating more disability). Additionally, 57 % of the patients described their MS as having a relapse remitting course, 43 % as having a progressive course.

Procedure

Prior to the diary part of the study, patients and partners completed questionnaires concerning demographics and disease related characteristics at home. Next, the couples were visited by the first author or a research assistant to provide additional information and instructions about the diary part of the study and to install an electronic diary on the couple's computer. Participants who did not own a computer were provided with a computer from the university. Computer software was developed especially for this study. The electronic diary was user-friendly and easy to complete. Even participants with little or no experience with computers were able to use the program after they were given clear instructions. Participants were instructed to complete the electronic diary every evening before going to bed, starting the following day. They were asked to complete the diary for fourteen days. Participants were explicitly asked not to share the answers with their partner while completing the diaries. The diary was designed to be completed in 5-10 minutes. Recordings were saved on a floppy disk and the participants did not have access to their reports after they were saved. After two weeks, the couples returned the floppy disk containing each night's responses by mail.

To verify compliance, the date and time of recordings were saved on the floppy disk. Participants were allowed to complete the diary the next morning if they did not manage to do it at night (2.6 % of the diaries were completed the next morning). Diaries that were completed too early (before 2 pm) or too late (after 2 pm the next day) were considered unreliable and were excluded from further analysis (1.6 % of the recordings). Further, participants who completed less than 10 days during the fourteen day period were excluded from further analyses. For this reason, two healthy partners were excluded who completed 6 and 9 days of recordings, respectively. An average of 13.1 days of recordings was reported across the fourteen day period.

Instruments

Negative responses were assessed each evening. Both patients and partners reported if and to what extent they had received negative responses from their partner that day. Negative

responses were assessed with four items including the following questions: Did it happen today that your partner: ‘made disapproving remarks of you?’, ‘avoided you?’, ‘hurt your feelings?’, and ‘demanded a lot of you?’. All answers were given on a 4-point scale (0 = not at all, 3 = very much). The four items were averaged to form a negative received support scale. However, the occurrence of negative responses was rare and participants almost never used the higher scores of the scale which resulted in strongly skewed distributions. Therefore, the scale was dichotomized into one variable that indicated the absence or presence of a negative response on a certain day. Consequently, we did not distinguish between the effects of the different items, nor did we differentiate between the strength of the responses that were reported. However, we considered this justified as the correlations between the four items and the dependent variables positive and negative mood were similar in magnitude and direction¹.

Emotional support was assessed each evening as well. Both patients and partners reported if and to what extent they had received emotional support from their partner that day. Three items were used to measure emotional support including the following questions: Did it happen today that your partner: ‘listened to you?’, ‘was affectionate towards you?’, ‘gave you a compliment?’. All answers were given on a 4-point scale (0 = not at all, 3 = very much). Cronbach’s alpha based on the aggregated scores was .84 for patients and .85 for partners.

End-of-day mood was measured with the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). The instrument consists of 10 positive and 10 negative adjectives that make up a negative and positive mood scale. Each evening, participants were asked to indicate to what degree they experienced the respective emotion ‘right now’, on a 5-point scale ranging from (1) slightly or not at all to (5) extremely. Scores on the positive items and the negative items were summed per day. Based on the aggregated scores, Cronbach’s alpha was .87 and .83 for the positive scale in patients and partners, respectively, and .81 and .76 for the negative scale in patients and partners, respectively. The correlation between positive and negative mood over days within patients and partners was close to zero ($r = .12$ and $r = .05$, respectively).

The number of *daily hassles* experienced each day was included as a control variable since hassles may influence the receipt of negative responses and emotional support. A checklist was used based on the Revised Hassle and Uplift Scale (DeLongis, Folkman, & Lazarus, 1988). However, we considered the original 53 item scale too long to be used on a daily basis, so we shortened the scale by conjoining several items. One item referring to the

¹ Correlations over persons and days between positive mood and the four items, ‘hurt feelings’, ‘criticism’, ‘demanding’ and ‘avoidance’ were -.01, .03, .01, and .01 in patients and -.01, -.02, .06 and .06 in partners, respectively. Correlations between negative mood and the four items ‘hurt feelings’, ‘criticism’, ‘demanding’ and ‘avoidance’ in patients were .28, .21, .18, and .16 and in partners were .39, .32, .21, and .26 respectively ($p < .01$).

occurrence of special incidents (e.g. accident, winning the lottery) was added. This resulted in a 22 item scale that represented all the areas that were included in the original scale.

Finally, the amount of *MS related symptoms* that a patient experienced was included as a control variable for the same reason as daily hassles. Patients were asked each evening to indicate to what extent they had experienced MS related symptoms that day. The answer was given on a 10-point scale ranging from (1) no symptoms to (10) many symptoms.

Analyses

Multi-level regression modeling, as implemented in the program MLwiN (Rasbash, Browne, Goldstein, & Yang, 2000) was used to determine the relationship between the predictors and dependent variables. Each model had three levels, a between-couple level (level 3), a between-person level (level 2) and a within-person level (level 1). The within-person level of the analyses allowed each individual's evening mood on a given day to be modeled as a function of that individual's received negative responses². We predicted end-of-day mood while controlling for previous day end-of-day mood, daily hassles, patient's MS related symptoms and received emotional support.

The analyses were started with an intercept only model that separated the variance of end-of-day mood in three independent components: mood-level variance, person-level variance and couple-level variance. In this study we were primarily interested in the predictive value of negative responses on end-of-day mood. Therefore we reported the amount of variance explained by the predictors at the daily level only. It is important to note that variance explained at the lowest level (that is days) cannot be explained by variables at higher levels, because these are constant at the days-within-persons level. Next, the predictors were entered in the regression equation hierarchically, starting with the control variables (step 1), followed by role (step 2), the main effects of emotional support and negative responses (step 3), the interaction between emotional support and negative responses (step 4), and the two-way and three-way interactions between role, emotional support and negative responses (step 5). All predictors were grand mean centered (i.e. the overall mean was subtracted from the values of a variable), thus the regression intercept represented mood when all variables were at their average level. The variables negative responses received from the partner and role (patient or partner) were effect coded. No negative responses received on a day was coded as -.5 and negative responses received as .5. Additionally, patients were coded as -.5 and partners as .5. When interaction effects were significant, regression equations were estimated for days on which individuals were scoring 1 *SD* below and 1 *SD* above the mean of the interaction variables (Aiken & West, 1991), to obtain a graphical diagram of the interaction.

² In additional analyses we investigated the lagged effects of negative interactions on mood on the following days. However, we did not find evidence for an effect beyond same day end-of-day mood.

Results

Descriptive analyses

Table 1 presents the means and standard deviations of the key study variables. Across the fourteen day period, 18 patients (30 %) and 13 partners (21 %) did not report receiving negative responses from their partner. The mean number of days on which patients or partners reported receiving negative responses was 2.6 (range 0-11) and 3.8 (range 0-13) respectively. Thus, across the fourteen day period, partners reported more days on which they received negative responses from their ill partner than patients ($p < .05$). Additionally, all participants reported receiving emotional support from their partner across the fourteen day period.

As shown in Table 1, patients who did not report receiving negative responses across the fourteen day period were older, had lower education and experienced less daily hassles than patients who did report receiving negative responses across the fourteen day period. Further, partners who did report receiving negative responses across the fourteen day period differed from partners who did not report receiving negative responses on the amount of daily hassles they reported. In line with the results for patients, they reported experiencing more daily hassles. Apparently, individuals who reported receiving negative responses from their partner reported more daily hassles in general. Individuals who did or did not report receiving negative responses across the fourteen day period did not differ from each other on other key study variables such as the amount of positive and negative mood, or the amount of emotional support that they reported receiving.

Based on the daily measures, the correlation between received negative responses and emotional support as reported by MS patients and their partners was $-.01$ and $-.02$ respectively. This suggests that patients or partners who reported receiving high levels of emotional support, did not necessarily also report receiving low levels of negative responses on the same day.

End-of-day positive mood

Table 2 presents the results of the multilevel analysis predicting end-of-day positive mood as a function of received negative responses and emotional support. The intercept indicates that the predicted amount of end-of-day positive mood for an average person on an average day was 25 (on a 10-50 scale). Additionally, the variance estimates of the intercept-only model showed that 51 % of all variance in the dataset was explained at the daily level. In the first step, the control variables were entered. Better previous day end-of-day positive mood and less MS related symptoms in patients were related to better end-of-day positive mood whereas the amount of daily hassles experienced was unrelated to positive end-of-day

Table 1 Means (SD) of patients and partners who did or did not report receiving negative responses from their partner across the 14-day period.

| | Patients | | | Partners | | |
|--|---------------|-------------------------|--------------------------|---------------|-------------------------|--------------------------|
| | Total N=61 | No ¹ N=18 | Yes ² N=43 | Total N=59 | No ¹ N=13 | Yes ² N=46 |
| Gender, % women | 87 % | 89 % | 86 % | 14% | 15% | 8% |
| Age | 46.8 (8.5) | 50.8 (5.9) | 45.0 (8.9)** | 49.3 (9.3) | 51.2 (11.7) | 48.8 (8.6) |
| Relationship duration | 22.6 (10.0) | 23.8 (9.5) | 22.1 (10.3) | 22.8 (10.3) | 21.0 (11.8) | 23.2 (10.0) |
| Education (1-8 scale) | 4.5 (2.3) | 3.5 (2.1) | 4.9 (2.2)* | 4.6 (2.2) | 4.3 (2.2) | 4.7 (2.3) |
| Year since diagnosis | 8.3 (6.0) | 7.6 (4.7) | 8.5 (6.5) | | | |
| Physical disability (0-64 scale) | 14.2 (9.5) | 13.2 (8.3) | 14.6 (10.0) | | | |
| Daily MS related symptoms (1-10 scale) | 4.8 (2.2) | 5.0 (2.4) | 4.8 (2.1) | | | |
| Daily hassles (0-22 scale) | 4.4 (2.5) | 2.9 (2.1) | 5.1 (2.3)** | 4.1 (3.4) | 2.4 (2.8) | 4.6 (3.5)* |
| Daily positive mood (10-50 scale) | 24.8 (5.8) | 23.5 (6.1) | 25.3 (5.6) | 25.4 (5.5) | 25.2 (6.2) | 25.4 (5.4) |
| Daily negative mood (10-50 scale) | 14.5 (4.0) | 14.3 (5.2) | 14.6 (3.5) | 14.1 (4.1) | 13.2 (2.3) | 14.3 (4.5) |
| Emotional support (0-3 scale) | 1.8 (.8) | 1.5 (.9) | 2.0 (.63) | 1.5 (.8) | 1.8 (1.0) | 1.5 (.72) |

Note * $p < .05$, ** $p < .01$ T-tests were used to compare those who did and did not receive negative response. ¹No: participants who did not report receiving negative responses across the 14-day period. ²Yes: participants who reported receiving negative responses over the 14-day period.

mood. Together the control variables accounted for 7 % of the variance at the daily level. In the second step, role (patient or partner) did not contribute significantly to end-of-day positive mood, indicating that patients and partners did not differ with respect to their positive end-of-day mood. In the third step, the main effects of emotional support and negative support were entered. Individuals reported better end-of-day mood when they received more emotional support, whereas end-of-day positive mood was unrelated to received negative responses. Together, received emotional support and negative responses accounted for 2 % of the variance in end-of-day positive mood. In the fourth step, the interaction between emotional support and negative responses was entered to examine whether the effects of negative responses differed as a function of emotional support. The interaction variable did not contribute significantly to the model (the explained variance was 0 %). Finally, the interactions between negative responses and emotional support on the one hand and role on the other hand were entered in order to examine whether the effects of negative responses and emotional support and the interaction term differed as a function of role. However, none of the effects were dependent on role, that is, the effects of emotional support and negative responses were the same for patients and partners.

In sum, both for patients and partners, received emotional support was related to end-of-day positive mood whereas received negative responses was unrelated to end-of-day positive mood.

Table 2 The effects of received negative responses from the partner on end-of-day positive and negative mood in patients and the moderating role of received emotional support

| | Positive mood | | | Negative mood | | |
|-------------------------------|---------------|-----|---------|---------------|-----|--------|
| | B | SE | beta | B | SE | Beta |
| Intercept | 24.92 | .53 | | 14.65 | .28 | |
| Step 1 Previous day mood | .16 | .03 | .16*** | .21 | .02 | .21*** |
| MS related symptoms | -.53 | .10 | -.18*** | .51 | .07 | .24*** |
| Hassles | -.08 | .07 | -.04 | .40 | .05 | .26*** |
| Step 2 Role (patient/partner) | .81 | .69 | .05 | -.50 | .49 | -.05 |
| Step 3 Emotional support | 1.43 | .27 | .17*** | -.27 | .18 | -.05 |
| Negative responses | -.13 | .43 | -.01 | 1.58 | .29 | .12*** |
| Step 4 Emo*neg | .40 | .44 | .02 | -.85 | .29 | .07*** |
| Step 5 Role*emo | <i>ns</i> | | | <i>ns</i> | | |
| Role*neg | <i>ns</i> | | | <i>ns</i> | | |
| Role*emo*neg | <i>ns</i> | | | <i>ns</i> | | |

Note *** $p < .001$. Interactions between role and the main effects are presented only when significant. Emo=emotional support; Neg=negative responses

End-of-day negative mood

Table 2 presents the final model of the multilevel analysis predicting end-of-day negative mood as a function of received negative responses and emotional support. The intercept

indicates that the predicted amount of end-of-day negative mood for the average person on an average day was 15 (on a 10-50 scale). The intercept-only model showed that 50 % of all variance in the dataset was explained at the daily level. In the first step, the control variables were entered and contributed all significantly to the equation. Worse previous day end-of-day mood, more MS related symptoms and more hassles were related to worse end-of-day negative mood which accounted for 12 % of the variance in end-of-day negative mood. In the second step, role (patient or partner) did not contribute significantly to end-of-day negative mood, that is, patients and partners did not differ with respect to their end-of-day negative mood. Next, the main effects of emotional support and negative support were entered. Individuals reported worse end-of-day negative mood when they received negative responses from their partner, but received emotional support was not related to end-of-day negative mood. The explained variance at the daily level was 5 %. In the fourth step, the interaction between emotional support and negative responses was entered. The interaction contributed significantly to the regression and explained 1% of the variance at the daily level. As is shown in Figure 1, the effect of negative responses received from the partner on end-of-day negative mood was reduced when patients and partners reported receiving high levels of emotional support on the same day as well ($b = 2.38, p < .00$ when high levels of emotional support were received; $b = .78, p = .05$ when low levels of emotional support were received). Finally, the interactions between negative responses and emotional support on the one hand and role on the other hand were entered. Again, no significant differences between patients and partners were found.

In sum, both for patients and partners, the effect of negative responses received from the partner was reduced when patients or partners received emotional support from the partner as well.

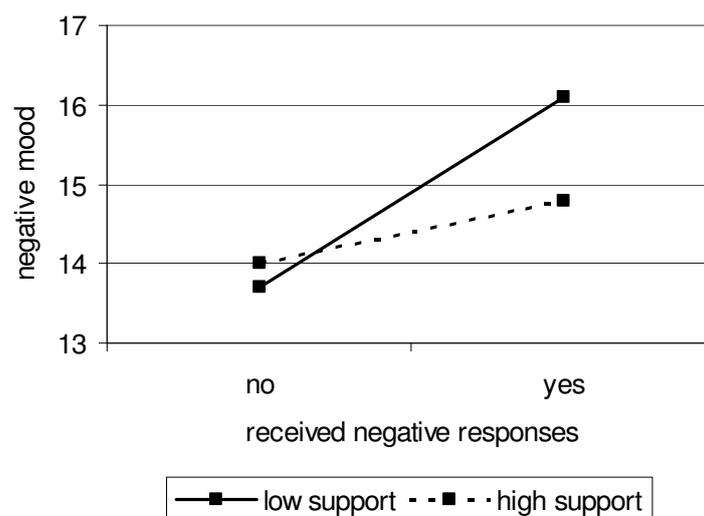


Figure 1 The relation between received negative responses and end-of-day negative mood moderated by received emotional support in both patients and partners.

Discussion

The present study examined daily received negative responses in MS patients and their intimate partners. First, the relation between daily received negative responses from the partner and end-of-day mood was examined. Second, the moderating role of receiving emotional support on the same day was addressed. An important feature of the study was the use of a diary method which allowed us to investigate the effects of negative responses within-persons over time.

In line with other studies, both patients and partners reported receiving few negative responses from their partner and some patients and partners did not report receiving any negative responses across the fourteen day period (e.g. Rook, 2001). In addition, it was found that patients and partners who reported receiving negative responses from the partner reported more daily stress in general, which is in line with results documented by Rook (2003). She reported that greater exposure to negative responses from others was related to higher life stress in older adults. Apparently, individuals who report receiving negative responses from their partner report more daily hassles in general. Further, patients who reported receiving negative responses from the partner were younger and higher educated. A comparable relation between age and exposure to negative interactions was found in a study by Krause and Shaw (2002).

In concordance with a domain specific model, the impact of received negative responses from the partner was limited to negative mood in both patients and partners. Received negative responses from the partner detracted from end-of-day negative mood but were unrelated to end-of-day positive mood. We expected a cross-over effect of received negative responses on mood in both patients and partners. This assumption was based on the potent effects of negative responses and the higher vulnerability to these responses in individuals under stress, such as in patients and partners dealing with MS. One reason that may explain why we did not find a cross-over effect of received negative responses may be that the effects of negative responses on mood were relatively weak as compared to the effects of MS related symptoms and daily hassles, for example. It may be that cross-over effects are only found when effects are potent. The received negative responses variable was dichotomized because of the low frequency in our sample. As a result we were not able to distinguish between days that participants reported receiving many negative responses and days that participants reported receiving few negative responses, which may have decreased the power of our predictor. However, despite a decrease in power, we found an important effect of received negative responses on end-of-day negative mood over and above daily hassles and MS related symptoms.

We did not find evidence that the effects of received negative responses were different for patients and partners. We expected that patients would be more vulnerable to negative interactions because they are often placed in a position of dependence and more dependent on their partner for support (Rusbult & Van Lange, 2003). As far as we know, this is the

first diary study that compared patient's and partner's vulnerability to received negative responses from the partner. Several studies have shown that patient's and partner's well-being is highly related and follows the same pattern during the course of illness (Pakenham, 1998; Segrin et al., 2005). Our results suggest that the effects of received negative responses from the partner are similar for both patients and their intimate partners.

The present study focused on the effects of negative interactions on same day end-of day mood. However, it is possible that these negative interactions have an effect on mood beyond the day on which they occur. We performed additional analyses to examine this issue (see note 2), but found no support for such an effect. These findings are in line with studies examining the association between daily stress and mood, which generally do not find an effect of stress on mood beyond the day as well (Stone et al., 1993). This is interesting considering the apparent importance of negative responses for long term well-being (e.g. Rook, 2001). As suggested by Stone and colleagues (1993), it may be that the impact of the events that were reported was not large enough or that an effect beyond the day only exists in some individuals, such as in individuals with high interpersonal sensitivity (Smith & Zautra, 2002). Additionally, there may be complex patterns of associations between received negative responses and mood that are cumulative and exceed over days or months. One aspect that may be important in this context is the frequency of days that individuals report receiving negative responses. Our sample showed a large variance in the frequency of days that patients and partners reported receiving negative responses from the partner. An interesting challenge for future research is to examine how daily negative responses affect long term well-being.

Our results showed that the impact of received negative responses from the partner on end-of-day negative mood can be buffered by receiving high levels of emotional support on the same day, both for patients as well as for partners. Our data does not reveal whether the emotional support is provided concurrently with, before or after the negative responses. However, it was shown that the adverse effects of received negative responses from the partner were reduced when individuals received high levels of emotional support as well within a relatively short time period (one day). The present study does not allow us to examine why emotional support buffers the effect of received negative responses. For example patients or partners may feel less rejected when they receive emotional support in addition to negative responses. Additionally, receiving negative responses may be less threatening to the relationship when emotional support is provided as well because, despite the negative responses, the partner knows that he or she is still liked by the other partner. Further, the present study showed that emotional support is important, not only directly but also in buffering the effects of receiving negative responses from the partner. Interventions should teach patients and partners about these mechanisms. They should not only focus on reducing negative interactions but they should also attend to mechanisms that can prevent negative responses from having its harmful effects.

Some limitations of the present study require attention. First, a diary method offers the unique opportunity to examine the effects of support processes across time. However, the non-experimental nature of the data precludes causal statements. As recordings of support and mood were collected at the same time (i.e. end-of-day), it is possible that patients or partners who were in a better mood were also inclined to report receiving more or less negative responses or emotional support. However, we controlled for important confounding variables, that is, previous day end-of-day mood, daily hassles and MS related symptoms. Herewith, we protected to some extent against the problem of mood simply predicting support interactions. Further, the selection of the fourteen day period for the diary measures was inherently arbitrary and we cannot be sure that the two week period we selected was characteristic for the couple's daily life. This is an intrinsic problem to diary studies. However, to protect against this problem the couples were instructed to complete the diaries during a period that was representative for their daily life with respect to, for example, days at work.

Further, given that the majority of our sample consisted of female patients and male partners, we were unable to address gender differences. Some of our findings may have been different if we had considered male patients and female partners. Additionally, we do not know whether the pattern of findings is specific to couples facing MS or whether the findings can be generalized to other chronic diseases. We assume that our findings apply to other resembling diseases as well, such as rheumatoid arthritis. Further, the MS patients in our study did not experience relapses during the fourteen day period. The effects of negative responses received from the partner may be different during crisis (i.e. flare ups). Other limitations concern the small sample size and the fact that we do not know whether our sample represented couples dealing with MS. It is possible that distressed couples were less willing to participate in a study like this. Related to this, on average the couples in this sample had been together for a long time suggesting that they somehow managed to deal with the MS in their relationship successfully.

Finally, the effects of negative responses and the moderating role of emotional support may depend on the individual. Indeed, our data suggested that the effects of received negative responses and emotional support varied as a function of between-person differences. However, we did not examine this any further because it was beyond the scope of this study. Variance explained by between-person differences means that certain aspects of the patient or partner moderates the effects of received negative responses or emotional support. For example, previous studies have suggested that reactivity to negative responses were dependent on an individual's self-esteem (Rook, 2003) or interpersonal sensitivity (Smith & Zautra, 2002).

To conclude, the present study adds to a growing body of research that describes the detrimental effects of receiving negative responses from the partner on end-of-day mood. Interestingly, our results indicated that the consequences of receiving negative responses

from the partner were for a large part dependent on the amount of emotional support that patients or partners received from their partner on the same day. Further, the study showed that examining daily within-person processes over time may provide us with valuable information considering the conditions under which the adverse impact of negative interactions may be more or less profound.

Chapter 5

Daily positive and negative support in relation to depression and anxiety in patients with multiple sclerosis (MS) and their partners: A prospective study

Abstract

This study examined the effects of daily emotional support and negative responses received from the partner on anxiety and depression prospectively among couples dealing with multiple sclerosis (MS). Forty-eight couples dealing with MS completed a fourteen-day computerized diary to assess their levels of emotional support and negative responses. Prior to completing the diary and at seven months follow-up both partners completed self-report questionnaires with respect to their levels of anxiety and depression and physical disability (patients only). It was postulated that emotional support would have a positive effect on anxiety and depression whereas negative responses were hypothesized to have a detrimental effect. However, the results did not support the proposed relations, although emotional support received from the partner showed a weak and marginally significant effect on depression, in both patients and partners.

Introduction

There is a widespread belief that social support has important implications for adjustment to stressful life events such as chronic illness. Spouses are usually the most important providers of support for married persons (Pistrang & Barker, 1995; Schuster, Kessler, & Aseltine, 1990) and during stressful periods people rely mostly on their partner for support. However, interactions with the partner are not exclusively supportive, partners can also be a source of stress by being critical, demanding or avoiding (Manne, Taylor, Dougherty, Kemeny, 1997; Manne & Zautra, 1989). Positive and negative interactions with the partner may co-occur within the same relationship and have independent effects on well-being (Finch, 1989; Major, Zubek, Cooper, Cozzarelli, 1997; Schuster et al., 1990).

In a recent study using a diary method, we examined the relation between emotional support and negative responses received from the partner and end-of-day positive and negative mood among patients and partners dealing with multiple sclerosis (MS) (Kleiboer, Kuijer, Hox, Frequin, Jongen, & Bensing, 2006a). In line with the few other studies that examined the impact of negative responses and emotional support on mood using a diary method (e.g. DeLongis, Capreol, Holtzman, O'Brien, & Campbell, 2004; Rook, 2001), independent relations between emotional support and negative responses on the one hand and end-of-day emotional well-being on the other hand were found. Emotional support received from the partner was related to end-of-day positive mood, whereas negative responses received from the partner were related to higher negative mood at the end of the day (Kleiboer et al., 2006a).

In that study (Kleiboer et al., 2006a) we examined daily changes in mood in response to emotional support or negative responses only. The effects of emotional support and negative responses on less transient measures of emotional well-being were not examined, that is, do patients or partners who generally receive more emotional support and less negative responses experience better emotional well-being in general? The aim of the present study

was to extend our previous findings by examining the effects of emotional support and negative responses on anxiety and depression prospectively in the same sample of couples dealing with MS.

Emotional support involves the communication of love and care, by showing affection, providing reassurance and listening, and is generally related to lower levels of distress (e.g. Druley & Townsend, 1998; Manne & Zautra, 1989; Schuster et al., 1990; Vinokur & Van Rijn, 1993)¹. In the context of chronic illness, patients often become more dependent on their partner for support and self-esteem, because other resources are often lost (such as work) (Cutrona, 1996; Druley & Townsend, 1998). Receiving emotional support from the partner may help them deal with the emotional distress generated by the disease and may enhance feelings of self-worth (Cutrona, 1996; Murray, 1995). Although little research has considered the partner as a support recipient, receiving emotional support from the ill partner may also be important for the healthy partner (Kleiboer, Kuijer, Hox, Schreurs, & Bensing, 2006b; Kriegsman, Penninx, & Van Eijk, 1994).

Negative interactions with the partner can take various forms such as well intended support attempts that may backfire because they are inappropriate, ineffective or unwanted by the recipient (Newsom & Schulz, 1998; Lehman & Hemphill, 1990). However, in this study we focus on more overt negative responses such as criticism, avoidance or being demanding (Rook, 1992). The latter form of negative interactions are often considered to be stressful events (Shinn, Lehman, & Wong, 1984) that involve a threat to the relationship with the provider and tax psychosocial resources (Rook, 1992).

Contrary to our expectations, the diary study (Kleiboer et al., 2006a) did not show evidence for the potent effects of negative responses as compared with the effects of receiving emotional support, as is frequently noticed in other studies (Newsom, Nishishiba, Morgan, & Rook, 2003; Manne et al., 1997; Schuster et al., 1990). Neither did we find differences between patients and partners regarding the effects of emotional support or negative responses they reported receiving (Kleiboer et al., 2006a). It was expected that supportive interactions would be more important for patients who are the most vulnerable in the relationship (Rusbult & VanLangen, 2003) due to their higher dependency on the partner (Cutrona, 1996).

However, a within-person design was used in the diary study which is different from a between-person design that was used in the current study (e.g. Gable & Reis, 1999). A within-person design examines the reactivity to events (e.g. emotional support or negative responses) *when* they occur or the *conditions* under which they have a larger effect (e.g.

¹ The idea that receiving emotional support is always beneficial for well-being is not unchallenged (e.g. Bolger, Foster, Vinokur, & Ng, 1996; Newsom & Schulz, 1998). Receiving support may also signal that one has failed, is dependent or incompetent (Fisher, Nadler, & Whitcher-Alagna, 1982; Liang, Krause, & Bennett, 2001). However, because we did not find evidence for these costs of emotional support in the diary study we conducted (Kleiboer, Kuijer, Hox, Schreurs, & Bensing, 2006b), we take emotional support as being beneficial for emotional well-being as a starting point.

when other stressors are present at the same time). Within-person effects are assessed independently of the amount of emotional support or negative responses that patients or partners receive in general. In contrast, between-person designs typically assess whether individuals who receive more emotional support or more negative responses in general, have more or less emotional distress. The latter design may reveal different results than the diary study.

As far as we know, this is the first study that examined the effects of emotional support and negative responses as measured with a diary prospectively in patients with chronic illness (i.e. multiple sclerosis). Examining the effects of emotional support and negative responses received from the partner on emotional distress is relevant for couples dealing with MS. This chronic progressive disorder of the central nervous system is characterized by a highly unpredictable and variable course. The repeated adjustment to new situations, the increasing physical disability and the psychosocial consequences can produce considerable distress both for patients and partners (Mohr & Cox, 2001; Murray, 1995). Moreover, both patients and their intimate partners have been identified as being at risk for depression and anxiety (Mohr & Cox, 2001; Pakenham, 2001; McKeown, Porter-Armstrong, & Baxter, 2003; Antonak & Livneh, 1995).

In sum, this study examined the effects of received emotional support and negative responses, as measured with a diary, on anxiety and depression among patients and partners dealing with MS prospectively. We postulated that patients and partners who reported receiving more positive support during the 14 day diary period will experience less anxiety and depression 7 months later. We further expected that patients and partners who reported receiving more negative responses from the partner will experience an increase in anxiety and depression. Additionally it is expected that these processes are more pronounced in patients because they are the most vulnerable in the relationship.

Method

Participants

Patients with MS and their partners were contacted through one MS Centre and the neurology department of one hospital in the Netherlands. MS patients registered in the patient files of these clinics received a letter with information about the study and a description of the inclusion criteria. The selection criteria for participation were that (a) patients were diagnosed with MS, (b) patients were currently involved in a heterosexual relationship (with minimum relationship duration of one year), (c) patients were living together with their partner, and (d) both partners were willing to participate in the study. Couples were excluded if their ability to read or understand Dutch was insufficient, or when one or both partners suffered from serious psychiatric problems or medical problems other than MS. As information on inclusion criteria were not available from the patient files (e.g. we do not know how many of these patients had a partner), we distributed letters to all

three-hundred-ninety patients that were registered. This means that the number of couples who responded to the information letter cannot be used to calculate response rates.

A total of 70 couples who met our inclusion criteria responded to the information letter and signed informed consent. Four participants decided not to participate in the study after they were contacted by the researcher for reasons of MS related health problems (being too ill to participate). Of the remaining 66 couples, a final sample of 48 patients and 48 partners (73%) completed all the materials (i.e. baseline measurement, 14-day diary, follow-up measurement 7 months later). Reasons mentioned for drop-out between baseline and follow-up ($n=18$) were MS related health problems ($n=3$) or personal reasons ($n=3$). One patient died before the end of the study and eleven couples never responded to our reminders. Couples who dropped out of the study did not differ from couples who completed the study with respect to age, relationship length, education, year since diagnosis and physical disability (All t-tests were non significant at $p<.05$).

Of the patients with MS, 85% ($n=41$) were female and 15% ($n=7$) were male. The mean age of patients was 47 years (range: 27 to 64, $SD = 8.7$), and on average they had been diagnosed with MS 8 years previously (range: 1 to 28, $SD = 5.5$). The partners of these patients were, on average 49 years (range: 29 to 69, $SD = 9.6$). Seventeen percent of the patients and 26% of the partners had completed the lowest level of secondary (vocational) education only, 44% of the patients and 36% of the partners had completed middle to higher levels of secondary (vocational) education, and 40% of the patients and 38% of the partners had a college degree or higher. The couples had been married or cohabiting for an average of 22 years (range: 2 to 41 years, $SD = 10.4$).

Measures

Patients and partners completed questionnaires prior to the diary part of the study (1-4 weeks), and at 7 months follow-up, with respect to demographics, physical disability (patient's only), anxiety and depression. The diary part of the study extended over a fourteen day period. Each night patients and partners completed a structured computerized diary assessing emotional support and negative responses that occurred during the day. Details about the computerized diary are described in Kleiboer et al. (2006a).

Patient's and partner's levels of *anxiety and depression* at baseline and follow-up were assessed with the Hospital Anxiety and Depression Scales (HADS; Zigmond & Snaith, 1983). Fourteen items make up this questionnaire measuring symptoms of anxiety and depression. Each item is scored on a four-point scale, with higher scores indicating higher levels of anxiety and depression. Scores between 8 and 10 are considered clinically borderline and scores of 11 and higher are considered clinically definite levels of anxiety and depression. The instrument has proven to be valid and reliable in Dutch patient samples (Spinhoven, Ormel, Sloekers, Kempen, Speckens, & Van Hemert, 1997) and is appropriate

for use in patients suffering from chronic illness because it is relatively free of criterium contamination by somatic items. Cronbach's alpha for the anxiety scale was .85 for patients and .77 for partners at baseline. Cronbach's alpha for the depression scale was .77 for patients and .70 for partners at baseline.

Patient's level of *physical disability* and *a change in physical disability* between baseline and follow-up were included as control variables because physical disability is highly related to both depression and to support needs. Patient's physical disability was assessed with the incapacity status scale (ISS; Kurtzke, 1981). The ISS provides a measure of severity of the physical disability caused by MS. For this study, the structured interview was adapted to a self-report questionnaire format, to be completed by patients. The items were rated on a five point scale ranging from 0 (normal functioning) to 4 (complete inability). The summated items indicate the amount of impairment MS patients experience. 'Healthy' individuals have scores of 0 and MS patients with a score up to 16 can be considered as affected but unimpaired. A score higher than 16 suggests impairment (Kurtzke, 1981; Stuijbergen, Seraphine, & Roberts, 2000). Cronbach's alpha of the scale at baseline in this study was .85. Difference scores were computed to measure a change in physical disability between baseline and follow-up. A positive score indicates an increase in physical disability and a negative score indicates a decrease in physical disability

Daily support

Emotional support received was assessed with three items: "My partner gave me a compliment", "My partner listened to me", and "My partner showed affection towards me". The answers were given on a 4-point scale (0 = not at all, 3 = very much). The items were averaged per day and subsequently were aggregated to form a scale for daily emotional support received. Internal consistency of the scales was calculated based on the aggregated scores over the 14 days; Cronbach's alpha was .79 for patients and .81 for partners.

Negative responses were assessed with four items: "My partner criticized me", "My partner avoided me", "My partner hurt my feelings", "My partner demanded a lot of me". The answers were given on a 4-point scale (0 = not at all, 3 = very much). The four items were averaged per day to form a scale for daily negative support received. However, the occurrence of negative interactions was rare and the participants almost never used the higher scores of the scale which resulted in strongly skewed distributions. Therefore the scale was dichotomized into one variable that indicated the absence or presence of a negative response on a certain day (Hox & Kleiboer, 2006; Kleiboer et al., 2006a). The number of days that patients or partners reported receiving negative responses was summed and resulted in a variable that indicated the amount of days that patients or partners reported receiving negative responses.

Analyses

To examine the effects of emotional support and negative responses on anxiety and depression, multi-level regression analysis was conducted as implemented in the program MLWin. Multi-level modeling was used because the data was hierarchically nested with persons (level 1) nested within couples (level 2). Multi-level modeling is a sophisticated regression analysis that takes into account the dependency within couples (Hox, 2002). Additionally, these analyses make it possible to examine whether the results were different for patients and partners. Separate regression analyses were performed for the outcome measures depression and anxiety at 7 months follow-up. The predictors were entered hierarchically. After calculating an intercept only model, baseline anxiety or depression was entered in the first step. In the second step, the control variables physical disability and a change in physical disability between baseline and follow-up were entered. Additionally, role (patient or partner) was entered to test whether a change in depression or anxiety between baseline and follow-up was different for patients and partners. In the fourth step, the main effects of emotional support and negative support received were entered. Finally, an interaction between role and the main effects was entered in the fifth step to examine whether the effects of negative responses and emotional support were different for patients and partners. All variables were grand mean centered (i.e. the overall mean was subtracted from the values of a variable), thus the regression intercept represented depression or anxiety when all variables were at their average level.

Results

Descriptive statistics

Descriptive statistics of the key study variables are presented in Table 1. On average, patients reported receiving more emotional support than their partners ($t(df)=3.38, p <.001$). In contrast, partners reported receiving more negative responses from their partner than patients ($t(df)= -2.57 p <.01$). The amount of emotional support that was reported receiving at baseline was related to lower levels of depression both at baseline and at follow-up in patients and partners. The amount of emotional support that was reported receiving at baseline was unrelated to the patient's or partner's level of anxiety. Additionally, negative responses reported receiving at baseline were unrelated to patient's or partner's level of depression. However, they were related to higher levels of anxiety in patients, both at baseline and at follow-up. The correlations between negative and positive interactions were relatively low both in patients (.08) and partners (.08) suggesting that they are independent and may co-occur within the relationship.

Table 1 Means, standard deviations, and correlations of the key study variables at baseline for patients (below diagonal) and partners (above diagonal)

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Partners, mean (SD) |
|----------------------------|----------|-----------|------------|-----------|-----------|-----------|-----------|---------------------|
| 1. Emotional support (BL) | | .08 | -.03 | -.08 | -.07 | -.44** | -.40** | 1.5 (.77) |
| 2. Negative responses (BL) | .08 | | .15 | .07 | -.04 | .10 | .03 | 4.6 (3.9) |
| 3. Disability (BL) | -.22 | .01 | | .34* | .24 | .27† | .20 | - |
| 4. Anxiety (BL) | -.01 | .36* | .06 | | .70** | .53** | .41** | 5.1 (3.3) |
| 5. Anxiety (FU) | -.04 | .32* | -.12 | .69** | | .46** | .63** | 5.6 (3.5) |
| 6. Depression (BL) | -.29* | -.04 | .28* | .56** | .22 | | .70** | 3.7 (2.7) |
| 7. Depression (FU) | -.34* | .16 | .10 | .47** | .55** | .61** | | 4.1 (2.9) |
| Patients, mean (SD) | 1.8 (.7) | 3.1 (3.5) | 13.2 (8.8) | 5.4 (4.2) | 5.4 (4.3) | 4.1 (2.8) | 4.9 (3.8) | |

Note †p < .10, *p < .05, **p < .01, ***p < .001 ; BL=Baseline measure FU=Follow-up measure

Depression and anxiety as a function of emotional support and negative responses

Table 2 presents the results of the regression analysis predicting depression and anxiety at follow-up as a function of emotional support and negative responses received from the partner. The results regarding depression showed that after controlling for baseline depression, baseline physical disability and a change in physical disability between baseline and follow-up, the amount of emotional support that was reported receiving predicted depression at follow-up, however, this effect was only marginally significant. Contrary to our expectations, negative responses that were reported receiving did not predict depression at follow-up. Additionally, it was tested whether the effects of emotional support and negative responses were different for patients and partners, however, these analyses were not significant.

The results with respect to anxiety showed that after controlling for baseline anxiety, baseline physical disability and a change in physical disability between baseline and follow-up, neither emotional support nor negative responses that were reported receiving predicted anxiety at follow-up. Again it was examined whether the effects were different for patients and partner. However, these analyses did not contribute significantly to the regression equation.

Table 2 Results for multilevel regression analyses to predict anxiety and depression at 7 months follow-up

| | Depression (FU) | | | Anxiety (FU) | | |
|--------------------------------|-----------------|--------|------|--------------|--------|------|
| | B | SE | Beta | B | SE | Beta |
| Intercept | 5.43 | .80*** | | 4.92 | .86*** | |
| Depression/anxiety (BL) | .71 | .10*** | .57 | .73 | .08*** | .71 |
| Patient's disability (BL) | .00 | .03 | .01 | -.03 | .04 | -.07 |
| Δ patient's disability | .14 | .06** | .18 | .10 | .07 | .11 |
| Role (patient or partner) | -.63 | .51 | -.09 | .40 | .54 | .05 |
| Negative responses (BL) | .10 | .07 | .11 | .06 | .08 | .06 |
| Emotional support (BL) | -.61 | .36† | -.14 | -.11 | .39 | -.02 |
| Role * Emotional support (BL) | ns | | | ns | | |
| Role * Negative responses (BL) | ns | | | ns | | |

Note † $p < .10$ * $p < .05$, ** $p < .01$, *** $p < .001$; BL= Baseline measures; FU=Follow-up measures

Discussion

This study examined the effects of daily emotional support and negative responses received from the partner on anxiety and depression among patients and partners dealing with multiple sclerosis prospectively. The study builds on and extends findings of a previous study in which we examined the effects of emotional support and negative responses received from the partner on end-of-day well-being (Kleiboer et al., 2006a).

The association between emotional support on the one hand and depression at baseline and follow-up on the other hand, together with the weak but marginally significant effect of emotional support on depression suggests that emotional support does play a role in depression as was expected and is found in others studies as well (Druley & Townsend, 1998; Manne & Zautra, 1989; Schuster et al., 1990; Vinokur & Van Ryn, 1993). Apparently, patients or partners who generally report receiving more emotional support are better off in terms of their levels of depression. Emotional support did not have an effect on anxiety at follow-up, and was not associated with patient's or partner's levels of anxiety at baseline or follow-up. This is in contrast with idea's that emotional support can decrease anxiety by serving as a personal resource and by enhancing feelings of security within the relationship as is suggested by several researchers (e.g. Sarason, Sarason, & Gurung, 2001; Rook, 1992)

The present study did not find evidence for an effect of negative responses received by patients and partners on their levels of depression or anxiety at seven months follow-up. Negative responses were associated with anxiety at baseline and follow-up in patients, however. Thus, although a predictive association was not found, it appears that patients who receive more negative responses are also more anxious. These results were in contrast with our expectations. Most studies that compare the effects of emotional support and negative responses find more potent effects of negative responses on well-being (Newsom et al., 2003; Manne et al., 1997; Schuster et al., 1990). In contrast, the present study showed a weak and marginal significant effect of emotional support on depression but did not show a predictive association between negative responses and well-being.

That we did not find considerable effects of emotional support and negative responses on depression and anxiety does not necessarily imply that they may not be important for well-being. Thus far, not much is known on how daily occurrences are related to longer term well-being. We explored one option by aggregating the emotional support that patients and partners reported receiving and by computing the number of days that patients or partners reported receiving negative responses. However there may be other mechanisms that explain how daily occurrences of supportive interactions contribute to well-being.

First, there may be complex patterns of associations between emotional support and negative responses that exceed over days or months to determine its effect. For example, couples experiencing periods of high conflict and low affection diverged by periods of low conflict and high affection may differ from couples who experience stable and moderate levels conflict and affection. A two week period may be too short to fully capture these kinds of processes. Additionally, the effects of emotional support or negative interactions may depend on the context in which they are given and received. For example, we found that the detrimental effects of negative responses received from the partner were buffered by receiving emotional support as well on the same day (Kleiboer et al., 2006a). In line, a recent study by Johnson and colleagues (Johnson, Davila, Rogge, Sullivan, Cohan,

Lawrence, Karney, & Bradbury, 2005) showed that the costs of negative responses were decreased when they were accompanied by high levels of positive affect. Currently, specific knowledge on how support processes evolve over time is lacking, although an increasing amount of diary studies and observational research contribute to gain better insight into these processes (Bolger, Zuckerman, & Kessler, 2000; Cutrona & Suhr, 1994; DeLongis et al., 2004; Gleason, Iida, Bolger & Shrout, 2003; Johnson et al., 2005).

Additionally, actually received emotional support and negative responses may have an indirect effect on well-being by their impact on evaluations of the relationship, such as the perceived availability of support or perceptions of inequity. For example, the perceived availability of support involves the perception that support is available when needed and has generally low relations with actual support (Kaul & Lakey, 2003). However, actual support may play a role in building perceptions of the availability of support (Helgeson, 2003; Sarason et al., 2001). Ample research has shown that the perceived availability of support is related to less emotional distress (Monahan & Hooker, 1995; Reinhardt, Boerner, Horowitz, & Lloyd, 2006; Sarason et al., 2001; Symister & Friend, 2003).

Other limitations of this study were the small sample size and the fact that the couples in our study had been living together for a considerable amount of time. This suggests that they are involved in solid and established relationships and that they somehow managed to deal with MS in their relationship successfully. For this reason, negative responses may be less threatening to them than for couples who are involved in less secure relationships.

To conclude, this study examined the effects of daily received and provided support on depression and anxiety among patients and partners dealing with MS. The results did not support the proposed relations, which does not necessarily imply that emotional support and negative responses are not important. More complex patterns and indirect relations may explain how interactions with the partner relate to well-being. Future research should shed more light on these processes.

Chapter 6

Depression in couples dealing with multiple sclerosis (MS):
A function of perceived equity within the relationship?

Abstract

This study addressed the imbalance between give-and-take in the relationship (i.e. perceptions of inequity) among couples dealing with multiple sclerosis (MS). We examined the relation between perceived inequity and patient's physical disability, and its impact on depression in patients and partners. Forty-eight couples dealing with MS completed self-report questionnaires at baseline and at seven months follow-up. Patients who felt overbenefited were more severely disabled. Healthy partners who felt underbenefited had ill partners that were more disabled. Further, patients who felt more overbenefited at baseline, felt more depressed at seven months follow-up compared to baseline depression. Additionally, partners who felt more underbenefited at baseline, felt more depressed at seven months follow-up, compared to baseline. The findings suggest that when patients are more disabled, patients and partners may perceive their relationship as more imbalanced in terms of give-and-take, which may have negative consequences for the level of depression of both.

Introduction

Multiple sclerosis (MS) is a chronic disease of the central nervous system which may have a profound effect on the lives of both patients as well as their intimate partners. The disease often starts in young adulthood (i.e. between the ages of 20 – 40) and is characterized by a highly unpredictable and variable course. Symptoms may include debilitating fatigue, loss of function, visual problems, disturbance of equilibrium, cognitive difficulties and emotional changes (Mohr & Dick, 1998). The onset of the disease can be gradual or acute and most people with MS experience periods of relapse followed by periods of (partial) remission (Lublin & Reingold, 1996). However, a progressive decline of health is also possible (Lublin & Reingold, 1996). The unpredictable course of the disease, the moderate effectiveness of medical treatment and the psychosocial consequences makes MS a very difficult disease to adjust to. Both patients as well as their intimate partners have to live with the uncertainty of the disease's progression, increasing physical disability and the psychosocial consequences (Antonak & Livneh, 1995; Mohr & Cox, 2001).

However, MS may not only have consequences for the individual lives of patients and their intimate partners, the disease is also likely to affect the relationship between both partners. An important way in which the intimate relationship may change is in the balance between give-and-take of support in the relationship. In order to deal with the disease, patients often need increasing amounts of support from the partner, however, their physical limitations may prevent them from providing support to the healthy partner in return (Cutrona, 1996; Thompson & Pitts, 1992). Hence, the healthy partner often has to take over many tasks that the ill partner can no longer perform (e.g., household tasks, assistance with self-care), providing an increasing amount of support to the ill partner without receiving much in return (Cutrona, 1996; Thompson & Pitts, 1992). This study concerns this

imbalance between give-and-take in the relationship (i.e. perceptions of inequity) that may arise as a consequence of chronic disease and is believed to have serious implications for the patients and partners level of depression.

Research that addresses the give-and-take in the relationship has most often been conducted from a social psychological perspective, namely equity theory (Adams, 1965; Walster, Walster, & Berscheid, 1978). According to equity theory, a relationship is out of balance or inequitable when the ratio of contributions and rewards of one partner deviates from the ratio of contributions and rewards of the other partner. Individuals who receive relatively many rewards are expected to feel overbenefited and individuals who receive relatively few rewards are expected to feel underbenefited. In the context of chronic illness, the relationship may become inequitable in such a way that patients may feel overbenefited (i.e. they receive more support than they provide) and partners may feel underbenefited (i.e. they receive less support than they provide) (Thompson & Pitts, 1992).

If the imbalance between give-and-take is provoked by the patient's physical illness as is suggested by several researchers (Cutrona, 1996; Thompson & Pitts, 1992), then one would expect that couples with a more severely disabled patient experience more imbalance (i.e. patients more overbenefit and partners more underbenefit), than do couples with a less severely disabled patient. Indeed, Thompson and colleagues (2002) found a positive association between patient's physical disability and feeling underbenefited in caregivers of stroke patients. However, other studies among caregivers of patients with MS and cancer (Ybema, Kuijer, Hagedoorn, & Buunk, 2002) or couples dealing with cancer (Kuijer, Buunk, Ybema, & Wobbles, 2002) did not find a relation between the patient's physical disability and perceptions of inequity. Therefore, more research is needed to examine the association between patient's disability and perceptions of inequity.

Additionally, equity theory predicts that perceptions of inequity may have negative consequences both for those who feel underbenefited as well as for those who feel overbenefited in the relationship (Walster et al., 1978). Individuals who experiences feelings of overbenefit may worry about becoming a burden or may feel guilty because of doing not enough. Individuals who experience feelings of underbenefit, on the other hand, may be frustrated because they believe they receive too little out of the relationship as compared to their contributions. Perceptions of inequity have consistently been associated with more distress among couples dealing with illness (Kuijer, Buunk, & Ybema, 2001; Thompson et al., 2002; Thompson, Medvene, & Freedman, 1995; Ybema et al., 2002). Moreover, a study by Ybema and colleagues (Ybema, Kuijer, Buunk, DeJong, & Sanderman, 2001) among couples dealing with cancer showed that perceptions of inequity were related to both patients' and partners' levels of depression. Patients reported more symptoms of depression when they felt that they invested too little in the relationship and their healthy partners where more depressed when they felt they received too little benefits from the relationship.

However, studies that examined the association between perceptions of inequity and well-being in the context of chronic illness all had a cross-sectional design. Therefore, these studies did not permit inferences on whether perceptions of inequity predicted a change in well-being over time. The present study will examine the impact of perceptions of inequity on depression at seven months follow-up. Previous cross-sectional studies have shown that perceptions of inequity may be an important determinant of depression (Longmore & DeMaris, 1997; Ybema et al., 2001). Moreover, depression is the most common psychological symptom in MS patients (Mohr & Cox, 2001; Patten, Beck, Williams, Barbui, & Metz, 2003). Additionally partners of MS patients have shown to have higher levels of depression as well as compared to healthy individuals (McKeown, Porter-Armstrong, & Baxter, 2003). Therefore it is important to examine whether perceptions of inequity are important to consider with respect to depression among couples dealing with MS.

In sum, the present study was guided by equity theory and examined two questions. First we were interested in the relation between perceptions of inequity in the relationship in MS patients and their intimate partners and patient's physical disability. We expected a positive relationship between feelings of being overbenefited in the relationship for patients and patient's level of physical disability. Additionally, we expected a positive relationship between feelings of being underbenefited in partners and patient's level of physical disability. Second, we examined whether perceptions of inequity predicted patient's and partner's level of depression at seven months follow-up. We expected that patients and partners who felt overbenefited or underbenefited would experience more symptoms of depression, compared to patients and partners who felt equitably treated.

Method

Participants and procedure

Patients with MS and their partners were contacted through one MS Centre and the neurology department of one hospital in the Netherlands. MS patients registered in the patient files of these clinics received a letter with information about the study and a description of the inclusion criteria. Inclusion criteria were (a) patients were diagnosed with MS, (b) patients were currently involved in a heterosexual relationship (with minimum relationship duration of one year), (c) patients were living together with their partner, and (d) both partners were willing to participate in the study. Exclusion criteria were insufficient ability to read or understand Dutch, or when one or both partners suffered from serious psychiatric problems or medical problems other than MS. As information on inclusion criteria were not available from the patient files (e.g. we do not know how many of these patients had a partner), we distributed letters to all 390 patients that were registered. This means that the number of couples who responded to the information letter cannot be used to calculate response rates.

A total of 70 couples who met our inclusion criteria responded to the information letter and signed informed consent. Four participants decided not to participate in the study after they were contacted by the researcher for reasons of MS related health problems ($n=3$) or personal reasons ($n=1$). Of the remaining 66 couples, a final sample of 48 patients and 48 partners completed all the materials (73%). Reasons mentioned for drop-out between baseline and follow-up ($n=18$) were MS related health problems ($n=3$) or personal reasons ($n=3$). One patient has died before the end of the study and eleven couples never responded to our reminders. Couples who dropped out of the study did not significantly differ from couples who completed the study with respect to age, relationship length, education, year since diagnosis and physical disability (all independent sample t-tests were non significant at $p < .05$).

Of the patients with MS, 85% ($n=41$) were female and 15% ($n=7$) were male. The mean age of patients was 47 years (range: 27 to 64, $SD = 8.7$), and on average they had been diagnosed with MS 8 years previously (range: 1 to 28, $SD = 5.5$). The partners of these patients were, on average 49 years (range: 29 to 69, $SD = 9.6$). Seventeen percent of the patients and 26% of the partners had completed the lowest level of secondary (vocational) education only, 44% of the patients and 36% of the partners had completed middle to higher levels of secondary (vocational) education, and 40% of the patients and 38% of the partners had a college degree or higher. The couples had been married or cohabiting for an average of 22 years (range: 2 to 41 years, $SD=10.4$).

Instruments

Data were collected at two points in time. At baseline, both patients and partners completed measures on demographics, perceptions of inequity and depression. At follow-up, both partners completed measures of depression. Only patients completed measures of their physical disability at baseline and follow-up.

Perceived equity was assessed with one question based on the Hatfield Global Measure (Hatfield, Traupmann, Sprecher, Utne, & Hay, 1984). This question was preceded by a short introduction: “The next questions are about the give-and-take that goes on in the relationship. Each partner contributes things to a relationship (e.g. providing support, doing things for each other, putting energy into the relationship) and receives things in return from the relationship (e.g. receiving attention, receiving practical help, commitment)“. Then the participants were asked: “When you look at your relationship from a viewpoint of give-and-take, how would you describe your relationship?” Participants made their estimates on a five-point scale ranging from “My partner is doing a lot more for me than I am doing for him/her” (+2), through “My partner is doing as much for me as I am doing for him/ her” (0) to “My partner is doing a lot less for me than I am doing for him/ her” (-2). Thus, positive scores indicate perceived inequity in the direction of overbenefit, negative scores, indicate

perceived in the direction of underbenefit. Based on this *linear term* for overbenefit/underbenefit, a term for deviation from equity was constructed through computing the absolute value from equity. This way we created a three point scale that represents *deviation from equity* ranging from 0 (equity) to 2 (inequity) (Kuijjer et al., 2002; Kuijjer et al., 2001). The higher the score on this deviation term, the more inequity in either direction (overbenefit or underbenefit) was perceived.

Depression was assessed with the depression scale of the hospital anxiety and depression schedule (HADS; Zigmond & Snaith, 1983). Seven items make up this scale and each item can be scored on a four-point scale, with higher scores indicating higher levels of depression. Scores between 8 and 10 are considered clinically borderline and scores of 11 and higher are considered clinically definite levels of depression. The HADS is relatively free of criterion contamination by somatic items and is therefore apt for use in patients suffering from chronic illness. The instrument has proven to be valid and reliable in Dutch patient samples (Spinhoven, Ormel, Sloeker, Kempen, Speckens, & Van Hemert, 1997). Cronbach's alpha at baseline was .77 for patients and .70 for partners.

Patient's level of *physical disability* was assessed with the incapacity status scale (ISS; Kurtzke, 1981). The ISS provides a measure of severity of the physical impairment caused by MS. The scale consists of sixteen items that were rated on a five point scale ranging from 0 (normal functioning) to 4 (complete inability). 'Healthy' individuals have scores of 0 and MS patients with a score up to 16 can be considered as affected but unimpaired. A score above 16 suggests impairment. Evidence has been collected in support of construct validity (Kurtzke, 1981; Stuijbergen, Seraphine, & Roberts, 2000). Cronbach's alpha in this study at baseline was .84.

Analyses

One-way analyses of variance were employed to examine whether patients and partners who were feeling either underbenefited, equitably treated or overbenefited, differed with respect to the level of physical disability that the MS patient experienced. Post hoc comparisons were conducted with the least significant difference test. Hierarchical regression analyses were performed on depression at follow-up to examine the contribution of perceptions of inequity to a change in depression. After controlling for baseline level of depression (step 1) baseline physical disability and a change in physical disability between baseline and follow-up (step 2), we entered the linear and deviation term for equity (step 3). The linear and deviation term were both entered into the regression equation because equity theory predicts a curvilinear relationship between perceived equity and depression. That is, those who feel equitably treated are expected to experience low levels of depression, whereas the underbenefited and overbenefited (two types of inequity) are expected to report higher levels of depression. All analyses were conducted for patients and partners separately.

Results

Table 1 shows that, on average, patients felt overbenefited in their relationship whereas their partners on average did not feel underbenefited. Three patients felt underbenefited in their relationship, 25 patients felt equitably treated and 20 patients felt overbenefited. Additionally, 9 partners felt underbenefited, 29 partners felt equitably treated and 10 partners felt overbenefited in their relationship. As is shown in Figure 1, patients who felt overbenefited were generally more physically disabled than patients who felt equitably treated. The overall difference between the groups was significant ($F = 3.402$ $p = .02$). For partners, the results were complementary, healthy partners who felt underbenefited had partners who were more disabled on average ($F = 3.809$ $p = .03$) (see Figure 1). As is shown in Table 1, the correlations between patient’s physical disability and feelings of inequity show the same pattern. Patients who were more physical disabled felt more often overbenefited and partners of more disabled patients more often felt underbenefited.

Table 1 Means, standard deviations and correlations between the key study variables

| | 1 | 2 | 3 | 4 | Patients Mean (SD) |
|---|------------|------|-----------|-----------|-------------------------|
| 1 Baseline equity: linear term ¹ | - | .35* | .33* | .41** | .54 (1.00) [#] |
| 2 Baseline disability patients | -.35* | - | .28 | .10 | 13.2 (8.8) |
| 3 Baseline depression | -.15 | .27 | - | .61*** | 4.1 (2.8) |
| 4 Follow-up depression | -.30* | .20 | .70*** | - | 4.9 (3.8) |
| Partners, Mean (SD) | -.04 (.92) | - | 3.7 (2.7) | 4.1 (2.9) | |

Note * $p < .05$, ** $p < .01$, *** $p < .001$; ¹Linear term for equity: A positive score means a departure from equity in the direction of overbenefit, a negative score in the direction of underbenefit. [#] indicates a significant departure from 0 (equity) at $p < .05$.; Correlations for patients are presented above the diagonal, correlations for partners are presented below the diagonal.

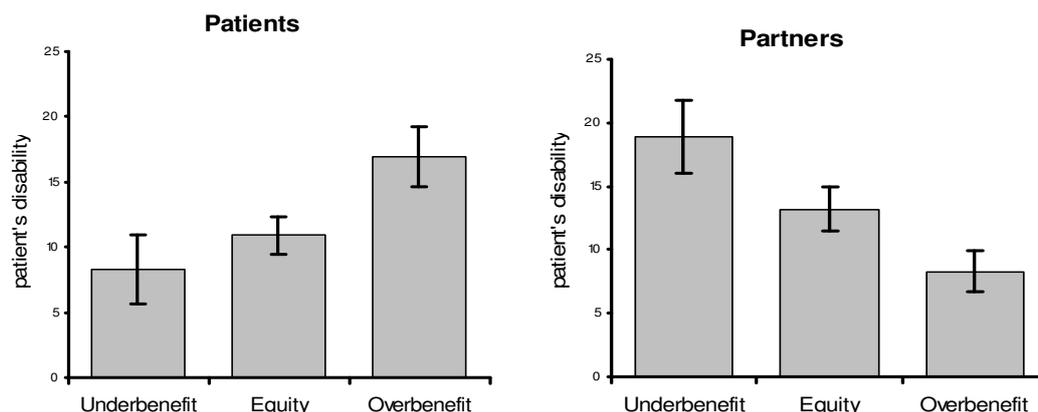


Figure 1 Patient's physical disability for patients and partners who feel underbenefited, equitably treated or overbenefited. Bars indicate means (SE).

Perceived equity and depression

Additionally, we examined to what extent perceptions of inequity at baseline predicted levels of depression at seven months follow-up. After controlling for baseline depression in step 1, and patient's baseline disability and a change in disability between baseline and follow-up in step 2, the baseline linear term for equity (the direction from equity) and the baseline deviation term for equity were entered in step 3. As is shown in Table 2, the linear term for equity was a significant predictor of depression at seven months follow-up both in patients and partners. Patients who felt more overbenefited at baseline experienced more symptoms of depression seven month's later, after controlling for a worsening in their physical condition. In contrast, partners who felt more underbenefited at baseline had higher levels of depression at seven months follow-up.

Table 2 Depression predicted by perceptions of inequity in patients and partners.

| | Patients | | Partners | |
|--|-------------|--------------|-------------|--------------|
| | Beta | ΔR^2 | Beta | ΔR^2 |
| Step 1 Baseline depression | .54*** | .37*** | .72*** | .49*** |
| Step 2 Baseline disability patients | .03 | .15** | -.12 | .01 |
| Δ disability patients, baseline-follow-up | .41** | | -.14 | |
| Step 3 Baseline equity: linear term | .30* | .06† | -.25** | .05† |
| Baseline equity: deviation term | -.21 | | -.07 | |
| | $R^2 = .58$ | | $R^2 = .55$ | |

Note † $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

Discussion

This study addressed the imbalance between give-and-take within the relationship (i.e. perceptions of inequity) among couples dealing with multiple sclerosis (MS). We examined the relation between perceived inequity and patient's physical disability, and its impact on depression in patients and partners.

Our results suggest that perceptions of inequity are (at least partially) related to the patient's physical disability. Patient's level of physical disability was related to feeling overbenefited in patients and feeling underbenefited in partners. However, there was a large variance within groups of patients and partners who felt underbenefited, equitably treated or overbenefited with respect to the patient's physical disability. This suggests that not all more severely disabled patients felt overbenefited in their relationships. Additionally, not all partners of more severely disabled patients felt underbenefited in their relationship. It is important to notice that equity is "in the eye of the beholder", that is, perceptions of imbalance in given-and-take are measured, not actual or objective imbalances. Despite an actual imbalance, patients or partners may not necessarily perceive their relationship as imbalanced. Moreover, equity theory suggests that when relationships become imbalanced, efforts will be made to restore equity (Hatfield et al., 1984; Thompson & Pitts, 1992). For example, patients and partners may adjust the standards by which they judge the contributions and rewards and take into account the patient's physical limitations (Kuijer, Buunk, & Ybema, 2001)

In line with previous cross-sectional studies among healthy couples and couples dealing with cancer (Ybema et al., 2001; Longmore & DeMaris, 1997), this study showed that perception of inequity predicted depression both in patients and partners. This study was the first study that examined perceptions of inequity among couples dealing with chronic illness prospectively. Our findings support the notion that perceptions of inequity in the intimate relationship are an important factor to consider with respect to depression in patients and partners. However, perceptions of inequity were only assessed at baseline preventing reciprocal effects to be studied. Therefore, the causal pathway from perceived equity to depression cannot be ascertained. It may also be that the predictive associations were the consequence of some unmeasured third variable.

Other limitations of this study were the small sample size and the possible reduced generalizability of our findings because we do not know whether our sample represented a random sample of couples dealing with MS. It is possible that distressed couples were less willing to participate in a study like this as a couple. Moreover, most of these couples had been living with the illness for a considerable time (on average 8 years); this suggests that they somehow managed to deal with the MS in their relationship successfully. Finally, the majority of our sample consisted of couples with a female patient and a male partner, preventing us from examining gender differences. The literature suggests that among

healthy couples men generally feel overbenefited in their relationship whereas women more often feel underbenefited (Van Yperen & Buunk, 1990).

To conclude, this study suggests that when patients are more disabled, patients and partners are more likely to perceive their relationship as imbalanced in terms of give-and-take, which may have negative consequences for their level of depression. As both patients and their intimate partners are at risk for depression it is important that future interventions should promote perceived equity within the relationship. A recent intervention study on perceptions of inequity in couples dealing with cancer was successful in altering perceptions of inequity (Kuijer, Buunk, DeJong, Ybema, & Sanderma, 2004). Future research should examine whether similar interventions do apply to couples dealing with MS as well.

Chapter 7

Summary and discussion

The study that has been described in the present dissertation has considered daily supportive interactions with the partner among patients and partners dealing with multiple sclerosis (MS). The study was centered around two main issues which concerned:

1. *The amount of support received and provided by MS patients and partners.* Interactions with the partner may change when one partner has a chronic illness. Partners are likely to provide more support and help to their partner, and receive less support in return. However, the extent to which supportive interactions are affected may depend on the type of support. Further, the amount of support that patients and partners provide to one another may depend on how physically disabled patients are and the amount of distress they experience. As a result of a shift in supportive interactions from the patient to the partner, patients and partners may perceive their relationship as imbalanced (i.e. patients may feel overbenefited and partners underbenefited). These topics were examined by the following questions: Do patients and partners receive and provide more or less support as compared to the other partner? Is the amount of support provided by patients and partners related to the patient's physical disability or emotional distress? Do patients and partners perceive their relationship as imbalanced?
2. *The costs and benefits of daily received and provided support for MS patients and their partners.* The costs and benefits of supportive interactions with the partner were examined within-persons over time with a diary method and between-persons prospectively over a period of seven months. The diary method allowed for a fine grained analysis examining the consequences of daily interactions within persons, while taking into account antecedents and correlates. Within this context we first asked to what extent reciprocal exchanges of received and provided emotional and instrumental support were related to end-of-day well being? Second we asked whether the relation between negative responses received and end-of-day mood is moderated by emotional support received on the same day? Additionally, a prospective between-person design was used to answer the following questions: What is the effect of emotional support and negative responses received on anxiety and depression seven months later in patients and partners? What is the impact of perceptions of inequity on depression seven months later in patients and partners?

To answer these questions, both partners of 61 couples dealing with MS completed diaries for fourteen days and filled out questionnaires prior to completing the diaries and at seven months follow-up. Interactions with the partner were assessed daily using a diary method whereas perceptions of inequity were assessed with a self-report questionnaire at baseline. Other important features of the study were that we used both patients and partners as receivers and providers of support and that we distinguished between emotional, instrumental and negative interactions. Further, we were interested in differences between

patients and partners, both in the amount of support that was given and received as well as the relation between supportive interactions and well-being.

In this concluding chapter the main findings of the study will be summarized and discussed guided by the two main issues that were studied. Additionally the study will be evaluated from a methodological point of view, contributions to theory and research will be discussed as well as clinical implications, and finally recommendations for future research will be considered.

Receiving and providing support in the context of chronic illness

The next paragraphs will summarize and discuss the main findings regarding the first issue. For each type of support the amount of support that patients and partners reported receiving and providing was compared and further whether the amount of support provided by patients and partners was related to the patient's physical disability and emotional distress (i.e. anxiety or depression). With respect to the latter, it is important to stress that we examined the relation between support provided by patients and partners in relation to the patient's physical disability and emotional distress only. Supportive interactions are most often assessed from either the recipient's or the provider's perspective and recipients or providers of support may not always agree on the amount of support received and provided (Abbey, Andrews, & Hallman, 1995; Coriell & Cohen, 1995). For example, it may be that partners do not report providing less support to depressed patients but that depressed patients report receiving less support (Danoff-Burg & Revenson, 2002). We decided to examine the perspective of the support provider in this respect because we were most interested in how the patient's physical disability and emotional distress interferes with patient's and partner's supportive behaviors. Finally, we discuss results with respect to perceptions of inequity.

Instrumental support

The findings in Chapter 3 showed an imbalance in instrumental support received and provided. That is, both partners agreed that patients received more and provided less instrumental support compared to the healthy partner. These results are in line with assumptions made by several researchers (Cutrona, 1996; Thompson & Pitts, 1992) that relationships become unidirectional when one partner is diagnosed with chronic illness and that the partner (at least with respect to instrumental support) has to provide the largest share. The results described in Chapter 2 suggest that this pattern is more pronounced when the patient is more disabled, as more severely disabled patients reported providing less instrumental support to the healthy partner and partners of more severely disabled patients reported providing more instrumental support to patients. The findings are in line with other studies that showed an increase in support provided by partners to more severely disabled patients (Revenson & Majerovitz, 1990; Moyer & Salovey, 1999). Additionally, a decline in

health and physical disability predicted a decrease in instrumental support provided by older adults (van Tilburg & Broese van Groenou, 2002).

Emotional support

Comparing the amount of emotional support that patients and partners reported receiving and providing (Chapter 3) showed that differences between patients and partners were less pronounced and more ambiguous as compared with the results for instrumental support (Chapter 3). Patients reported receiving and providing equal amounts of emotional support, whereas partners reported receiving less emotional support than they provided. As was mentioned previously, receiving and providing support are subjective perceptions. It may be either that patients overestimated the amount of support they provided (e.g. due to their own needs they may be less attuned to the needs of their partners) or that partners did not notice the amount of support they received (e.g. they may have too many other distractions to be aware of the support that is provided to them) or they may have interpreted the support differently (e.g. statements that are intended to be supportive by the provider are sometimes perceived as criticism by the recipient (Dakoff & Taylor, 1990)). Additionally, the results in Chapter 2 showed that the amount of emotional support provided by patients and partners was not related to the patient's physical disability, anxiety or depression. Apparently, the amount of emotional support that patients and partners provide to one another is not affected by the patient's levels of physical disability, anxiety or depression. These findings are important when one considers that emotional support is a central function of marriage (Erickson, 1993) which may contribute to higher intimacy and higher relationship quality (Reis & Shaver, 1988). Although we were not able to compare current receipt and provision of emotional support with supportive interactions before the onset of the illness, and therefore do not know if they actually changed, the results in Chapter 2 and 3 suggest that emotional support may be preserved in the context of chronic illness.

Negative responses

Regarding negative interactions the results showed that partners reported receiving (Chapter 5) and providing (Chapter 2) at least as much or maybe even more negative responses than patients. Similar to the findings regarding emotional support, the pattern of findings was less pronounced and more ambiguous than the results for instrumental support. Patients and partners reported providing equal amounts of negative responses whereas patients reported receiving less negative responses than partners. Thus far, most studies have limited their attention to investigating reasons why partners respond negatively towards the patient (Manne, Alfieri, Taylor, & Dougherty, 1999; Revenson & Majerovitz, 1990; Thompson, Galbraith, Thomas, Swan & Vrungos, 2002), neglecting the fact that patients may also express negative responses towards the healthy partner. Based on our findings a more balanced approach including both partners is recommended.

In general negative interactions with the partner did not occur very often en some patients and partners did not report receiving negative responses at all during the fourteen day period (Chapter 4) which is in line with findings in other studies (e.g. Rook, 2001). Patients and partners provided more negative support to one another when the patient was more disabled or anxious and they provided less support to one another when the patient was more depressed (Chapter 2). The results for physical disability were in line with our expectations and other studies (Revenson & Majerovitz, 1990; Manne et al., 1999) and are most likely related to a shift in role responsibilities that patients and partners are often forced to take on. For partners applies that when patients become more severely disabled they have to provide more support and help which may conflict with their own needs (e.g. may limit their personal time and activities). For patients, being more severely disabled implies higher dependency on the partner and repeatedly asking for help. This may be frustrating which is often expressed to the partner.

The contrasting results for anxiety and depression were unexpected. However, one explanation may be that depression often reflects the loss of one's physical well-being or psychosocial resources, whereas anxiety may include fear for the future (Antonak & Livneh, 1995). In the context of chronic illness, depression may be seen as an appropriate reaction to the disease by the healthy partner (Dunkel-Schetter & Skokan, 1990; Revenson, 1994). In contrast, anxiety may be more difficult for the partner to deal with, is uncontrollable and offers little options to be helpful. It has been documented that patient's level of anxiety is highly related to the partner's level of anxiety (Pakenham, 1998; Segrin et al., 2005). When both patient and partner are anxious, they may criticize each other for not dealing very well.

Perceptions of inequity

Due to a shift in supportive interactions from the patient to the partner that may occur in response to illness, patients and partners may perceive their relationship as imbalanced (Cutrona, 1996; Thompson & Pitts, 1992). In line with previous research among patients with cancer (Kuijer, Buunk, & Ybema, 2001; Kuijer et al., 2002), the results in Chapter 6 showed that on average patients felt overbenefited in their relationship, that is, they felt that their partner was doing more for them than the other way around. Feelings of being overbenefited were related to higher levels of disability, indicating that more severely disabled patients felt more overbenefited in their relationship. Also in line with previous findings among patients with cancer (Kuijer et al., 2001; Kuijer et al., 2002), partners on average did not feel underbenefited, they felt that they were doing as much as patients. Thus, despite an actual imbalance in instrumental support (Chapter 3), partners did not feel underbenefited in their relationship on average. However, feelings of being underbenefited in partners were related to the patient's disability (Chapter 6). When patients were more severely disabled, partners felt more underbenefited in their relationship. It may be that

partners tolerate a certain level of actual imbalance before they also perceive their relationship as imbalanced.

The costs and benefits of receiving and providing support

The following paragraphs discuss the main findings with respect to the costs and benefits of the three different types of support and the perception of inequity. First, the costs and benefits of all three types of support were examined within persons over time (Chapters 3 and 4). To briefly repeat the design of this part of the study, each night on fourteen consecutive days we asked participants to report on supportive interactions, stressful events and MS related symptoms that occurred during the day and their end-of-day mood and self-esteem. This design allowed us to identify conditions under which emotional support and instrumental support had costs and benefits for patients and partners (i.e. we hypothesized that one-sided emotional or instrumental support receipt or provision had costs for end-of-day well-being, but that these costs could be offset by reciprocating the support) and whether the costs of negative responses could be buffered by receiving emotional support on the same day.

Additionally, the effects of received emotional support and negative responses were examined prospectively at seven months follow-up (Chapter 5) as was the effect of perceived inequity (Chapter 6). We chose to examine the effects of emotional support and negative responses received on anxiety and depression because the within person analyses showed that emotional support may be beneficial for both patients and partners and negative responses were found to induce the greatest costs. Therefore we found it most interesting to examine whether these types of support also predicted anxiety and depression at seven months follow-up

All findings are discussed per type of support.

Instrumental support

As expected, the results for instrumental support showed that receiving instrumental support without providing instrumental support in return, had costs for the recipient's self-esteem on the end-of-day (Chapter 3). This was true for both patients and partners. For patients, receiving instrumental support without providing support in return may stress their dependency and emphasize their status as an impaired person (DiMatteo & Hays, 1981; Liang, Krause, & Bennett, 2001). For partners, not being able to reciprocate instrumental help may threaten their competence as a caregiver. Considering the imbalance in instrumental support described in Chapter 3 (i.e. patient receive more help and support and provide less in return as compared to the healthy partner), it is important to note that at this point patients will probably be worse off since they are likely to have more days characterized by one sided support receipt.

Other noteworthy findings with respect to instrumental support concern the beneficial effects of providing instrumental support for end-of-day mood both for patients and partners (Chapter 3). These findings are interesting in the light of the caregiver literature that emphasizes the burden of taking care of the ill partner (Martire & Schulz, 2001; McKeown, 2003). In contrast, our results suggest that doing things for your partner is a positive experience both for patients and partners. At this point, it is important to note that our findings by no means indicate that taking care of an ill partner cannot be burdensome. Our results only showed that doing things for your partner (i.e. providing instrumental help) is a pleasant experience. These findings may not be unique to chronically ill patients and their partners, however. Although only a handful of studies have considered the effects of providing support, beneficial effects have been found in studies among healthy couples as well (e.g. Shrout, et al., 2006).

Emotional support

The results with respect to emotional support did not underscore the costs of receiving or providing support (Chapter 3, 4 & 5). One previous study by Gleason, Iida, Rafaeli, & Bolger (2003) showed that receiving emotional support had negative consequences for end-of-day mood when it was not reciprocated on the same day in healthy couples. They suggested that for couples experiencing chronic illness this pattern of findings would be more pronounced because chronic illness would lead to less inequitable days. However, our results did not support the assumption that immediate reciprocity of emotional support was important with respect to end-of-day mood or self-esteem. In contrast, our findings showed that emotional support was beneficial for end-of-day mood although the effects depended on the patient or partner role. Patients benefited most from providing support and partners benefited most from receiving support. In line with Thompson & Pitts (1992) we argued that providing support may be particularly important for patients because it gives them the opportunity to show appreciation for the help and care they receive from their partner. For partners, receiving emotional support may be especially valuable because it communicates appreciation and love.

In addition, receiving emotional support had an indirect effect on end-of-day mood by buffering the costs of negative support both for patients and partners (Chapter 4). This suggests that negative responses are less threatening when they are given by a partner who also shows affection and interest on the same day. These findings show close parallels to a recent research by Johnson, Cohan, Davila, Rogge, Sullivan, Lawrence, Karney, & Bradbury (2005) that showed that the affective tone that accompanies negative interactions partially determined the detrimental effects of negative interactions.

Finally, contrary to our expectations, we did not find considerable effects of emotional support on depression and anxiety at seven months follow-up (Chapter 5). We did find a weak and marginal significant effect of emotional support on depression, however. Patients

or partners who received more emotional support at baseline felt less depressed seven months later. Not much is known on how daily interactions between partners accumulate and affect less transient measures of well-being. In the study described in Chapter 5, the effects of the average amount of emotional support that patients and partners reported receiving on a day was examined. The relation between emotional support received on a day and anxiety and depression may be more complex, however. In this respect, the variability of emotional support over days, or the context in which the support is given may also be important. Additionally, emotional support may play a role in building evaluations of the relationship such as the availability of support.

Altogether, our findings showed the importance of emotional support with respect to different aspects of well-being. This makes the previously made notion that emotional supportive interactions may not necessarily be affected by the disease even more important (Chapter 2 and 3).

Negative responses

The costs of negative responses on end-of-day mood were examined within persons over time (Chapter 4), as well as prospectively with respect to anxiety and depression (Chapter 5). The results in Chapter 4 showed that receiving negative responses indeed had costs for end-of-day mood. Additionally, as was described in the previous section, these costs were buffered by receiving emotional support as well on the same day (Chapter 4). Further, the results did not show the potent effects of negative responses that are frequently noticed in other studies comparing the effects of negative responses and positive support (Rook, 2001; Schuster, Kessler & Aseltine, 1990). We expected that the effects of negative responses would be more potent among couples dealing with MS due to the higher stress of living with a chronic illness, especially for patients who are the most vulnerable in the relationship because they are dependent on their partner for support and self-esteem (Druley & Townsend, 1998).

Several reasons may explain why we did not find potent effects of negative responses. First, as a consequence of the low frequency of negative responses in our sample we had to dichotomize the negative response variable and were not able to distinguish between days that participants reported receiving many negative responses and days that participants received few negative responses, which may have decreased the power of our predictor. We will elaborate on this in the methodological considerations section. Second, the fact that the couples in our study were living together for a relatively long time, suggest that they are involved in solid and established relationships and they somehow managed to deal with the MS in their relationship successfully. For this reason it may be that negative responses are not very threatening to patients and partners.

The same reasons may also explain why negative responses received from the partner did not have an effect on anxiety and depression at seven months follow-up (Chapter 5). In

Chapter 5 we examined the number of days that patients or partners reported receiving negative responses during the fourteen day period to predict anxiety and depression. As was mentioned above, specific knowledge on how support processes evolve over time is lacking. More complex patterns of associations may be involved in explaining how negative interactions accumulate to effect anxiety and depression. For example, the context in which the negative responses are given may be important (e.g. in Chapter 4 it was shown that the relation between negative responses and end-of-day mood was buffered by receiving emotional support on the same day) or the pattern of occurrences (e.g. whether negative responses are clustered across days or not).

Perceived inequity

With respect to perceptions of inequity, Chapter 6 showed that feelings of being overbenefited in their relationship in patients and feelings of being underbenefited in partners predicted depression prospectively at seven months follow-up. The results are in line with cross-sectional studies among couples facing cancer (Ybema et al., 2001) and healthy couples (Longmore & DeMaris, 1997) and support the notion that perceptions of inequity in the intimate relationship are an important factor to consider with respect to depression in patients and partners.

In contrast to the effects of perceived inequity, we did not find much evidence for the importance of the immediate reciprocity of support within one day (although receiving instrumental support without providing much in return had costs for the recipients self-esteem) (Chapter 3). It is important to note that in the latter study we did not ask whether patients or partners felt equitably treated or not. This means that participants in inequitable situations may not have felt inequitably treated.

Contributions to theory and research

The present study adds to and refines existing theory and research with respect to supportive interactions in the context of illness in a number of ways.

To begin with, the present thesis showed that it is important to distinguish between emotional and instrumental support. As was described in Chapter 2 and 3, emotional support and instrumental support are affected by the illness in different ways. For example, it was found that the patient's disability was related to the amount of instrumental support given and received by patients and partners, however, not to the amount of emotional support. Additionally, as was shown in Chapter 3 instrumental support and emotional support had different relations with well-being. Not distinguishing between the two may lead to inconsistent results.

Second, little research has considered patients and partners as receivers and providers of support. Moreover, hardly any research has compared differences between patients and partners with respect to the amount of support received and given and the effects of

supportive interactions on well-being. The present thesis made a start in studying this. We found differences between patients and partners with respect to the effects of emotional support received and provided (Chapter 3). However, overall our findings revealed much similarity between patients and partners also when we expected differences. For example, we expected that patients would be more vulnerable to negative responses than partners due to the higher dependency of patients on the partner, however, this was not supported by the results (Chapter 4). Many researchers suggest that patients react to chronic illness as unit (e.g. Cutrona, 1996; Pakenham, 1998), that is they react to and are affected by circumstances in similar ways. This may explain why we did not find many differences between patients and partners.

Third, current writings on the effects of emotional and instrumental support suggest that receiving and providing support may have costs and benefits (Abbey et al., 1995; Bolger et al., 2000; Manne et al., 1999; Newsom & Schulz, 1998). Several researchers suggest that supportive interactions may be harmful by threatening self-esteem (Bolger et al., 2001; Gleason, et al., 2003; Shrout, et al., 2006). Our findings showed that receiving instrumental support indeed had costs to self-esteem when it was not reciprocated. Apart from this result, we did not find evidence for the costs of receiving and providing emotional and instrumental support (chapter 3, 4 & 5). Moreover, emotional support had beneficial effects on well-being most of the time, both for patients and partners.

Finally, this thesis contributes to equity theory in several ways. First, in line with assumptions made by many researchers (Cutrona, 1996; Thompson & Pitts, 1992), this thesis confirmed that instrumental interactions between patients and partners may become imbalanced, and patients and partners may also perceive their relationship as imbalanced. Further, the present thesis showed that perceptions of inequity are important in the context of multiple sclerosis and predicted levels of depression at seven months follow-up. We did not find much evidence for the importance of immediate reciprocity of support within one day (with one exception, that is the relation between instrumental support and self-esteem; Chapter 3). However, regarding the latter, we examined the effects of actual receipt and provision of support on end-of-day mood and not whether patients or partners perceived their relationship as imbalanced. Equity theorists emphasize that equity only exists in the eye of the beholder (Walster et al., 1978) and that actual provision and receipt of support is not important. Our results suggests that, at least on a day-to-day basis, prompt repayment in kind after receiving emotional support was not necessary in the context of illness.

Methodological considerations

The study described in the present thesis has important strengths and limitations, which will be briefly discussed in the next paragraph.

Strengths

To begin with, both MS patients as well as their intimate partners participated in this study, whereas previous studies mainly focused on the patient or the partner. Additionally we examined both patients and partners as receivers and providers of support, whereas most studies examined patients as support recipients and partners as support providers. Including both partners in the study together with the fact that we examined both partners as receivers and providers of support offered us the opportunity to compare differences in the amount of support received and provided by patients and partners as well as to examine differences in the effects of support received and provided. This led to several noteworthy findings. For example, the results in Chapter 3 described that patients benefited most from providing support whereas partners benefited most from receiving support.

Another strength of this study is the computerized diary we used. The diary was installed on the couple's computer and the recordings were saved on a floppy disk after completion. One advantage of the computerized diary was that the date and time of recordings were saved on the floppy disk, which allowed us to verify that reports were actually obtained daily. The fidelity checks showed that the compliance in our study was relatively high (see Chapters 3 and 4), which is important as previous studies have shown that compliance to daily reports is sometimes low (Stone, Shiffman, Schwartz, Broderick, & Hufford, 2002; 2003). A second advantage was that recordings were saved on the floppy disk each night and participants did not have access to their reports after completing the diary. This prevented participants from changing their scores after completion and it was not possible for them to look back on previous days of recordings. Another advantage of saving the recordings after completion was that partners could not look into the other partner's diaries, with one exception, that is when partners sat next to the other partner during completion. The latter could not be prevented, however, participants were explicitly asked not to exchange the answers while completing the diaries.

Limitations

A first limitation of the study concerns the sample size. Sixty-one couples participated in the study and completed baseline measures and the diary part of the study and 48 couples completed all the materials including the follow-up measure. It is always difficult to recruit couples especially in a diary study like this, which may be burdening to participants. We approached 390 patients for participation, however, we do not know why people did not respond to our information letter. Information on inclusion criteria were not available from the patients files, therefore one reason for non responding may be that people did not meet

the inclusion criteria (e.g. they did not have a partner). Another reason may be that distressed couples were less motivated to participate in a study like this (e.g. it may be too confronting or add to the burden they already experience). Participation in this study was entirely voluntarily and for reasons of privacy we were not allowed to contact non-responders. Sample size was not a large problem when considering the diary part of the study and the within-processes over time because we collected many days from each couple which increased the power of our study. However the small sample (48 couples) that completed the follow-up measures limited us in performing all the statistical analyses we had wanted. For example, in Chapter 5 it would have been interesting to examine an interaction between negative responses and emotional support, however, the sample was too small to obtain reliable results.

Secondly and related to the first limitation, is the generalizability of our findings. The large variability within our sample with respect to demographics and disease characteristics suggests that the group we selected was not biased with respect to these aspects. This was supported when we compared our sample with a larger sample of MS patients in the Netherlands (Zwanikken, 1997). Our sample and the Zwanikken sample were comparable with respect to age and disease characteristics, however, the patients in our sample were more recently diagnosed with MS. This is conceivable since more recently diagnosed patients are likely to have higher motivation to participate in a study like this because they are still in the adapting phase.

Further, the couples in this study primarily consisted of couples with a female patient and a male partner. This reflects the distribution of MS in the general population, however, compared to the distribution of MS in the study by Zwanikken (1997), women were slightly overrepresented in our study. It is possible that differences between patients and partners that we found in the current dissertation may actually reflect gender differences. For example, there is evidence that women and men attach different meanings to supportive behaviors and that women are generally more responsive to supportive transaction than are men (Acitelli & Antonucci, 1994; Vaananen, Buunk, Kivimaki, Pentti, & Vahtera, 2005). Where possible gender differences were explored in the current thesis and we did not find support for such an effect. However, the gender imbalance in the sample did not allow examining gender differences in a reliable way.

Other limitations worth mentioning concern the timing of the measurements. In the present study, patients and partners completed diaries each night for a two-week period. A two week period was chosen because we aimed to collect data that gave us a good impression of the 'normal' life of couples without unnecessarily burdening them too much. We believed that a two week period would be sufficient for this purpose. The selection period for the diary measures (i.e. the fourteen days) was inherently arbitrary and we cannot be sure that the two week period we selected was characteristic for the couples' daily life. This is an intrinsic problem to diary studies, however and to protect against this problem,

the couples were instructed to complete the diaries during a period that was representative for their daily life with respect to for example days at work. A related noteworthy issue is that the MS patients in this study did not experience flare-ups during the two week period. Receiving and providing support may have a different meanings during crisis as (e.g. flare ups) as compared to periods without crisis (e.g. Helgeson & Cohen, 1996), which limits the generalizability of our findings in this respect.

This study combined a diary method with self-report questionnaires. It was examined whether daily interactions with the partner and perceptions of inequity predicted a change in well-being at seven months follow-up. However, it is generally unknown at which time intervals daily interactions and perceptions of inequity have their effects. Additionally, the patients in this study had been ill for varying periods of time and had different levels of physical functioning. We do not know whether the processes we examined in this study may have been going on over longer time periods.

Finally, negative responses proved to be rare and the higher categories of the scale were never used which resulted in strongly skewed distributions (Hox & Kleiboer, 2006). Therefore we had to dichotomize the scale and could not differentiate between days that patients reported receiving more or less negative responses. One approach to solve this problem may be to increase the number of items. Another option is to increase the number of response categories to gain more information. However the latter approach is unlikely to succeed because even with the four-category items, the higher categories are almost never used (Hox & Kleiboer, 2006). Finally, increasing the fourteen day period may be an option as this will result in more days of reports of negative responses.

Clinical implications

The present research may have several clinical implications. First, in psychosocial interventions for couples dealing with chronic illness, the exchange of emotional support is an important issue (Helgeson & Cohen, 1996; Martire, Lustig, Schulz, Miller, & Helgeson, 2004). Our findings underline this importance, showing that emotional support may have beneficial effects for well-being both for patients and partners. In this regard, it is important that emotional support was relatively unaffected by the disease as was shown in Chapters 2 and 3. Further, this thesis showed that negative responses have different effects depending on whether or not it was accompanied by received emotional support on the same day (Chapter 4). Apparently, when negative responses are provided in a context of love and affection, they may be less harmful. Patients and partners should be educated about these processes.

Second, although social support is a central concept in health psychology, the vast majority of research and interventions thus far have focused on received support. Especially when individuals have a chronic illness it is uncommon to consider that they may also provide support. Only recently some studies have considered providing support (Brown,

Ness, Vinokur, & Smith, 2003; Krause & Shaw, 2000; Liang et al., 2001; Shrout et al., 2006) and showed that this may have benefits for well-being. An important topic of interventions should be how patients can still do things for their partner, within the reach of their capabilities. Encouraging patients to provide support may also be important with respect to perceptions of inequity. Patients who are still making efforts to provide support may feel less overbenefited and as a result, the partner may feel less underbenefited. Additionally, perceptions of inequity could be a target of interventions. A recent intervention study on perceptions of inequity in couples dealing with cancer was successful in altering perceptions of inequity (Kuijjer, Buunk, DeJong, Ybema, & Sanderman, 2004). Future research should examine whether similar interventions do apply to couples dealing with MS as well.

Recommendations for future research

Apart from overcoming the limitations of this study, as outlined above, several suggestions for future research are made. To begin with, this thesis made a start in examining the mechanisms underlying support processes in couples dealing with MS. However, mechanisms underlying the effects of interactions with the partner are complex. For example, as we emphasized previously, interactions with the partner are subjective perceptions. In this thesis, we asked participants to report the amount of support received and given. We did not address cognitions (e.g. were they satisfied with the support?) or support expectations (did patients or partners expect support to be given?), however. To shed more light on mechanisms explaining support effects, future research should attend to these aspects.

Another, challenge for future research is to unravel how daily occurrences accumulate to predict longer term well-being. In Chapter 5 we made a first step by aggregating the amount of emotional support that patients and partners reported receiving and by counting the number of days that patients or partners reported receiving negative responses. Examining these processes more thoroughly was beyond the scope of this thesis, however.

Further, beyond the patient or partner role we did not explore individual differences in the current thesis. Several studies have shown that the effects of supportive interactions may depend on characteristics of the individual such as the patient's disability (Manne et al., 1997), self-esteem (Rook, 2003) or relationship satisfaction (Frazier, Tix, & Barnett, 2003). Moreover, our data suggested that the association between daily supportive interactions and end-of-day mood was different dependent on the person, suggesting that the costs and benefits of support depend on individual differences. Our sample was too small to examine these differences reliably and future research should examine this more thoroughly.

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Appendix

Diary questionnaires

Supportive interactions

Did the following occurrences happen today?

RECEIVED

Emotional support

- My partner showed affection towards me
- My partner gave me a compliment
- My partner listened to me

Instrumental support

- My partner gave me practical help

Negative support

- My provided criticized me
- My partner hurt my feelings
- My partner avoided me
- My partner demanded a lot of me

PROVIDED

Emotional support

- I showed affection towards my partner
- I gave my partner a compliment
- I listened to my partner

Instrumental support

- I gave my partner practical help

Negative support

- I criticized my partner
- I hurt my partners feelings
- I avoided my partner
- I demanded a lot of my partner

Answers were scored on a 4-point scale ranging from 0 (=not at all) to 3 (very much)

PANAS (Watson, Clark, & Tellegen, 1987)

Instructions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to the word. Indicate to what extent you feel right now.

Positive items

Interested

Excited

Strong

Enthusiastic

Proud

Alert

Inspired

Determined

Attentive

Active

Negative items

Distressed

Upset

Guilty

Scared

Hostile

Irritable

Ashamed

Nervous

Jittery

Afraid

Answers were scored on 5 point scale ranging from 1 (not at all) to 5 (extremely)

Self-esteem

To what extent valued you yourself today?

Answer was scored on a 7 point scale ranging from 0 (very strong) to 6 (Not at all)

MS-related symptoms and complaints

To what extent did you experience MS related symptoms or complaints today?

The answer was scored on a 10 point scale ranging from 1 (no symptoms or complaints) to 10 (many symptoms and complaints)

Hassles Adapted version of the hassle part of the hassle and uplift scale (DeLongis, Folkman, & Lazarus, 1988)

Instruction

Hassles are irritants –things that annoy or bother you; they can make you upset or angry. Some hassles occur on a fairly regular basis and others are relatively rare. Some have only a slight effect, others have a strong effect. This questionnaire lists things that can be hassles in day-to-day life.

To what extent were the following occurrences a hassle to you?

Your partner
Your children?
Your family/ friends?
Social obligations
Your workload (e.g. paid or voluntary work)
Social contacts at work
The nature of your work (e.g. paid or voluntary)
Financial matters
News, political or social issues
Your environment (e.g. neighbors, greenery, noise level)
The weather
Housework
Administration
Recreation and relaxation
Exercise/ sports
Your physical appearance
Your behavior (e.g. drinking, smoking, eating)
Your health
Your physical abilities
Medical care
Incidents (winning the lottery, car accident)
Legal matters

Answers were scored on a 4 point scale ranging from 0 (not at all or not applicable) to 3 (very much). The number as well as the intensity of the hassles can be computed.

Samenvatting



Een chronische en progressieve aandoening zoals multiple sclerose (MS) heeft vaak grote consequenties voor het leven van patiënten en hun intieme partners. Naast het omgaan met de fysieke beperkingen van de patiënt zullen beide partners moeten leren leven met de onzekerheid over het verloop van de aandoening, veranderende rolpatronen en de psychosociale gevolgen van de ziekte. Sociale steun van de partner wordt verondersteld een belangrijke rol te spelen bij de aanpassing aan de ziekte. Onderzoek wijst uit dat het idee dat er iemand is die je steunt op momenten dat je dat nodig hebt samenhangt met beter fysiek en psychisch welbevinden. Onderzoeksresultaten zijn echter minder eenduidig wanneer het gaat om het daadwerkelijk ontvangen en geven van steun (*steunende interacties*). Sommige onderzoeken vinden positieve effecten terwijl andere onderzoeken geen effect vinden of negatieve effecten. Deze inconsistente resultaten suggereren dat de invloed van steunende interacties op welbevinden niet voor iedereen hetzelfde is en/of dat ze afhangt van andere factoren die mede bepalend zijn voor het effect. Effecten van steun kunnen bijvoorbeeld anders zijn voor patiënten dan voor partners. Ook kan steun ontvangen van de partner een ander effect hebben afhankelijk van of iemand zelf ook steun geeft aan de partner.

Steunende interacties tussen partners die leven met MS zijn het centrale onderwerp van dit proefschrift. De belangrijkste onderzoeksvragen centreren zich rondom twee aspecten: (1) *De hoeveelheid steun die patiënten en partners geven en ontvangen*. Interacties tussen partners kunnen veranderen wanneer een partner chronisch ziek is. Als gevolg van de fysieke beperkingen van de patiënt zullen partners waarschijnlijk meer steun en hulp geven aan de patiënt terwijl ze minder zullen ontvangen. De mate waarin steun van de partner verschuift zal waarschijnlijk afhangen van het type steun (bv instrumentele steun, emotionele steun of negatieve interacties). Daarnaast kan de hoeveelheid steun die patiënten en partners aan elkaar geven worden bepaald door het fysiek functioneren van de patiënt en de hoeveelheid angst en depressie die de patiënt ervaart. Wanneer steunende interacties verschuiven van de patiënt naar de partner kunnen beide partners hun relatie als ‘uit balans’ ervaren (patiënten kunnen zich bevoorreed voelen omdat ze meer steun ontvangen dan zij geven en partners kunnen zich benadeeld voelen doordat ze meer steun geven dan zij ontvangen). Deze onderwerpen zijn onderzocht aan de hand van drie onderzoeksvragen: Geven en ontvangen patiënten en partners meer of minder steun vergeleken met de andere partner? Is de hoeveelheid steun die patiënten en partners geven gerelateerd aan het fysiek functioneren van de patiënt en de hoeveelheid angst en depressie die de patiënt ervaart? Ervaren patiënten en partners hun relatie als ‘uit balans’?

(2) *De effecten van steun geven en ontvangen op het welbevinden van beide partners*. Een dagboekmethode is gebruikt om het effect van steunende interacties te onderzoeken omdat een dergelijke methode mogelijkheden biedt om binnen personen te kijken naar omstandigheden waaronder interacties een ander effect hebben. De volgende vragen zijn op deze manier beantwoord: In hoeverre zijn wederkerige uitwisselingen van geven en ontvangen van emotionele en instrumentele steun van belang voor het

welbevinden aan het einde van de dag in patiënten en partners? Wordt de relatie tussen negatieve reacties van de partner en welbevinden aan het eind van de dag beïnvloed door de hoeveelheid emotionele steun van de partner die ontvangen wordt. Vervolgens is een prospectief design gebruikt om te onderzoeken of partner steun en gevoelens van bevoordeling en benadeling welbevinden zeven maanden later voorspellen. De volgende vragen zijn beantwoord: Wat zijn de effecten van ontvangen emotionele steun en negatieve reacties van de partner op gevoelens van angst en depressie zeven maanden later in patiënten en partners? Voorspellen percepties van onbillijkheid (bevoordeling of benadeling) gevoelens van depressie zeven maanden later in patiënten en partners?

Eenzestig paren waarvan één partner de ziekte MS heeft deden mee aan het onderzoek. Beide partners hielden een gecomputeriseerd en gestructureerd dagboek bij gedurende twee weken en voorafgaand aan het dagboek en na zeven maanden vulden zij een aantal vragenlijsten in. Interacties met de partner zijn gemeten via het dagboek en percepties van onbillijkheid met een vragenlijst op het eerste meetmoment. De paren die deelnamen aan het onderzoek zijn geworven via de afdeling neurologie van het St. Antonius Ziekenhuis in Nieuwegein en het MS Centrum Nijmegen te Nijmegen. Belangrijke kenmerken van de studie zijn dat er onderscheid is gemaakt tussen drie typen van steun namelijk instrumentele steun, emotionele steun en negatieve interacties. Een ander belangrijk kenmerk van de studie is dat beide partners als gevers en ontvangers van steun werden onderzocht. Verder hebben we gekeken naar verschillen tussen patiënten en partners zowel in de hoeveelheid steun die werd gegeven en ontvangen als in de effecten van steun op welbevinden.

In de volgende paragrafen zullen wij kort weergeven wat de belangrijkste bevindingen zijn uit het onderzoek. De resultaten zullen worden besproken aan de hand van de twee aspecten die boven zijn weergegeven en afzonderlijk voor de drie typen van steun en de perceptie van onbillijkheid.

Geven en ontvangen van steun in de context van een chronische ziekte.

Instrumentele steun

De resultaten die zijn beschreven in hoofdstuk 3 laten een disbalans zien in instrumentele interacties tussen patiënten en partners. Beide partners gaven aan dat patiënten meer instrumentele steun ontvangen van hun partner en minder instrumentele steun geven aan hun partner dan andersom. Deze bevindingen zijn in overeenstemming met onze verwachtingen en eerder onderzoek dat verondersteld dat steun binnen relaties meer eenrichtingsverkeer wordt en dat partners (in ieder geval met betrekking tot instrumentele steun) de grootste bijdrage leveren. In hoofdstuk 2 is gekeken of dit patroon sterker is wanneer de patiënt meer fysieke beperkingen heeft. Dit was inderdaad het geval, patiënten met meer fysieke beperkingen gaven aan minder steun te geven aan hun partner. Tegelijkertijd gaven partners van patiënten met meer fysieke beperkingen aan meer steun te geven.

Emotionele steun

De resultaten wat betreft de vergelijking van de hoeveelheid emotionele steun die patiënten en partners hebben gegeven en ontvangen waren minder eenduidig en minder uitgesproken dan de resultaten voor instrumentele steun. Patiënten gaven aan dat ze net zoveel emotionele steun aan hun partners geven dan ze ontvangen, terwijl partners aangaven dat ze over het algemeen minder emotionele steun van patiënten ontvangen dan ze geven. Steun geven en ontvangen zijn subjectieve waarnemingen. Het kan zijn dat patiënten de hoeveelheid steun die zij geven overschatten (door de eigen ziekte hebben ze misschien minder aandacht voor wat de partner nodig heeft), maar het kan ook zijn dat partners de steun die zij ontvangen niet waarnemen (ze hebben wellicht zoveel andere dingen aan hun hoofd dat ze geen oog hebben voor wat ze aan steun ontvangen van de patiënt) of ze interpreteren de steun die ze ontvangen op een andere manier (het kan zijn dat gedragingen die bedoeld zijn als steunend door de gever op een andere manier geïnterpreteerd worden door de ontvanger). De resultaten in hoofdstuk 2 laten verder zien dat de hoeveelheid emotionele steun die patiënten en partners geven niet gerelateerd is aan het fysiek functioneren van de patiënt, of aan gevoelens van angst en depressie die de patiënt ervaart. Het lijkt erop dat de hoeveelheid emotionele steun die patiënten en partners ervaren niet beïnvloed wordt door deze factoren. Deze bevinding is van belang gezien het idee dat uitwisselingen van emotionele steun een centraal aspect zijn van intieme relaties en kunnen leiden tot een hogere intimiteit en relatie tevredenheid.

Negatieve interacties

Net als de resultaten voor emotionele steun waren de resultaten wat betreft de vergelijking van de hoeveelheid negatieve interacties die patiënten hebben gegeven en ontvangen minder eenduidig en minder uitgesproken dan de resultaten voor instrumentele steun. Partners rapporteerden dat zij evenveel negatieve reacties gaven aan hun partner dan zij ontvingen terwijl patiënten rapporteerden dat zij meer negatieve reacties gaven dan zij ontvingen (Hoofdstuk 2 en 5). Over het algemeen kwamen negatieve interacties tussen partners niet veel voor en sommige patiënten en partners rapporteerden geen negatieve interacties gedurende de veertien dagen. Bij een minder goed fysiek functioneren van de patiënt rapporteerden zowel patiënten als partners meer negatieve interacties (hoofdstuk 2). Dit heeft vermoedelijk te maken met veranderde rolpatronen en een verschuiving van verantwoordelijkheden. Verder kwam naar voren dat wanneer patiënten meer gevoelens van angst ervoeren, patiënten en partners meer negatieve interacties rapporteerden. Wanneer patiënten meer gevoelens van depressie ervoeren, rapporteerden patiënten en partners echter minder negatieve interacties. Dit resultaat was onverwacht en kan te maken hebben met het feit dat in de context van een chronische ziekte, depressie vaak te maken heeft met verlies en gezien wordt als een gepaste reactie door de partner. Angst daarentegen heeft veelal te

maken met angst voor de toekomst en wat komen gaat. Dit is oncontroleerbaar en biedt weinig opties voor hulp waardoor het moeilijker is voor de partner om mee om te gaan.

Waargenomen billijkheid

Door de ziekte kunnen steunende interacties verschuiven van de patiënt naar de partner waardoor patiënten en partners hun relatie als ‘uit balans’ ervaren. De balans tussen geven en nemen van steun staat centraal in hoofdstuk 6. De resultaten laten zien dat patiënten zich over het algemeen bevoordeeld voelen in hun relatie (ze hebben het idee dat ze meer steun krijgen van hun partner dan ze geven aan hun partner). Deze gevoelens van bevoordeling waren sterker wanneer het fysiek functioneren van de patiënt slechter was. Partners daarentegen gaven aan dat zij over het algemeen hun relatie als billijk (in balans) beoordeelden in termen van geven en ontvangen van steun. Gevoelens van billijkheid in partners waren gerelateerd aan het fysiek functioneren van de partner. Partners van patiënten met een minder goed fysiek functioneren voelden zich vaker benadeeld in hun relatie. Mogelijk tolereren partners een bepaald niveau van daadwerkelijke disbalans alvorens zij hun relatie ook als ‘uit balans’ ervaren.

De effecten van steun ontvangen en geven voor welbevinden

Instrumentele steun

De resultaten voor instrumentele steun laten zien dat eenzijdig ontvangen van instrumentele steun op een dag zonder steun te geven gevolgen heeft voor de zelfwaardering aan het eind van de dag (hoofdstuk 3). Dit was het geval voor patiënten en partners. Eenzijdig instrumentele steun ontvangen zonder steun te kunnen geven kan voor patiënten hun afhankelijkheid benadrukken. Niet in staat zijn om instrumentele steun terug te geven kan bij de partner zijn/ haar competentiegevoelens als zorgverlener aantasten. In dit kader is het belangrijk om te realiseren dat patiënten waarschijnlijk meer dagen van eenzijdig steun ontvangen kennen en dus wat betreft dit slechter af zijn.

Andere belangrijke bevindingen betreffen de positieve effecten van steun geven voor stemming aan het eind van de dag (hoofdstuk 3). In de zorgverleners literatuur ligt sterk de nadruk op de belasting van zorg verlenen. Onze resultaten suggereren dat praktische hulp bieden aan je partner een positieve ervaring is voor zowel patiënten als partners. Opgemerkt moet worden dat dit niet betekend dat zorgen voor een zieke partner niet zwaar kan zijn. Onze resultaten suggereren enkel dat dingen doen voor je partner een plezierige ervaring is. Deze bevindingen zijn echter niet uniek voor patiënten en partners. Hoewel er in de literatuur nog niet veel aandacht is voor het geven van steun, ook onder gezonde paren zijn soortgelijke effecten gevonden.

Emotionele steun

Het effect van emotionele steun is onderzocht op verschillende aspecten van welbevinden en de resultaten laten geen nadelige effecten van emotionele steun ontvangen of geven zien (hoofdstuk 3, 4 & 5). Op basis van een eerdere studie bij ‘gezonde’ paren verwachtten we dat eenzijdig steun ontvangen op een dag, zonder ook steun te geven, negatieve consequenties zou hebben voor iemands stemming aan het eind van de dag (hoofdstuk 3). Dit was niet het geval. De bevindingen laten zien dat de effecten van emotionele steun verschillend waren voor patiënten en partners. Patiënten profiteerden het meest van steun geven terwijl partners de meeste baat hadden bij steun ontvangen. Voor patiënten kan emotionele steun van belang zijn omdat dit hen de gelegenheid geeft om dankbaarheid te tonen voor alle hulp en zorg die zij ontvangen van hun partner. Om diezelfde reden kan het ontvangen van steun waardevol zijn voor partners, omdat het dank en waardering laat zien. Emotionele steun ontvangen had tevens een indirect effect op de stemming van patiënten en partners doordat het de negatieve effecten van negatieve reacties van de partner verminderde (hoofdstuk 4). Dit suggereert dat negatieve interacties minder dreigend zijn wanneer de partner ook affectie en interesse toont op dezelfde dag. Tot slot is gekeken naar het effect van emotionele steun ontvangen als voorspeller van gevoelens van angst en depressie zeven maanden later in patiënten en partners. We vonden een marginaal significant effect van emotionele steun op gevoelens van depressie zeven maanden later en dit effect was minder uitgesproken dan we hadden verwacht. Opgemerkt kan worden dat er weinig bekend is over hoe dagelijkse interacties met de partner gerelateerd zijn aan welbevinden op de lange termijn. In dit onderzoek is simpelweg gekeken naar de gemiddelde hoeveelheid steun die mensen gedurende de twee weken hebben ontvangen als voorspeller van angst en depressie. De relatie tussen dagelijks ontvangen emotionele steun en gevoelens van angst en depressie kan echter meer complex zijn en te maken hebben met de variabiliteit van emotionele steun over de dagen of de context waarin de steun wordt gegeven. Daarnaast kan emotionele steun een rol spelen bij het ontwikkelen van ideeën over de relatie zoals de waargenomen beschikbaarheid van steun. Al met al kan geconcludeerd worden dat emotionele steun van belang is met betrekking tot verschillende aspecten van welbevinden. Dit maakt de eerdere opmerking dat de ziekte niet per definitie ten koste gaat van emotionele steun des te belangrijker.

Negatieve interacties

De resultaten voor negatieve interacties laten zien dat het ontvangen van negatieve reacties op een dag samenhangt met minder welbevinden aan het eind van de dag (hoofdstuk 4). Zoals in de vorige paragraaf beschreven staat was dit effect minder sterk wanneer de partner ook emotionele steun gaf op dezelfde dag (hoofdstuk 4). De negatieve effecten van negatieve interacties waren minder sterk dan verwacht kan worden op basis van bestaande literatuur. Vooral voor patiënten was verwacht dat negatieve interacties een sterk effect

zouden hebben op welbevinden omdat patiënten het meest kwetsbaar zijn in de relatie en afhankelijk zijn van hun partner voor het krijgen van steun. Een aantal redenen kunnen mogelijk verklaren waarom we geen sterke effecten van negatieve reacties vonden op welbevinden. Doordat negatieve interacties weinig voorkwamen moesten we de variabele dichotomiseren, waardoor de variabele voor negatieve interacties een minder voorspellende *power* had. Een andere reden kan zijn dat de paren in dit onderzoek relatief lang bij elkaar waren en zich in stabiele relaties bevonden. Het kan zijn dat negatieve interacties daarom als minder bedreigend ervaren werden. Deze redenen verklaren mogelijk ook waarom negatieve reacties ontvangen van de partner niet gerelateerd waren aan gevoelens van angst en depressie zeven maanden later (hoofdstuk 5).

Waargenomen billijkheid

De resultaten in hoofdstuk 6 laten zien dat patiënten die zich bevoordeeld voelen en partners die zich benadeeld voelen meer gevoelens van depressie ervaren zeven maanden later. Deze bevindingen ondersteunen dat gevoelens van billijkheid belangrijk zijn met het oog op depressie in zowel patiënten als partners. In contrast met deze bevindingen vonden we weinig bewijs voor het belang van onmiddellijke reciprociteit van steun dat wil zeggen op dezelfde dag (hoewel steun ontvangen zonder dat er ook steun gegeven werd slecht was voor de zelfwaardering) (hoofdstuk 3). Een belangrijk verschil tussen de studie beschreven in hoofdstuk 6 en de studie in hoofdstuk 3 is dat in het laatste geval niet gevraagd is of patiënten en partners hun relatie als uit balans ervoeren. Het kan zijn dat, ook al was er geen sprake van reciprociteit van steun, patiënten en partners niet het idee hadden dat er sprake was van disbalans.

Klinische implicaties

De meeste interventies voor chronisch zieken zijn gericht op steun ontvangen en het is voorsnog ongebruikelijk om te kijken of patiënten ook steun geven. Dit onderzoek laat zien dat steun geven belangrijk is voor het welbevinden van patiënten (en partners). Hoe patiënten ondanks hun beperkingen nog steeds steun kunnen geven aan hun partner zou een waardevol aangrijpingspunt voor interventies kunnen zijn. Tegelijkertijd zou het aanmoedigen van patiënten om steun te geven van belang kunnen zijn wat betreft gevoelens van billijkheid. Patiënten die meer steun geven zullen zich minder snel bevoordeeld voelen en partners zullen zich dan minder snel benadeeld voelen. Verder ondersteunt dit onderzoek het belang van emotionele steun voor het welbevinden van patiënten en partners. Naast een direct effect blijkt dat emotionele steun werkt als buffer tegen de negatieve gevolgen van negatieve interacties. Het is belangrijk om in interventies voor patiënten en partners aandacht te geven aan deze processen.

(Bijna) Klaar!

Het schrijven van dit dankwoord is werkelijk het allerlaatste loodje. In gedachten heb ik het al tientallen keren geschreven, maar nu ik wat op papier moeten zetten vind ik het toch best lastig, ik houd het maar kort.

Als eerste wil ik mijn promotoren bedanken, prof. dr. J.M. Bensing en prof. dr. J.J. Hox. Beste Jozien, jij bent de enige die van begin tot eind bij het project betrokken was. Dank voor je begeleiding, je motiverende feedback en je aandacht voor de grote lijnen. Beste Joop, jij hebt altijd en overal een oplossing voor, dat is erg prettig. Bedankt voor je interesse, je enthousiasme en je altijd heldere uitleg. Ik ken niemand die zo snel denkt als jij. Veel dank ben ik verschuldigd aan mijn copromotor dr. R.G. Kuijer. Roeline, je stapte pas laat in het project en ging voortijdig weer weg. Desondanks was je mijn grootste steun. Je feedback was altijd helder en constructief, en dat ik altijd op je kon rekenen was heel erg belangrijk voor me. Veel dank daar voor! Ik vind het erg leuk en gezellig dat je er bij bent in december. Dr. K.M.G. Schreurs, Karlein, jou wil ik graag bedanken voor de begeleiding in de beginfase van het project. Jij wilde graag een dagboekstudie en ik kan met terugwerkende kracht zeggen, we hadden geen idee waar we aan begonnen. Toch ben ik blij met die keuze.

De leden van de leescommissie wil ik graag bedanken voor de tijd die ze hebben gestoken in de beoordeling van het manuscript: prof. dr. A.B. Buunk, prof. dr. H.J.A. Hoijtink, dr. A.C.J.W. Janssens, prof. dr. D.T.D. de Ridder en prof. dr. M.J. Sorbi. Beste Denise, ik ben nog bij je afgestudeerd lang geleden en mijn enthousiasme voor onderzoek heb ik daar deels aan te danken. Dank daarvoor en ook voor alle leerzame jaren in de StiTch. Beste Marjolijn, jou wil ik graag bedanken voor je prettige samenwerking en alle mogelijkheden die je me biedt om in vernieuwende projecten mee te draaien. Ik hoop dat onze wegen nog een tijdje samenlopen.

Het proefschrift was nooit tot stand gekomen zonder alle patiënten en partners die bereid waren om deel te nemen aan het onderzoek. Ik wil jullie graag bedanken voor jullie inzet, jullie openheid en de hartelijkheid waarmee ik over het algemeen ontvangen werd. Ik heb daar veel aan gehad. Daarnaast gaat mijn dank uit naar de neurologen die meegewerkt hebben aan het project en altijd geïnteresseerd waren in de voortgang: dr. P.J.H. Jongen, directeur van het MS Centrum Nijmegen in Nijmegen en dr. S.T.F.M. Frequin, neuroloog in het St. Antonius Ziekenhuis te Nieuwegein.

Verder wil graag Lizet, Willemijn en Pascale van de onderzoeksschool Psychology & Health bedanken voor de ondersteuning en prettige samenwerking, hetzelfde geldt voor alle dames en later ook enkele heren van de p-raad. De etentjes waren altijd erg gezellig!

Mijn oude en wat nieuwere collega's van gezondheidspsychologie wil ik bedanken voor de prettige sfeer op de afdeling, onze supergezellige kerstfeesten, alle lunches, discussies en andere leuke dingen die we hebben gedaan. (Is het pannenkoekenhuis een nieuwe trend?) Ik heb het altijd erg naar mijn zin gehad op de afdeling en ben blij dat ik nog

een tijdje kan blijven. Ik ga jullie allemaal niet bij naam noemen, sorry, het zijn er inmiddels teveel en ik zou maar eens iemand vergeten. GP is nu samen met KP KGP geworden. Sinds ik als docent ben aangesteld voel ik me ook wat meer bij het KP gedeelte betrokken. Jan, Liesbeth en Lisalotte, we hebben elkaar nog niet vaak gesproken sinds september, maar ik heb het in ieder geval erg naar mijn zin, ik ben blij dat jullie me hebben aangenomen. KGP-ers, we hebben al een super uitje gehad, dat moeten we vaker doen.

Paula kamergenoot en paranimf. Mijn hele promotietijd heb ik van begin tot eind met je meegemaakt en daarin ook je hele zwangerschap, best bijzonder. Jij bent al over de streep en je deed het geweldig op je promotie. Ik ben blij dat je mijn kamergenoot was en nu mijn paranimf wilt zijn.

Dankbaar ben ik voor alles en iedereen die afleiding bood. Het schrijven van een proefschrift is met periodes best zwaar en dan is het fijn om mensen te zien die er helemaal niets mee te maken maar je toch steunen. In het bijzonder wil ik de 'vrienden' van de zaterdagmiddag bedanken voor alle gesprekken die dan weer nergens over gingen. Helaas hield ik er soms wel hoofdpijn en een beetje misselijk gevoel aan over. Veel afleiding bracht ook toneel (nu theatersport) hoewel ik me soms een beetje schuldig voel wanneer ik weer op de energie van anderen teerde. Straks ga ik er weer helemaal voor! Mireille we waren een tijdje heel sportief, jammer dat dit er door omstandigheden niet meer van komt. We kennen elkaar al zo ontzettend lang, ik ben heel blij dat je mijn paranimf wilt zijn. Verder dank aan alle vrienden/ vriendinnen die ik veel te weinig zie maar er niet minder om waardeer. Ook mijn ouders wil ik bedanken. Lieve pa en ma, jullie staan altijd voor Jos en mij klaar en vinden dat heel vanzelfsprekend, maar dat is het natuurlijk niet. Nu heb ik eindelijk de kans om jullie daar een keer zwart op wit voor te bedanken! Jos en Esther, kleine zusjes worden ook groot maar blijven altijd kleine zusjes.

Tot slot, lieve Jan, jou ben ik de meeste dank verschuldigd op alle fronten. Bedankt voor het schrijven van de software voor het elektronische dagboek, waarmee ik weer indruk kon maken op reviewers. Je bent ook mijn persoonlijke helpdesk bij excelproblemen, degene met wie ik leuke dingen doe en lief en leed deel. Dat je me alle vertrouwen geeft en onvoorwaardelijk steunt bij alles wat ik doe en elke keuze die ik maak -ook wanneer je het niet begrijpt- vind ik heel bijzonder. Mijn dank en liefde zijn groot.

Curriculum Vitae

Annet Kleiboer werd op 2 mei 1972 geboren te Apeldoorn. Na het behalen van haar VWO diploma studeerde zij van 1992-1998 Psychologie aan de Universiteit Utrecht. Zij studeerde af in de richting Klinische en Gezondheidspsychologie. In 1999/2000 werkte zij als psycholoog bij de RIAGG Rotterdam-Zuid op de afdeling volwassenen en als docent communicatie bij het UMC Utrecht. Daarnaast was zij in 2000/ 2001 als junior onderzoeker werkzaam bij de opleiding tot huisarts van de Katholieke Universiteit Nijmegen.

In 2001 werd zij aangesteld als Assistent in Opleiding bij de capaciteitsgroep Gezondheidspsychologie van de Universiteit Utrecht en de onderzoeksschool Psychology and Health (P&H). Binnen deze aanstelling voerde zij het onderzoek uit waar in dit proefschrift verslag van wordt gedaan. Sinds september 2005 is Annet als post doctoraal onderzoeker werkzaam bij de disciplinegroep Klinische en Gezondheidspsychologie van de Universiteit Utrecht (voormalige capaciteitsgroep Gezondheidspsychologie) op een project naar 'online coaching van migraine patiënten'. Tevens is zij sinds september 2006 werkzaam als docent bij de zelfde disciplinegroep.