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Volume I

Research Component

A Literature Review of the Impact of a Monitoring Coping Style on Psychological Adjustment in People with Real or Potentially Life Threatening Illness

and

An Investigation of Psychological Adjustment and Coping style in Patients Undergoing Bone Marrow/Stem Cell Transplantation

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Overview

Volume I

Volume I contains a literature review and an empirical paper. The literature review, which is presented first, reviews recent findings for a relationship between informational coping style and psychological adjustment in patients confronted with potential or real life threatening illness. Empirical data is systematically reviewed within the theoretical framework of Miller's (1995) Monitoring Process Model. Suggestions are made for future research on order to develop effective interventions for those individuals who are most vulnerable to psychological, social, and emotional complications secondary to their illness

The empirical paper examines psychological distress in patients undergoing stem cell transplantation in a prospective longitudinal design. Specific aims are to examine the degree of psychological distress over the course of transplantation, which pre-treatment demographic, medical and psychosocial factors predict psychological distress and adjustment after transplantation, and whether informational coping style was associated with distress levels before and after transplantation. The findings of this study illustrate the need for pre-treatment assessment and intervention, focusing on treatment related anxiety management, depression, and dysfunctional illness attributions which may help reduce post-treatment distress.

Volume II

Volume II contains a series of clinical Practice Reports (CPR's), which relate to work undertaken in various clinical settings since September 2005. CPR1 presents the case of a man with learning disabilities, which was formulated from both cognitive and behavioural perspectives. CPR 2 presents a small scale service evaluation project investigating factors associated with re-referral in a psychology and counselling service for people with learning disabilities. CPR 3 presents a single case experimental design evaluating a cognitive behavioural intervention with a boy with a specific phobia of rubber masks. CPR 4 presents an account of Adjuvant Psychological Therapy with a woman with breast cancer related anxiety and depression. CPR 5 (abstract only) details the cognitive behavioural intervention undertaken in treating a man with social anxiety difficulties.

Dedication

This thesis is dedicated to all my parents, who have supported me over the years, wherever I went and whatever I chose to do. Even from across the pond you have all done a brilliant job in keeping me motivated and focused, and offering me a place to relax and escape it all.

Also, this thesis is dedicated to a very special little person, who– although probably (hopefully!) not consciously aware - has been present for most of the write-up. I hope I did not do you any harm with my occasional bouts of panic and elevated cortisol levels during the last stressful weeks. I promise I will make it up to you!

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Literature Review

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Abstract

Research has shown both short-term and long-term psychological and physical benefits of informational preparation in threatening medical situations. Previous literature suggests that informational coping style may affect patient response to information provision. Miller (1987) identified two informational coping styles: 'monitoring' (attentional bias for threatening information) and 'blunting' (ability to distract from threatening information). The Monitoring Process Model predicts that in threatening medical situations, 'monitors' and 'blunters' differ, with monitors displaying increased distress compared to blunters. The aim of this literature review was to critically review the literature since 1995 for support for the MPM and to make recommendations for preventive interventions for those individuals who are most vulnerable to psychological, social, and emotional complications secondary to their illness.

Twenty-one relevant empirical studies were identified and critically reviewed. Attention was paid to gender, type of medical condition, medical context, study design, chosen methodology, and characteristics of the sample.

The results show that strongest support for the MPM when (a) researched within a context of 'short term' threat as in screening and diagnosis, (b) when researched in female only samples, and (c) when researched in cancer. Comparison of studies was hampered by inconsistencies with regard to dimensionality of the monitoring/blunting construct and related methodology. Nonetheless, there was enough evidence to suggest that screening for informational coping style and subsequent tailoring of information in the initial and 'acute' phases of illness may be beneficial to subsequent adjustment.

Glossary of abbreviations used in literature review

BBB	Benign Breast Biopsy
BCRC	Breast Cancer Risk Counselling
BRCA1	Breast Cancer 1
GHE	General Health Education
HADS	Hospital Anxiety and Depression Scale
HIV	Human Immunodeficiency Virus
HM/HB	High Monitoring/High Blunting
HPV	Human Papilloma Virus
IES	Impact of Event Scale
LM/LB	Low Monitoring/Low Blunting
MBQ	Monitoring Blunting Questionnaire
MBSS	Miller Behavioural Style Scale
MBSS-SF	Miller Behavioural Style Scale-Short Form
MOS	Medical Outcome Studies
MPM	Monitoring Process Model
MPM-	Unsupportive of MPM
MPM+	Supportive of MPM
MPM+/-	Inconclusive with regard to support for MPM
POMS	Profile of Mood States
PPI	Pre-dialysis Psycho-educational Intervention
RCT	Randomized controlled trial
RSCL	Rotterdam Symptom Checklist
TMSI	Threatening Medical Situation Inventory
TVS	Transvaginal Ultrasound

Introduction

Being affected by a life threatening illness has important consequences for someone's physical, emotional and psychological wellbeing. It has been known for some years that in many life-threatening medical situations up to 50 percent of patients experience some form of psychological distress (Sellick & Edwardson, 2007; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Besides their effect on wellbeing, it has been reported that stress, anxiety and depression can have adversarial effects on recovery and even survival. To illustrate, a recent review has reported that pre-treatment negative emotions amongst patients undergoing allogenic stem cell transplant, a high risk and invasive treatment for haematological diseases, is correlated with a reduction in post-transplant survival time (Hoodin, Uberti, Lynch, Steele & Ratanatharathorn, 2006).

Research has shown both short-term and long-term beneficial psychological and physical benefits (reduced anxiety, depression, improved mood, shorter duration of hospital stay, less use of pain medication, better treatment adherence) of informational preparation in threatening medical situations such as surgical procedures and high risk treatments (Petersson *et al.*, 2002; Hoodin, 2006; Ludwick-Rosenthal & Neufeld, 1993; Horne, Vatmanidis and Careri, 1994). Such preparation typically involves information provision about treatment events, associated pain, common side effects and risks, and long-term treatment consequences and is usually provided by nursing or medical staff. Information provision has become a common component of preparation for screening and treatment in life threatening illnesses (Fallowfield, Ford & Lewis, 1995; Suls & Wan, 1989).

Although there is a general consensus regarding the benefits of information provision, there seems to be room for improvement. A recent review (Kiesler & Auerbach, 2006) on patient satisfaction with information provision reported that a considerable number of patients (median 52%, range 26% to 95%) are dissatisfied with the level and amount of information they receive and that the majority of patients preferred more information. Another important conclusion was that patient distress was lower when information provision matched patients' information preference for the level of information and amount of involvement in decision-making (Kiesler & Auerbach, 2006). Given these findings, the question remains on how the optimal level of information provision for individual patients can be determined. Which patient factors influence satisfaction with informational preparation? Previous literature also suggests that an informational coping style seems to determine how a patient responds to information provision (Fallowfield, 1995; Steptoe, Sutcliffe, Allen, & Coombes, 1991) Thus, how patients respond to informational provision depends on the match between characteristics of the information provision (amount, content), and the individual informational coping style of the patient.

Information preference in the domain of medical threat

Coping styles are referred to as 'personal cognitive or behavioural strategies to master, reduce or tolerate a stressful situation' (Folkman & Lazarus, 1984; Krohne, 1989; 1993). One of the most used classifications of coping efforts is the distinction between 'emotion focused coping' (focus on managing the emotions arising from exposure to the stressful situation) and 'problem focused coping' (focus is managing or altering the problem causing the distress) (Folkman and Lazarus, 1984; Folkman, 2001). Miller (1987) distinguished two concepts of information seeking behaviour in which individual coping styles are expressed as 'monitoring' and 'blunting'. Monitoring involves the extent to which an individual has an attentional bias for negative, potentially painful or dangerous aspects of information, whereas blunting involves the extent to which an individual distracts himself or herself from the threatening information. Monitoring has been described as an adaptive strategy when individuals perceive themselves as having control, as the individual can use their monitoring style in a problem-focused way, for example to change certain health behaviours. However, when individuals perceive their situation as hopeless and out of control, a monitoring coping style may be maladaptive in that it may make the individual more vulnerable to distress. In these situations 'monitors' are more focused on internal and external threat cues, which generates intrusive thoughts about the threat. In addition, monitors have a tendency to perceive neutral/ambiguous information as negative or threatening, to ruminate about it and amplify it, resulting in a vicious circle of increased perceptions of personal risk, intrusive ideation and heightened anxiety. This is the basis for the Monitoring Process Model (MPM; Miller, 1995; Miller, Rodoletz, Schroeder, Mangan & Sedlacek, 1996; Miller, Roussi, Caputo, & Kruus, 1995).

In the last few decades, research has focused on how patients deal with threatening health relevant information in cancer screening programmes or other medical situations. Previous research on the interaction between informational coping style and informational preparation in cancer has shown that patients cope better when information provision is in tune with their informational coping style (Miller, 1995; Ong *et al.*; 1999). Unfortunately, often information is provided in a 'one size fits all' format, potentially resulting in a mismatch with the coping style of the individual. For example, when information provision is extensive and detailed, patients with a monitoring coping style will experience less distress because their preferences are met, whereas "blunters" will experience least distress when only basic information is given.

There appears to be a wide variation of findings in studies looking at the interaction between informational coping style and psychological well-being and adjustment. A preliminary investigation of the literature showed that there are a number of empirical studies looking at the relationship between informational coping style and wellbeing and psychological adjustment in threatening medical situations, as well as several review articles (Miller, 1995; Miller, 1999; Case, Andrews, Johnson, & Allard, 2005). Miller's (1995) review highlighted the implications of the emerged research evidence for the Monitoring Process Model (MPM) in the cancer field. Hence, it seems worthwhile to systematically review papers published since 1995, both in cancer and other real or potentially life threatening illnesses, in order to take stock of the support for the MPM and to bring to light any emerging patterns which may have implications for the medical context or method in which the tailoring of information to the coping style of the individual is most beneficial.

Aims

The main aim of the paper is to review the literature published since Miller's publication in 1995. The literature will be critically reviewed for a relationship between informational coping style and adjustment in individuals who are faced with a real or potentially life threatening medical situation. Attention is paid to medical context, type of disease, methodology, and sample characteristics. A further aim is to make recommendations for future research with regard the usefulness of the MPM in the diverse medical contexts.

Method

Search strategy/selection of articles

Web of Science, Pubmed/Medline and PsychInfo were searched to identify literature on the relationship between informational coping style and adjustment in threatening medical situations published from 1995 until 2007. Search terms were ‘monitoring’, ‘blunting’, ‘information’, ‘coping’, ‘monitoring process model’, ‘threatening medical situation’, and ‘cancer’. In a similar manner abstracts citing ‘MBSS’ (Miller Behavioural Style Scale) and ‘TMSI’ (Threatening Medical Situation Inventory), two measures used in informational coping style research, were retrieved from these databases. A cross-search of papers referencing Miller’s (1995) review was conducted to identify further relevant papers. References in the retrieved articles were further searched for relevant papers. Lastly, cited books and book chapters were searched for relevant references. These searches yielded a total of 178 hits on which the following inclusion criteria were applied:

Year	Studies published after 1995.
Sample	Adults suffering from, or at risk of, a life threatening medical condition.
Study design	Study designs that include a reference or control group; correlational studies.
Measures	Use of validated measures of adjustment, psychological wellbeing or distress, or informational coping style.
Exclusion	Case studies, studies described in editorials, commentaries, or conference abstracts or other non peer reviewed studies (i.e.

	book chapters), qualitative studies, studies involving routine benign surgical or dental procedures.
Language	English language.

Study characteristics

The following sample and study characteristics were taken into account:

Gender

In order to identify whether gender plays a role in the relationship between informational coping style and adjustment and thus affects support for the MPM, the reviewed studies are classified according to the gender distribution in the sample.

Type of medical condition

In order to identify whether support for the MPM is associated with a certain medical diagnosis, as well as with duration (long-term conditions versus acute conditions), the reviewed studies were classified according to medical condition.

Medical context

Studies of coping with health threat have focused on two different populations; patients coping with short-term aversive diagnostic or screening procedures, and patients coping with chronic health conditions (Miller, 1991). Therefore it seemed worthwhile to identify whether support for the MPM is associated with either medical context, e.g., studies that investigated psychological adjustment to medical screening or being given a diagnosis versus studies investigating psychological adjustment to medical treatment or ongoing disease.

Methodological characteristics of the studies to be reviewed

Study design

In order to identify whether support for the MPM was associated with study design, studies were classified according to their use of a cross sectional-correlational design, prospective-correlational design, or experimental design (i.e., randomized trial, or randomized control trial, RCT).

Sample size and statistical power

Attention was paid to the dimension of the research sample in order to identify any possible interaction with the robustness of the findings which may affect support for the MPM.

Use of measures and dimensionality of the constructs

Reviewed studies were classified according to choice of measures to operationalize adjustment/distress, as well as informational coping style. The same was done for methodology to divide the sample into ‘monitors’ and ‘blunters’. The strategy whereby typically only the monitoring scale is used is indicative of a view that monitoring and blunting are two independent dimensions. However, using a *summary* score is indicative of a view that the monitoring and blunting concepts are the opposite poles of one dimension.

Criteria for support for Monitoring Process Model

A study was found to be supportive of the MPM (MPM+; see Table 2 page 11) if

(a) Participants with a high monitoring style experienced more psychological distress/less adjustment (e.g., heightened perceived risk, anxiety, intrusive ideation, avoidant ideation, depression), preferred detailed information, or scanned for threatening cues

(b) Participants with a high monitoring style demonstrated poor behavioural adjustment (e.g., poor dietary regimen adherence, poor medication adherence, disengagement with treatment regimen).

If the study findings demonstrated neither (a) nor (b), the study was classified as not supportive of the MPM (MPM-). If the study findings demonstrated (b), but not (a), or with any other outcome, it was classified as partially supportive (MPM+/-).

Results

After applying the quality criteria and eliminating duplicate hits, 21 relevant empirical studies published between 1995 and 2007 were left for review (see Appendix 2). A schematic outline of the results can be found in Table 1, page 13.

General description of search results

Gender

Eight studies included women only. Twelve studies included both male and female participants, and one study (Andrewes, Camp, Kilpatrick, & Cook, 1999) omitted to specify the gender distribution of their sample.

Type of medical condition

The majority of the studies (N=15) focused on cancer, of which one study (Miller, Rodoletz, Schroeder, Mangan & Sedlacek, 1996) included a mixed sample of women positive for Human Papilloma Virus (HPV; a risk-factor for cervical cancer) and HIV positive men. Of the remaining studies, two focused on kidney disease, one focused on cardiac rehabilitation, one on epilepsy, one on chronic Hepatitis C, and one study on HIV (2 studies when including the study by Miller *et al.* (1996) cited above).

Medical context

Nine studies investigated psychological adjustment to medical screening or diagnosis, and 12 studies investigated psychological adjustment to medical treatment and long-term ongoing disease.

Table 1[1]**.** *Schematic outline of outcome and characteristics of the included studies*

	MPM+	**MPM+/-**	**MPM-**
Study characteristics			
Gender			
Mixed sample	**2** (7,11)	**6** (4,5,6,13,14,18)	**4** (8,12,19,20)
Female	**7** (2,3, 9,10,15,17,21)	**1** (16)	
Type of medical condition			
Cancer	**8** (2,3,9,10,11,15,17,21)	**5** (13,14,16,18,20)	**2** (12,19)
Epilepsy	**1** (1)		
HIV			**1** (20)
Cardiac rehab		**1** (5)	
Kidney disease		**1** (6)	**1** (8)
Chronic Hepatitis C	**1** (7)		
Medical context			
Screening/diagnosis	**7** (2,3,9,11,15,16,21)	**1** (20)	**1** (14)
Treatment/disease	**3** (1,7,10)	**6** (4,5,6,13,16,18)	**3** (8,12,19)
Study Design			
Correlational	**7** (2,3,7,10,11,15,17)	**6** (4,5,6,14,16,18)	**2** (12,20)
Intervention	**3** (1,9,21)	**1** (13)	**2** (8,19)
Cross-sectional	**3** (7,10,15)	**4** (4,5,14,16)	**2** (12,20)
Longitudinal	**5** (1,2,3,11,17)	**2** (5,10)	
RCT	**2** (9,21)	**1** (13)	**2** (8,19)
Sample size			
>100	**9** (2,3,7,9,10,11,15,17,21)	**5** (4,13,14,16,18)	**4** (8,12,19,20)
<100	**1** (11)	**2** (5,6)	
Measure/methodology			
MBSS	**6** (1,9,10,11,15,17)	**4** (4,6,14,16)	**2** (1,20)
MBSS-SF	**3** (1,2,21)		
TMSI		**3** (5,14,18)	**2** (12,19)
MBQ	**1** (7)		
Summary score	**4** (1,7,9,11)	1 (13)	
Only monitoring scale used	**5** (1,2,10,15,17)	**3** (6,14,16)	**1** (19)
Both scales used		**1** (18)	**3** (8,12,20)

Study design

Table 2, below, shows both medical context and methodological design of included studies. Five studies were Randomised Controlled Trials (RCTs), nine used a cross-sectional design, and seven studies used a longitudinal design.

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[1] Numbers in bold refer to number of studies; numbers between brackets refer to the number of the paper in Appendix 2.

Table 2. *Medical context and methodological design of included studies (for a full description of included studies please see Appendix 2)*

Medical context:	**Screening/Diagnosis**		**Treatment or Ongoing Disease**	
Type of study:	**Correlational**	**Intervention using randomized groups**	**Correlational**	**Intervention using randomized groups**
RCT		Lerman *et al.*, 1996 Williams-Piehota *et al.*, 2004		Devins, *et al.*, 2003 Van Vliet *et al.*, 2004 Petersson *et al.*, 2002
Cross sectional	Schwartz *et al.*, 1995 Warburton *et al.*, 1997 Pieterse *et al.*, 2005		Miller *et al.*, 1996 Brown & Bedi, 2001 Constant *et al.*, 2005 Sheehan *et al.*, 2007 Ong *et al.*, 1999 Barnoy *et al.*, 2006	
Prospective longitudinal	Tercyak *et al.*, 2001 Andrykowski *et al.*, 2002 Nordin *et al.*, 2002 Andrykowski *et al.*, 2004		Christensen *et al.*, 1997 Timmermans *et al.*, 2007	Andrewes *et al.*, 1999

Sample size and statistical power

Eighteen studies had sample sizes larger than 100 participants. Of the remaining studies, the samples were between N=51 and N=85.

Use of measures and dimensionality of the constructs

Twelve studies used the Miller Behavioural Style Scale (MBSS; Miller, 1987) to measure informational coping style, five used the Threatening Medical Situation Inventory (TMSI; Van Zuuren, 1992), three studies used the MBSS-Short Form (Steptoe, 1989) and one study used the Monitoring Blunting Questionnaire (MBQ; Muris, Van Zuuren, de Jong, de Beurs, & Hanewald, 1994). Nine studies used only the monitoring scale to classify their sample into ‘high and low monitors’, five used the summary score to divide the sample into ‘monitors’ and ‘blunters’, four used both monitoring and blunting scales and two studies did not give detail about the used methodology.

The main study findings of the 21 reviewed studies will be presented next. Please also see Appendix 2 for a schematic overview of the reviewed studies.

Studies finding support for the MPM

Schwartz, Lerman, Miller, Daly, & Masny (1995) found that amongst women at risk for developing ovarian cancer, “high monitors” reported increased perceived risk to develop ovarian cancer compared to “low monitors”. They hypothesised that “high monitors” have a tendency to overestimate their risk and as a result have increased vulnerability to intrusive thoughts and psychological distress. In addition, this study also demonstrated the mediating role of increased perceived risk and intrusive ideation in the relationship between monitoring and psychological distress. However, because they used a cross sectional design conclusions about causality could not be drawn. Unfortunately, no subsequent research has replicated Schwartz *et al.*’s (1995) findings. A longitudinal study by Nordin, Lidén, Hansson, Rosenquist, & Berglund (2002) on patient distress, perceived risk and satisfaction before and after genetic counselling for hereditary cancer was unable to replicate the relationship between informational coping style and increased perceived risk. Nonetheless, this study demonstrated monitors’ increased worry and anxiety before and immediately after the counselling session compared to non-monitors. This finding is consistent with the MPM, which suggests that under conditions of threat, which a genetic counselling session can be for individuals at risk for developing hereditary cancer, high and low monitors differ in the way they prepare for and respond to the information given.

A longitudinal study by Lerman, Schwartz, Miller, Daly, Sands, & Rimer (1996) was unable to replicate Schwartz et al’s (1995) findings. These researchers aimed to help women at risk for breast cancer to shift their focus away from unrealistically high-risk perceptions and intrusive thinking towards more adaptive coping. Lerman and colleagues (1996) compared two educational interventions - Breast Cancer Risk Counselling (BCRC), counselling specifically aimed at providing education on breast cancer risk and providing individualised probability estimates, and a control condition, General Health Education (GHE; general health guidelines for women of different ages). The researchers predicted that the effects of BCRC would be mediated by reduced perceptions of perceived risk, as well as increased emotional distress and intrusive ideation in monitors. The data did not confirm the mediating role of perceived risk on distress as found by Swartz *et al.* (1995). However, the results confirmed the predicted increase of distress in 'high monitors' in response to the BCRC intervention. More interestingly, and consistent with the MPM, they found similar results for the GHE condition. Thus, for monitors, even 'general' information about cancer may activate a perception of threat, leading to psychological distress.

Similar to Lerman and colleagues (1995), Tercyak *et al.* (2001) investigated the psychological and emotional response of women at risk of ovarian and breast cancer to genetic counselling and testing. They measured patients' distress at three time points; (1) at baseline, before counselling; (2) immediately before disclosure of the test results, and (3) immediately after disclosure of the test results. Consistent with the MPM, they found that high monitors experience more anxiety than low monitors at baseline and pre-disclosure. However, immediately after women had been given their results, carriers of the gene were significantly more distressed than non-carriers, regardless of monitoring coping style or not. A possible explanation could be that the differences predicted by MPM are most clear in ambiguous situations, e.g. during the anticipation of the result when one is faced with a health *threat*. After disclosure, although the result might not be desirable, this threat can be seen as reduced or even removed, showing fewer differences between “high” and “low monitors”.

In a series of studies, Andrykowski *et al.* (2002) and Andrykowski, Boerner, Salsman, & Pavlik (2004) studied the short and long-term negative psychological impact of test results of Benign Breast Biopsy (BBB) and Transvaginal Ultrasound (TVS). BBB and TVS are both diagnostic procedures that test for malignancy in the case of abnormal or inconclusive results during routine screening. The results of the BBB study showed that in the immediate aftermath of BBB, individuals high on monitoring showed increased intrusion and avoidance, indicative of disease specific psychological distress. This effect was particularly strong in individuals low on dispositional optimism, confirming the MPM. Andrykowski *et al.*’s (2004) TVS study confirmed the findings of the earlier study on BBB that women who were characterized by low dispositional optimism and a monitoring coping style responded with more disease specific distress to abnormal TVS result. In summary, the results from both studies suggest that high optimism can act as a protective factor to a monitoring coping style in a threatening health situation.

Williams-Piehota, Pizarro, Schneider, Mowad, & Salovey (2005) investigated the impact of informational coping style tailored health messages on future screening behaviour (mammography) in women phoning a cancer hotline. Their results showed that overall, women with a monitoring coping style reported more worry about future breast cancer risk than non-monitors (e.g. blunters), confirming the MPM. Moreover, the results showed that “monitors” receiving a ‘blunting’ health message (e.g., a general health message: ‘Early detection is your best protection. Get a mammogram. It can save your life!’) were most distressed, and “blunters” receiving a ‘blunting’ message were least distressed. Furthermore, the results indicated that matched messages were associated with mammography use at 6-month follow-up, but that the effects faded at 12 months.

Miller *et al.* (1996) examined the illness responses of two groups of individuals experiencing a long-term health threat: women with human papillomavirus-related precancerous cervical dysplasia, and HIV-infected men. In both samples, a more profound monitoring coping style was characterized by elevated intrusive ideation (e.g., thinking about the disease when not meant to, trouble falling sleep because of it, often being reminded of it), elevated avoidant ideation (e.g., avoiding thinking about it), and were more likely to cope by more primitive avoidant and disengaging coping strategies (e.g., avoiding talking about it, avoiding reminders of it, denial). Moreover, they found that the relationship between intrusive ideation and avoidant ideation was much stronger in the HIV sample. To explain these findings, the authors postulated that in women with HPV, which is a relatively controllable and less threatening condition, intrusive ideation may be less profound and more easily dealt with because the prognosis of treatment is relatively positive. HIV on the other hand, is associated with more severe, potentially life threatening consequences for the individual and therefore intrusive ideation may be more distressing, resulting in more severe avoidance reactions. As an alternative explanation, the authors hypothesized that gender differences in coping may account for the found differences. Although not mentioned by the authors, it could be argued that the social stigma around HIV infection may add to the distress caused by the medical implications of the disease.

Andrewes *et al.* (1999) studied the effects of pre-treatment information provision on pre-operative anxiety in patients undergoing monitoring for epilepsy surgery. They examined whether this high information group differed from the control group who received standard admission information. The main finding of the study was that patients receiving the ‘high information’ preparation showed a significant decrease in preoperative anxiety and depression compared to the low information group. Moreover, Andrewes *et al.* (1999) showed an interaction between informational coping style and distress in these patients. On arrival in hospital, monitors reported significantly higher anxiety than blunters, needed more support, and needed more information about the surgery and the after-effects, which can be viewed as support for the MPM.

Constant, Castera, Quintard, Bernard, de Ledinghen, Couzigou, & Bruchon-Schweitzer (2005) found a significant interaction effect between informational coping style and perceived severity of disease and anxiety in chronic Hepatitis C patients. Based on the scores of both monitoring and blunting subscales, they divided the sample into ‘blunters’, ‘high monitors’ and ‘low monitors’. The findings showed the high monitors had the highest scores on perceived illness severity and trait anxiety, followed by low monitors and blunters. Moreover, after dividing the sample for gender, the data showed that this effect held true for men, but not for women. In conclusion, the findings appear to support the MPM, but only when both genders are included in the analyses.

Studies not finding support for the MPM

Warburton, Fishman, & Perry (1997) investigated the relationship between informational coping style and emotional distress in a population of 249 people undergoing testing for HIV, but regarded the informational coping style to be a ‘state’ rather than a ‘trait’ as was the case in the other studies. They argued that individuals can score high or low on both scales, or high on one scale and low on the other. Hence, Warburton *et al.* (1997) examined psychological distress in all four group combinations of monitoring and blunting. They found no significant effects for any of the four groups on distress. However, when looking at individuals who predicted their test result to be HIV positive, there was a strong association between being high or low on *both* monitoring or blunting and increased psychological distress. Furthermore, the results showed that individuals who were high monitoring/low blunting experienced *least* distress compared to the other three groups. The authors postulated that the use of more than one coping style (HM/HB) in the face of a health threat may lead to ineffective coping, resulting in increased distress.

Ong, Visser, Van Zuuren, Rietbroek, Lammes, & de Haes (1999) examined whether informational coping style impacted on the interaction between cancer patients and consultants during a first consultation. The data showed significant positive relationships between monitoring coping style, but not blunting coping style, and preferences for detailed information and participation in decision-making. This contradicts earlier findings by Miller (1995) that 'monitors' prefer to be less involved in decision-making. Interestingly, however, they did not find significant associations between coping style and preference for information, good or bad. Contrary to predictions in the MPM, they found no relationship between information coping style and patients' prognosis, disease specific quality of life measured by the Rotterdam Symptom Checklist (RSCL; De Haes, van Knippenberg, & Neijt, 1990), or generic quality of life measured by the Medical Outcome Studies (MOS; Stewart & Ware, 1992). They did not, however, use specific measures to assess distress as used in other studies, which makes it difficult to draw conclusions on psychological wellbeing or psychological adjustment based on these findings. With regard to communicative behaviours, this study found a positive relationship between monitoring and patients' question asking and dominance during the consultation, but this relationship did not reach statistical significance. In summary, this study did not provide support for the MPM, nor did it provide clear enough evidence for a relationship between informational coping style and adjustment.

Van Vliet, Grypdonck, Van Zuuren, Winnubst, & Kruitwagen (2004) investigated whether a 'coping style-matched' pre-treatment intervention affected post-treatment adjustment, but failed to demonstrate the expected positive effects of preparing patients in accordance with their informational coping style. For 'high monitors', detailed information provision did not result in less anxiety than providing standard information. Similarly, 'low monitors' in the basic information condition did not respond more favourably than in the control condition. Thus, the data do not provide support for the MPM. Regrettably, the results did not provide information on the statistical significance of the differences in pre-or post intervention emotional distress between 'low' and 'high' monitors. This hinders meaningful interpretations about a relationship between informational coping style and psychological adjustment.

Devins, Mendelssohn, Barre, & Binik (2003) examined the effects of psycho-education intervention versus usual care on 'delay to dialysis' (i.e., duration of time before commencement of dialysis treatment was unavoidable) in a sample of end-stage renal patients. The results showed no differences in depression, anxiety and social support between the two conditions, but time to dialysis was decreased by almost three months in the psycho-education condition compared to the usual care condition. Furthermore, despite expectations that a 'monitoring' coping style would enhance the beneficial effects of the intervention, the data did not demonstrate increased time to dialysis for this group. A 'blunting' coping style, however, was found to be related to shorter time to dialysis, particularly in the usual care condition. Hence, these results indicate that that a stronger tendency to avoid threat-relevant information is maladaptive in this particular chronic health condition, especially when patients are not educated about their condition. The finding that a blunting style, and not a monitoring style, is associated with poorer adjustment contradicts predictions from the MPM.

Studies finding partial support for the MPM

Pieterse, Van Dulsem, Ausems, Schoenmaker, Beemer, & Bensing (2005) examined genetic counselees' preferences and needs, informational coping style, and pre-counselling anxiety prior to genetic counselling for hereditary cancer. They found a significant positive relationship between a monitoring coping style and the perceived importance of receiving information on the procedural aspects of the counselling session as well as on cancer related issues (e.g., determination and meaning of carrying the cancer gene, sensitive communication, emotional consequences for oneself and close family). The data also showed that individuals with a monitoring coping style valued the communication style of the counsellor as more important than their counterparts. Furthermore, they found a positive relationship between monitoring coping style and a need for emotional support, although this finding did not reach statistical significance. Although the paper reported a positive relationship between counselees' pre-counselling anxiety and perceiving receiving information on the procedure and cancer related issues as important, no mention was made of a relationship of these with a monitoring coping style. Concluding, although the findings show a relationship between monitoring and information need, and suggest support for the MPM, results did not reach statistical significance.

Christensen, Moran, Lawton, Stallman, & Voights (1997) examined the interaction between monitoring coping style and adherence in chronically ill renal patients receiving haemodialysis treatment. The results of the study showed that more pronounced monitoring was associated with poorer fluid intake and dietary regimen adherence, but not with medication adherence. Thus, the authors found "partial" support for a relationship between monitoring and poorer emotional and behavioural adjustment. Furthermore, they found that patients with more pronounced monitoring tendencies experience less perceived control over the management of their illness, but not increased use of avoidant coping strategies. Based on their inconclusive findings and methodological limitations (e.g., modest reliability of Ways Of Coping Questionnaire, Lazarus & Folkman, 1984), not enough measures used to assess emotional state, as well as a relatively low sample size of 51 participants, the authors concluded that the data were not strong enough to support the MPM model.

Similar to the study by Ong *et al.* (1999), Timmermans, van Zuuren, van der Maazen, Leer, & Kraaimaat (2007) investigated how informational coping style affected communicative behaviours during cancer patients' first radiotherapy consultations, as well as their subsequent evaluations of these consultations. Interestingly, the authors found the expected relationship between informational coping style (i.e. 'monitors' asked more questions than 'blunters') and question asking in patients treated palliatively, but not in patients treated curatively. Furthermore, the results showed that in the palliative group alone, a monitoring coping style was associated with more doubts about treatment decisions six weeks after the consultation, and a blunting coping style with fewer doubts and a more positive evaluation. Although it is difficult to explain the differences in findings between the groups, the MPM suggests that the more threatening a consultation situation is for a patient, the clearer the differences will be between 'monitors' and 'blunters'. It may well be that disease status (i.e., palliative vs. curative) affected the level of threat experienced during the consultation. Summarizing, the results provide evidence for a relationship between informational coping style and adjustment, but based on the results it remains unclear to what extent the MPM can be supported by these findings.

Brown & Bedi (2001) examined the effects of informational coping style on wellbeing and affect in patients recovering from a recent cardiac event. The TMSI (Van Zuuren *et al.*, 1992) was used to measure informational style, but used methodology to divide the sample was not mentioned. Assuming both the monitoring and blunting scales were used, the authors hypothesised that a blunting coping style would be positively, and a monitoring coping style would be negatively associated with wellbeing. Furthermore, they hypothesised that patients' outcome and self-efficacy expectancies (i.e., optimism, sense of control over the outcome) moderated this relationship, i.e., that distress in monitors is more likely to occur under conditions of low outcome expectancy. Similarly, they hypothesised that under the same conditions, patients with a blunting coping style are more likely to do well. The results of this study confirmed their hypotheses and also showed that monitoring was associated with lower wellbeing, but a moderating effect of low outcome expectancy and self-efficacy in monitoring could not be demonstrated. The results of this study provide evidence for a relationship between informational coping style and adjustment.

Similar to earlier mentioned intervention studies by Van Vliet *et al.* (2004), and Devins *et al.*(2003), Petersson *et al.* (2002) examined whether matching the structure and contents of a rehabilitation programme to the informational coping style of patients resulted in improved adjustment and wellbeing. They compared adjustment after a rehabilitation programme (i.e. several sessions including information and education, relaxation training, and CBT) to adjustment after the usual care (basic standard information provision) in a mixed sample of breast, gastrointestinal and cancer patients. The authors expected an interaction effect between informational coping style and group assignment for anxiety, depression and subjective distress after the intervention. Contrary to expectations there were no differences between ‘monitors’ and ‘blunters’ on depression, anxiety or subjective distress (i.e., intrusion, avoidance) before or after the intervention. However, effects emerged between ‘monitors’ and ‘blunters’ when the sample was divided according to cancer site. In the breast cancer group, monitors experienced significantly higher subjective distress in the rehabilitation condition, but ‘blunters’ did not. In contrast, in the prostate cancer group, ‘blunters’ experienced significantly more distress in the rehabilitation programme than in the control condition. Thus, the rehabilitation programme reduced distress in prostate cancer ‘monitors’, but not in breast cancer ‘monitors’, which might be explained by differences in disease specific cancer realities (e.g., time since diagnosis, treatment decision, whether or not patients had already started their treatment). Although not mentioned by the authors, gender may also have been a factor as the prostate cancer sample was all male and the breast cancer sample was all female. The results do not show unequivocal evidence for a relationship between informational coping style and adjustment in this mixed sample of cancer patients. However, when looking more specifically at effects within cancer sites, there seems partial support for the MPM in the prostate cancer group.

Sheehan, Sherman, Lam & Boyages (2007) examined the moderating effect of informational coping style on post decisional regret in women with breast cancer who had undergone mastectomy and reconstructive surgery. Congruent with the theoretical framework of the MPM, they predicted that informational coping style would act as a moderator of the relationship between information satisfaction and post reconstruction distress and regret. More specifically, they predicted that a monitoring coping style would be associated with greater psychological distress and lower satisfaction with preparatory information. Contrary to predictions, the data failed to show the expected relationship between informational coping style and post decision regret. It needs to be mentioned however that only the monitoring scale was used. Furthermore, the data demonstrated a moderating effect of monitoring coping style on the relationship between anxiety and regret. It appeared that when patients experienced relatively low levels of anxiety, there were minimal differences in post decision regret between patients with high and low monitoring coping style. However, as anxiety levels increased, high monitors experienced significantly more decision regret and dissatisfaction with information provision than low monitors. In summary, the data failed to show evidence for a relationship between informational coping style and post decision regret. Furthermore, the data showed partial evidence for a moderating effect of monitoring coping style on the relationship between anxiety and adjustment, but only under conditions of high anxiety, hereby only partially supporting the MPM.

Barnoy, Bar-Tal, & Zisser (2006) examined psychological adjustment to cancer in the context of correspondence in informational coping style between the two marital spouses (i.e., patient and caregiver). The researchers predicted that correspondence in informational coping style between the partners would benefit psychological wellbeing, but that gender and role would affect this relationship. The results of their study demonstrate a gender effect for correspondence in monitoring coping style between patient and caregiver on patient wellbeing and psychological distress; for female high monitoring patients, higher monitoring of her spouse (the caregiver) improved psychological wellbeing and decreased psychological distress, but for male patients, correspondence in monitoring did not affect either. In contrast, the results show beneficial effects of correspondence in blunting coping style between male patient and caregiver (his spouse) on their levels of psychological distress, but this effect could not be replicated for female patients. Thus, male higher blunting patients experienced less distress if their female caregiver was also a 'high blunter'. Furthermore, the results show that correspondence in blunting style benefited wellbeing, regardless of gender. A second interesting but unexpected finding was that higher caregiver's blunting coping style, regardless of gender, was associated with higher psychological distress and lower wellbeing. Consistent with the MPM and findings for patients, Barnoy and colleagues (2006) had expected to find an interaction effect for monitoring in caregivers. They hypothesised that the discrepancy between a blunting coping style and the role of caregiver (i.e. gathering information about the patient's situation, being supplied with information by medical staff etc.) could possibly lead to distress in these caregivers. Summarizing, the results of this study appeared to find evidence for a relationship between informational coping style and adjustment, although there was a gender effect. It was, however, not possible to fully support the MPM based on the inconclusive findings.

Summary

To summarise, ten studies found support for the MPM, four failed to find support for the MPM, and seven studies reported partial support for the MPM.

Based on the results as outlined in Table 1 on page 13, several patterns could be observed in the reviewed literature in relation to demonstrating support for the MPM. First, most support for the MPM was found in studies including only women in their study sample. It may be that the adverse effects of monitoring are stronger in this group. Secondly, it appeared that most support for the MPM was found in cancer research, however this was also the area with the highest proportion of female only samples and has been the most researched area in informational coping style research. Thirdly, the majority of the studies in the context of screening and diagnosis found support for the MPM, whereas in the context of treatment and ongoing disease the results were much more inconsistent. Lastly, it appeared that most support for the MPM was found in studies utilising a correlational design as supposed to intervention studies.

Discussion

Overall, the research evidence shows most support for a relationship between informational coping style and adjustment consistent with the MPM framework (Miller, 1995; Miller, Rodoletz, Schroeder, Mangan & Sedlacek, 1996; Miller, Roussi, Caputo, & Kruus, 1995) when (a) researched within a context of 'short term' threat as in screening and diagnosis, (b) when researched in female only samples, (c) when researched in cancer, and (d) when researched within a correlational design. It needs to be mentioned however that the majority of the reviewed studies focused on cancer, and that a considerable proportion of these studies researched gynaecological cancers, hence included women only. Nonetheless, it might be that the adverse affects of a monitoring style are stronger in women than in men because of their stronger need for self-control and collection of health information, as was suggested by Barnoy *et al.* (2006). It would be interesting to investigate the interaction between informational coping style and adjustment in a predominantly 'male' sample, for example prostate cancer.

With regard to support for the MPM when researched in the context of screening and diagnosis compared to studies researching informational coping style in the context of 'long term' threat or ongoing disease, a few comments can be made. It may be that perception of threat in the 'acute' phases, around the time of diagnosis, are more attributable to informational coping style than other factors compared to when patients have had time to adjust to the reality of a given condition. It may be that once patients have had time to get used to the reality of living with an illness or diagnosis, factors other than informational coping style play a role in adjustment, for example the presence or absence of a support system, relationship with healthcare professionals, or socioeconomic factors.

The majority of the studies included in this review had reasonable sample sizes (range N=51 to N=540), although some caution needs to be taken when interpreting the results of smaller studies, e.g. Christensen *et al.*(1997) and Nordin *et al.* (2002).

A significant proportion of the reviewed literature used a cross-sectional approach (N=9). The disadvantage is that no conclusions can be drawn about causality of this relationship. Hence for some of the studies included in this review it remains unclear what the direction was of the association found. Longitudinal studies such as Andrykowski *et al.* (2002; 2004) allow firmer conclusions to be drawn about the direction of the relationship between informational coping style and adjustment.

Several difficulties came to light when interpreting and comparing the results of the reviewed literature. One difficulty was that different measures were used to measure informational coping style, as well as to measure adjustment/distress. For example, some of the studies used the MBSS, whereas others used the TMSI or MBQ. The TMSI measures coping style in the domain of medical threat, whereas the MBQ and the MBSS measure coping style across a range of situations, of which some may be too far removed from the everyday experience of patients, for example the ‘hostage scenario’ (MBSS; ‘being held hostage by a group of armed terrorists’), hence harder to imagine. Similarly, a range of measures was used to measure distress, with some studies using well validated questionnaires such as the HADS or the IES, whereas other studies using less robust measures like Visual Analogue Scales, or ‘indirect’ measures of behavioural adjustment such as excess fluid intake in renal disease study by Christensen *et al.* (1997). Furthermore, some studies used outcome measures of ‘general’ distress such as the POMS, whereas others used ‘disease specific’ measures such as the IES. Secondly, it became apparent that in only a small proportion of the reviewed literature (N=6) the theoretical framework of the MPM was used, and that these studies were predominantly within the context of screening and diagnosis. Thus, for the remaining studies a scoring system was put in place to assess support for the MPM. However, the subjective nature of this scoring system means that the results could well be analyzed differently by someone else. Thirdly, some studies took a 'uni-dimensional' approach to the monitoring-blunting construct by using a combined monitoring-blunting score, whereas others used these scales separately indicating a 'bi-dimensional' approach. This inconsistency posed a difficulty to compare studies. Although it is beyond the scope of this review, it is important to note that comparison of studies utilizing different methods to classify 'monitors' and 'blunters' makes comparison and contrasting of the results complicated.

Implications for clinical practice

Based on the findings of this review, it can be concluded that moderation of the relationship between monitoring coping style and adverse adjustment or distress in individuals with a real or potentially life threatening medical condition is strongest when it is researched within the context of screening and diagnosis, particularly in cancer. Although some support was found within the context of ongoing disease, these findings were less conclusive. It seems therefore that screening for informational coping style in the initial and 'acute' phases is most beneficial to patients' subsequent adjustment. Attempts to limit distress may be particularly important in the early phases as it can be expected that this distress is more likely to increase than to decrease once treatment begins.

A recommendation that could be made based on these results are for health care professionals to be more aware about individual differences in the preferred amount and nature of medical information when patients are screened for or diagnosed with a potentially life threatening illness. It may be helpful for health care practitioners (GPs, consultants, nursing staff) to identify in the early stages which patients may be prone to high levels of psychological distress. Specific strategies or interventions (e.g., training patients to use self-regulatory skills to manage treatment related anxiety, providing illness specific psycho-education, risk counselling, CBT) can then be implemented promptly in order to help them cope with their psychological distress, or they may be referred on to receive additional services. As such, patients may be better prepared to anticipate and deal with the psychological demands of their disease. This in turn may reduce the negative attentional bias for their health status, allows them to cope more effectively, and prevents interference with treatment adherence and disengagement, resulting in better long term quality of life and adjustment.

Although the strongest support for the MPM was found within the context of (medical) cancer, this is also the field that so far is most researched. There is clearly a need for further prospective longitudinal research in other illnesses to develop effective preventive interventions for those individuals who are most vulnerable to psychological, social, and emotional complications secondary to their illness. Examples may be further research in (chronic) health conditions which are known to affect long term psychological well-being and quality of life, for example diabetes, arthritis, and heart disease.

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Main Paper

Psychological Adjustment and Coping Style in Patients Undergoing Bone Marrow/Stem Cell Transplantation

Word count (exclusive abstract, tables, references): 7,509

Abstract

This longitudinal study aimed to: (1) evaluate psychological distress in patients undergoing Bone Marrow and Stem Cell Transplant (BMT/SCT); (2) examine whether pre-treatment demographic, medical and psychosocial factors predicted post-treatment psychological adjustment; (3) examine to what extent informational coping style (i.e., monitoring, blunting) predicts psychological adjustment, and; (4) explore if informational coping mediates the association between illness perception and psychological adjustment.

Sixty-two participants undergoing BMT/SCT completed questionnaires upon hospital admission, 2 days prior to discharge, 1 week post discharge, and 120 days post-transplant. Adjustment was operationalized as reporting low anxiety, depression, total mood disturbance, fatigue and post-traumatic stress symptoms. Predictor variables were demographic, medical and pre-treatment psychosocial factors, which included illness perceptions and informational coping style.

Depression, anxiety and mood disturbance peaked prior to discharge. During this time 63% reported clinically elevated depressive symptoms. Significant predictors of post-treatment adjustment included lower distress at admission, a blunting coping style, and illness attributions (e.g., perceiving psychological factors as a cause of illness). Informational coping style did not mediate the association between illness perceptions and adjustment.

It is possible to predict post-treatment adjustment on the basis of pre-BMT/SCT levels, patients’ preferential coping style, and specific illness attributions. Offering patients a pre-treatment intervention focusing on these factors may help reduce post-treatment distress.

Glossary of abbreviations and terms related to BMT/SCT

ALL	Acute Lymphoid Leukaemia
Allogenic	Transplant whereby the patient receives stem cells from a different individual; this can be a matched unrelated donor or a family member, usually a sibling. Also termed ‘allograft’
AML	Acute Myeloid Leukaemia
Autologous	Transplant whereby the patients’ own stem cells are first harvested and transplanted back later. Also termed ‘autograft’.
BMT	Bone Marrow Transplantation
CLL	Chronic Lymphoid Leukaemia
CML	Chronic Myeloid Leukaemia
COREC	Regional Ethics Committee
HADS-A	Hospital Anxiety and Depression Scale–Anxiety subscale
HADS-D	Hospital Anxiety and Depression Scale–Depression subscale
IES-R	Impact of Event Scale-Revised
IPQ-R	Illness Perception Questionnaire-Revised
POMS-SF	Profile of Mood States – Short form
POMS-TMD	Profile of Mood States – Total Mood disturbance
R&D	Research and Development
Remission	Term used to describe the shrinkage of the cancer. *Complete remission* means the cancer can no longer be detected in tests, scans or x-rays. *Partial remission* is used to categorize cancer that has shrunk but is still present. In this case there is a higher chance the cancer may relapse or return.
SCT	Stem Cell Transplantation
SPSS	Statistical Package for the Social Sciences
T1	Time 1, day of admission
T2	Time 2; 0-2 days prior to discharge
T3	Time 3; 1 week post discharge
T4	Time 4; 120 days post-transplant
TMSI	Threatening Medical Situations Inventory
Transplant related mortality	chance the patients dies within 3 months post-transplant

Introduction

In parallel with the development of better cancer treatments, remission and survival rates have increased over the past decade. As a result, more investments are made in research that focuses on psychological adjustment and quality of life during and after treatment. Bone Marrow Transplantation (BMT) and, as a more recent development, Stem Cell Transplantation (SCT), represent one of the most important innovative curative strategies in haematological malignancies. These treatments are the only curative options in many leukaemias and lymphomas. SCT/BMT is combined with the delivery of high doses of chemotherapy and radiotherapy and is therefore a very intensive treatment, during which the patient may feel very ill and requires prolonged hospitalization. Understandably, SCT/BMT may cause psychological distress and patients often experience intense worries regarding the outcome and their future (Trask *et al.*, 2002).

Distress and BMT/SCT

It is reported that in mixed oncology populations up to 50% of patients experience clinical levels of emotional distress (Baker, Marcellus, Zabora, Polland, & Jody, 1997; Zabora, BrintzenhofeScoc, Curbow, Hooker & Piantadosi, 2001; Spiegel, 1996), and this number can be expected to be even higher for BMT patients because of the nature of the treatment (e.g., isolation, fear of transplant failure, intense treatment regimen) (Ho, Horne, & Szer, 2002). There is no reason to believe that the situation is any different with SCT which has largely supplemented more traditional BMT treatment (Craddock, 2006, personal communication).

Research concerning psychological distress in the BMT population has mostly focused on the post-treatment period, and studies examining psychological functioning *prior* to BMT are relatively sparse (Trask *et al.*, 2002; Neitzert *et al.*, 1998; Fife *et al.*, 2000; Colon, Callies, Popkin, & Mcglave, 2001). As Fife *et al.* (2000) pointed out, the earliest phases of BMT, including the pre-BMT period, are crucial to understanding problems of long-term adjustment. For example, studies have linked pre-transplant psychological functioning with post-transplant emotional and physical recovery (Trask *et al.*., 2002; Fife *et al.*, 2000; Colon, Callies, & Popkin, 1991), and even survival (Prieto *et al.*, 2005).

The limited number of studies that investigated distress prior to BMT, have shown high levels of depression and anxiety during the pre-transplant phase (Siston *et al.*, 2001; Fife *et al.*, 2000; Sherman, Simonton, Latif, Spohn, & Tricot, 2004). It seems probable that once the aggressive BMT/SCT treatment is initiated, these symptoms are more likely to increase than to decrease. Considering the potentially predictive value of pre-treatment distress for subsequent adjustment, and the lack of knowledge about how this distress compares to other phases (during, or post treatment), further research in this area is clearly warranted. Such research may help inform psychological interventions by, for example, identifying which patients, and during what phases of treatment, are most vulnerable to psychological morbidity, and identifying what types of interventions are most beneficial during particular phases of BMT/SCT treatment (Rodrigue, Boggs, Weiner & Behen, 1993).

Identification of psychological distress in BMT patients

On most bone marrow transplant units an informal assessment of psychological distress is performed by cancer specialist medical and nursing staff with no specific psychological training. When staff are under the impression that the patient is not coping well, a referral may be made to a clinical psychologist or psychiatrist for psychological assessment and intervention. It is clear from the literature, however, that often psychological distress is not identified and goes untreated (Ryan *et al.*, 2005; Fritsche, Struss, Hammel, Bertz, & Stein, 2004; Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Newell, Sanson-Fisher, Girgis, & Bonaventura 1998). For example, Fallowfield *et al.* (2001) conducted a large scale study in 2297 cancer patients which investigated the ability of oncologists to identify psychological distress in their patients. The results showed that only 29% of patients with clinically significant psychological distress were correctly identified. Moreover, Trask *et al.* (2002) not only found that care staff systematically underestimated the levels of emotional distress, but also that ratings primarily reflected patient anxiety; other aspects of distress, such as depression, anger, frustration and loneliness, were often not identified (Trask *et al.*, 2002). Thus, care staff ratings of patient distress lack both sensitivity and specificity. In spite of these empirical findings, and in spite of the high levels of distress in BMT patients and the importance of pre-BMT distress for post-BMT adjustment, pre-BMT screening for psychological distress is often not a standard element of the admission process.

Distress and informational coping style

Evidence has shown that preparation for invasive treatment in patients undergoing surgery has positive long term effects on emotional (less anxiety and depression) and physical recovery (shorter duration of hospital stay and less pain medication) (Horne, Vatmanidis and Careri, 1994; Ludwick-Rosenthal & Neufeld, 1993; Mott, 1999). One type of preparative intervention that is very common to many medical treatments, including in BMT/SCT treatment, is information provision (Petersson *et al.*, 2002). This intervention typically involves providing patients and carers with booklets, a pre-treatment ward visit, and opportunities to ask the consultant or specialist nurse any details pertinent to the treatment. Most patients are dependent on their nurses or oncologists for this information, who, as indicated earlier, may be less well trained to identify elevated distress in these patients.

A related problem is that the type of information and level of detail that is best for patient well-being in the long term may not be the same for each patient. Indeed, information is often provided in a "one-size-fits-all fashion", whereby it is often overlooked that there are large individual differences in the preferred amount and nature of medical information (Miller, 1995). Hence, it is possible that standard information provision may not help all patients equally well to cope with the impeding treatment, for example when the information is perceived as too detailed or, rather, not enough.

Which patient factors influence satisfaction with informational preparation? Literature suggests that there are stable individual differences in how patients deal with medically threatening information, which, in turn, may help these patients cope with the impeding treatments (Miller, 1995; Fallowfield, 1995; Steptoe 1991). Coping is conceptualized as 'personal cognitive or behavioural strategies to master, reduce or tolerate a stressful situation' (Folkman & Lazarus, 1984). Folkman and Lazarus were amongst the first coping theorists to make the distinction between 'emotion focused coping' (in which the focus is on managing the emotions arising from exposure to the stressful situation) and 'problem focused coping' (in which the focus is on managing or altering the problem causing the distress) (Folkman and Lazarus, 1984). Other theorists have added a third dimension, namely 'avoidance focused coping' (Endler & Parker, 1993) or related two-dimensional conceptualizations, such as 'engagement versus disengagement' and 'approach versus avoidance' (Tobin, Holroyd, Reynolds, & Wigal, 1989; Krohne, 1996; Endler & Parker, 1994).

Miller (1987) has reported two coping styles which reflect the individual's tendency to either actively seek ('monitor') or avoid ('blunt') potentially stressful health-related information. *Monitoring* involves the extent to which an individual has an attentional bias for information regarding the negative, potentially painful or dangerous, aspects of the medical situation. *Blunting* involves the extent to which an individual distracts themselves from such threatening information. Thus, whether someone is relieved or distressed by certain information is dependent on their informational coping style. Several researchers have therefore emphasized the need to tailor patient communications to these individual coping styles (Miller, 1995; Ong *et al.*, 1999). Generally speaking, patients with a monitoring coping style will do better (show less psychological distress) when given more information, and patients with a blunting style do better with less information. Overall, blunting is associated with less anxiety than monitoring in cancer patients (Petersson *et al.*, 2002).

Coping behaviours in medically threatening situations are partly determined by the illness perceptions of the patient (Haggar & Orbell, 2003). Although not previously studied, this may also hold true for informational coping style. Illness perceptions can be described as cognitive representations, or beliefs, that people have about their illness (Leventhal, Benyamini, & Brownlee, 1997). The 'Common Sense Model' (CSM) of illness hypothesises that individuals create such mental representations of their illness based on the sources of information available to them in order to cope with (i.e., make sense of and manage) the problem (Bishop and Converse, 1986). As information seeking (or avoidance) is an important aspect of coping behaviour in patients, for example to reduce uncertainty (Fallowfield, Ford & Lewis, 1995), it may be assumed that illness representations will partly guide these coping behaviours. Thus, a major tenet of the CSM is that a causal relationship exists between illness cognitions and psychological adjustment that is moderated by coping. For example, individuals who believe that their behaviours can influence the treatment outcome may have stronger information needs than individuals who lack such beliefs. As shown in previous research, a strong information preference may in turn be related to worse post-treatment adjustment (i.e., more distress) (Miller, 1995). Such moderation could thus explain the associations between illness representations and adjustment in medical conditions (Moss-Morris *et al.*, 2002).

Aims

To summarise, BMT/SCT patients are known to experience considerable levels of distress prior to and during their transplant. Importantly, this distress may be influenced by their need for information provision. Furthermore, patients' beliefs regarding their illness may shape such informational coping styles, and hereby contribute to the development or maintenance of distress. In the light of the preceding discussion, four aims were formulated for the current study.

1. To evaluate the psychological adjustment in patients over the course of BMT/SCT treatment. Assessment of adjustment included anxiety, depression, overall negative mood, post-traumatic stress symptoms, and fatigue. Fatigue was included as it is one of the most common and distressing symptoms reported post-BMT (Neitzert *et al.*, 1998).
2. To examine which pre-treatment demographic, medical and psychosocial factors predicted adjustment after the BMT/SCT.
3. To examine whether patients with a ‘monitoring’ coping style experienced higher distress levels before and after the BMT/SCT treatment than patients with a ‘blunting’ coping style.
4. To explore a possible mediation of informational coping (monitoring, blunting) in the association between illness perception and psychological adjustment.

Method

Participants

From May 2007 until January 2008, 114 patients were admitted on the Bone Marrow Transplant Unit of a UK University Hospital; 44 for allogenic transplant (patient receiving stem cells from a donor) and 70 for autologous Stem Cell Transplant (patient uses their own stem cells). Inclusion criteria were (a) being a potential transplant candidate, (b) being over 18 years of age, (c) no previous transplant and (d) fluency in the English language.

At admission (Time 1, T1) the sample consisted of 62 participants (38 males) ranging in age from 19 to 70 years (M=48.6, S.D.=14.4). This reflected a response rate of 82%. (Please see Figure 1 for a schematic outline of the recruitment process). Further medical and demographic characteristics of the sample can be found in Table 1.

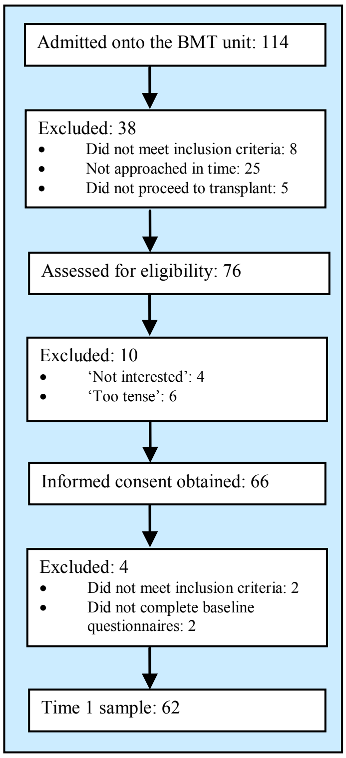

Figure 1. Recruitment at Time 1 (T1)

Table 1.

Demographic and Medical data of the Participants

	N	(%)
Type of transplant		
Allograft	33	53.2
Autograft	29	46.8
Diagnosis		
Leukemia (ALL, CLL, AML, CML)	24	38.7
Lymphoma (Hodgkins, non Hodgkins)	15	24.2
Myeloma	13	21
Multiple Myeloma	3	4.8
Myelodysplastic syndrome	6	9.7
Other	1	1.6
Medical status [1]		
In full remission	21	33.9
Part remission	9	14.5
Other (relapse, chronic disease, progressive disease)	32	51.6
Ethnic Background		
White	56	90.3
Asian Indian	2	3.2
Black British	2	3.2
Black Caribbean	2	3.2
Sex		
Male	38	61.3
Female	24	48.7
Marital status		
Married/cohabiting	44	71.0
Divorced/single/widowed	18	29.0
Education		
No diploma	1	1.6
Secondary school	42	67.7
Undergraduate	14	22.6
Graduate	5	8.1

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[1] [1] In order to achieve the highest transplant success rate (i.e., lowest chance of relapse after the transplant), ‘in remission’ status is desirable in patients. Usually, patients are treated with an intense chemotherapy regimen (‘remission induction’), in the 6 months before transplant. Although after this treatment the patient may not have any clinical symptoms anymore, it is very unlikely that all the cancer cells have been destroyed by the induction therapy. Sometimes, more than one course of induction therapy is needed to bring the cancer in remission. When the highest possible remission rate is achieved, the patient moves on to ‘consolidation therapy’ (the BMT/SCT treatment) to prevent the cancer from coming back (Cancer Research UK, 2008).

Procedure

Ethics and operational approval. In preparation of the study, the study design and practicalities of the data collection were discussed with the director of the Blood and Marrow Transplant Unit and two BMT coordinator nurses responsible for transplant scheduling. The BMT nurses informed the researcher regarding time and number of admissions. Ethics approval was gained from a Regional Ethics Committee (COREC) and the Research and Development department of the University Hospital. For a full account of the ethics process of this study and correspondence between the author and both R&D and Local Ethics Board, please see Appendix 14.

Recruitment procedures. Transplant patients were approached about the study on the day of admission to the ward. During this visit the researcher explained the study and offered the opportunity to ask questions. If the patient was interested, a research pack containing patient information sheet (Appendix 11), consent form (Appendix 10), and questionnaires was left with the patient until the following day when the researcher visited again. If the patient was willing to participate, informed consent was obtained and the patient completed the questionnaires before the onset of treatment (T1). Consent forms, demographic forms and questionnaires were separated immediately after consent was obtained to ensure that participation was anonymous as patient demographic information could only be linked to questionnaire data by study number on the demographic form. A letter (Appendix 13) was sent to the participant's GP informing them about enrolment in the study. For T2 data collection, scheduled shortly before discharge from hospital, the researcher visited the ward. For T3 data collection, one week post discharge in the outpatient clinic, the BMT coordinator nurses handed out the questionnaires. T4 data collection was scheduled 120 days after the transplant when questionnaires were posted to the participant's home address. Figure 2 shows the loss to follow up from T1 to T4. The sample of participants for whom data was collected at all four time points was 27 (44%).

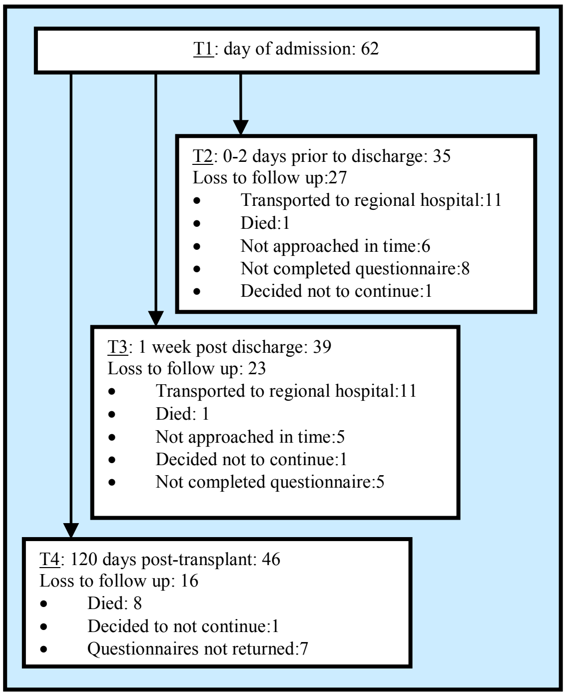

Figure 2. **Attrition rates at T2 to T4**

Measures

Figure 3 provides an outline of the study, indicating which measures were taken at the different time points of the study. A description of the measures is provided in the next sections.

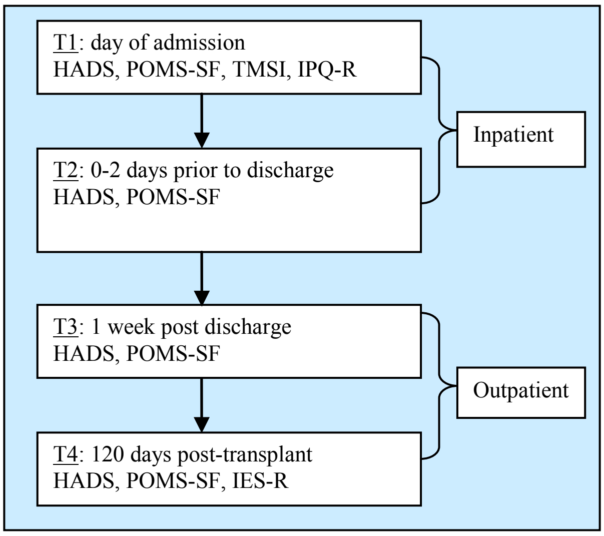

Figure 3. **Outline of the study**

Demographic information: At T1, patients were asked to complete a demographic information sheet (Appendix 9). This sheet included information on age, gender, ethnic group, marital status, diagnosis, educational level, medical status and type of transplant.

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983): The HADS (Appendix 4) was used to measure patients' level of psychological distress. It is a self-report questionnaire designed to ask non-psychiatric hospital patients about their depressive and anxiety symptoms in the past week. The scale consists of 14 items; 7 items for anxiety (HADS-A) and 7 for depression (HADS-D). The items are scored on a four-point scale from zero (not present) to three (considerable). The item scores are added, giving sub-scale scores on the HADS-A and the HADS-D from zero to 21. Both scales can be scored independently. A score of 8 or above on individual subscales is considered to indicate clinically significant depression or anxiety. Total scores between 0-7 are considered 'normal', scores between 8-10 are considered mild, scores between 11 and 14 are considered moderate and scores over 15 are considered severe. The psychometric properties of the HADS are considered good; the reliability of the HADS anxiety scale is >.83 and the HADS depression scale is > .82 (Lloyd-Williams, Friedman, & Rudd, 2001; Skarstein, Aas, Fossa, Skovlund, & Dahl, 2000; Osborne, Elsworth, Sprangers, Oort, & Hopper, 2004; Bjelland, Dahl., Haug, & Neckelmann, 2002; Lampic, Thurfjell, Carlsson, & Sjoden, 2002), the construct and criterion validity were supported through numerous studies (Bjelland *et al.*, 2002, Lampic *et al.*, 2002). The HADS was administered at T1, T2, T3 and T4. The test-retest reliability of the HADS-D is .86, and the test-retest reliability of the HADS-A is .89 (Spinhoven *et al.*, 1997). The retest correlations found in the current study can be derived from Table 2 and Table 3.

The Profile of Mood States (POMS-SF; Shacham, 1983): The POMS-SF (Appendix 5) was used to measure mood disturbance, or symptoms of psychological distress. The POMS-SF is a 37-item self-report questionnaire that assesses a series of mood states (such as "bewildered" or "hopeless"). It takes an average of 5 minutes to complete and is therefore suitable for a severely ill population. The respondent rates each item based on how well it describes their mood during the past week, including today. The items are rated on a 5-point scale ranging from “Not at all” to “Extremely”. The POMS-SF measures six identified mood factors; ‘Tension-Anxiety’, ‘Depression-Dejection’, ‘Anger-Hostility’, ‘Vigour-Activity’, ‘Fatigue-Inertia’, and ‘Confusion-Bewilderment’, for which subscale scores can be obtained. A seventh score of Total Mood Disturbance can also be calculated by subtracting the score on the one positively scored subscale, ‘Vigour–Activity’, from the sum of the other five subscales. Cronbach’s alphas range between .76 and .95 for the subscales in POMS-SF. For the total score, the range is between .87 and .92 (McNair, Lorr, & Droppleman, 1992). The POMS-SF was administered at T1, T2, T3 and T4. The test-retest reliability of the POMS-SF is not included in published validation studies; being a state-measure retest-coefficients are supposed to be low. The re-test correlations for the total mood disturbances in the current study can be derived from Table 4.

Threatening Medical Situations Inventory (TMSI; Van Zuuren, de Groot, Mulder, & Muris, 1996): The TMSI (Appendix 6) is a self-report questionnaire which assesses monitoring and blunting styles in the domain of medical threat. The inventory provides the respondent with four hypothetical medical scenarios that each differ in their predictability and controllability. Each scenario is followed by three monitoring and three blunting alternatives, in random order, to be answered on five-point scales (1 = ‘Not at all applicable to me’ to 5 = ‘Strongly applicable to me’). Total monitoring and blunting scores are obtained by summing up the relevant items. The range for both the monitoring and the blunting scales is between 12 and 60. The TMSI has acceptable reliability (Van Zuuren *et al.*, 1996) and shows good correlations with monitoring and blunting dimensions of Miller’s (1987) Behavioral Style Survey (MBSS; Muris, Van Zuuren & de Vries, 1994). Cronbach’s Alpha reliability analyses showed a coefficient of 0.82 for both monitoring and blunting, which was replicated in the current study (Monitoring $\alpha = .87$; Blunting $\alpha = .77$). The TMSI was administered at T1.

Illness Perception Questionnaire-Revised (IPQ-Revised; Moss-Morris et al., 2002): The IPQ-R (Appendix 8) was used assess patients' cognitive and emotional representations of illness based on Leventhal's Common-Sense Model of Illness Representation. The IPQ-R is a self report questionnaire which takes about 10 minutes to complete. The IPQ-R is divided into three separate sections. The first section is the 'identity' scale, which consists of 14 items. Respondents indicate whether they have experienced each symptom on a yes/no scale and whether they believe this symptom is related to their illness in any way on a yes/no scale. The second section has 38 items. Participants are asked to rate their views on their illness on the dimensions 'consequences', 'timeline acute/chronic', 'timeline cyclical', 'coherence' and 'emotional' on a 5 point Likert scale from 1 'strongly disagree' to 5' strongly agree'. The third section has 18 items and asks participants to indicate on a 5 point Likert scale whether they think a certain cause has something to do with their illness e.g. 'overwork', or 'stress or worry'. High scores on the identity, timeline, consequences, and cyclical dimensions represent strongly held beliefs about the number of symptoms patients believe to be related to the illness ('identity'), the duration of the illness ('timeline-chronic'), the consequences of the illness ('negative consequences'), and whether the illness is sustained or cyclical ('timeline-cyclical'). High scores on the personal control, treatment control and coherence dimensions represent positive beliefs about the controllability of the illness and a coherent personal understanding of the condition. Subscale 'emotional representations' relates to the emotional impact of the illness. Moss-Morris *et al.* (2002) demonstrated good structural validity as well as good internal reliability for all the subscales, Cronbach's Alphas ranging from .79 to .89. The test demonstrated also good stability over time, with correlations between .46 and .88 depending on time. The IPQ-R was administered at T1.

Impact of Events Scale - Revised (IES-R; Weiss & Marmar, 1997): The IES-R (Appendix 7) is a 22-item self-report measure to assess current subjective distress with regard to a particular life event. The IES-R was adapted from the original 15-item IES (Horowitz, Wilner, & Alvarez, 1979), which intended to measure PTSD symptoms intrusion and avoidance. The IES-R has three subscales, ‘intrusion’, ‘avoidance’ and ‘hyper-arousal’. The respondent rates their experience in the past seven days on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). Both individual subscale scores and a total IES-R score can be calculated. The IES-R is considered reliable; Crohnbach’s Alpha for the intrusion subscale ranged from .87 to .92, for the avoidance subscale ranged from .84 to .86, and for hyper-arousal subscale ranged from .79 to .90 (Briere, 1997). The IES-R was administered at T4.

Study design and power analysis

The overall design was a longitudinal, repeated measures design (see Figure 3 page 50). Power calculations showed that with a sample size of 62 participants at baseline and 30 participants at subsequent time points any effect above 0.63 standard deviations can be observed with statistical significance and 80% power, assuming a type 1 error rate of 0.05 in t-test and linear regression analyses.

Data analysis

To evaluate the presence of psychological distress in patients at T1 compared to T2, T3, T4 and normative data, paired samples t-tests were conducted. In addition, Pearson correlation coefficients were used to investigate the effect of gender, age, marital status, ethnic background, education level, type of transplant (allogenic, autologous), psychological state at entry and illness attributions on the psychological outcome measures. Only variables that associated significantly with the psychological outcome variables were entered into a regression analysis to examine which pre-treatment psychosocial factors predicted the psychological outcome measures. Finally, a mediational analysis using regression coefficients (please see Figure 4, page 55) was conducted to explore a possible mediation of informational coping (monitoring, blunting) in the association between illness perception and psychological adjustment. SPSS 15.01 (SPSS Inc., Chicago, IL, USA) was used to analyze the data.

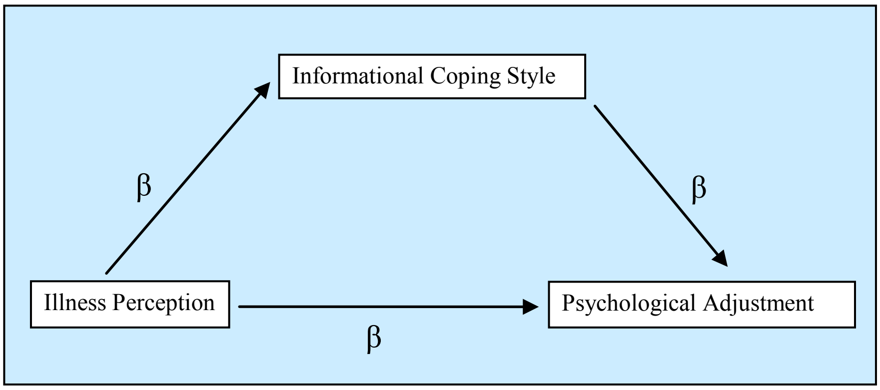

Figure 4. Diagram of meditational model testing the effects of illness perceptions and informational coping style on psychological adjustment. To establish mediation, it is necessary to demonstrate 1) the independent variable (illness perception) must be associated with the dependent variable (distress); 2) the independent variable must be associated with the mediator (informational coping style); 3) the selected mediator is associated with the dependent variable; and 4) the association between the independent and the dependent variable diminishes after accounting for the mediator.

Results

Analyses of Attrition

A first series of analyses tested for selective attrition between admission (T1) and 120-day follow-up. Analyses showed that patients who were lost to follow-up (N=16) did not significantly differ on demographic variables (age, gender, marital status), medical variables (autologous/allogenic), and psychological variables (T1 HADS-D, HADS-A, POMS-TMD, POMS-fatigue, TMSI scores) (all analyses p>.05, using t-tests or χ^2 tests).

Psychological adjustment over the course of BMT/SCT treatment

Subsequent analyses aimed to establish the dynamics of psychological distress over the course of BMT/SCT treatment. As shown in Figure 5a, HADS-depression (HADS-D) scores increased significantly between T1 (admission) and T2 (0-2 days pre-discharge). HADS-D scores subsequently declined although they were still significantly elevated at T4 (120-days post-transplant) as compared to admission (See Figure 5a). The proportion of patients that scored above the clinical threshold (HADS-D ≥ 8) varied between 19.4% at admission, 62.9% at its peak at T2, and 22.6% at T4. These values were consistently higher than found in the general population (11.4%; Crawford, Henry, Crombie & Taylor, 2001). The proportion of patients that could be classified as 'moderate' to 'severe' on the HADS-D (cut-off ≥ 11) was 9.7% at T1 and 34.2% at T2 (the norm value in the general population is 3.6%; Crawford, Henry, Crombie & Taylor, 2001).

As shown in Figure 5b, the highest scores on the HADS-Anxiety (HADS-A) were reported during the hospital stay (T1 and T2). The proportion of patients that scored above the clinical threshold at those times were 32.3% and 28.6%, respectively. At T4 this proportion was 17.4%. Remarkably, these proportions are substantially lower than found in a UK non-clinical sample (33.2% - 1792 members of the general adult population; Crawford, Henry, Crombie & Taylor, 2001).

However, compared to other published research (Dahl et al., 2005) utilising a non-clinical Norwegian population (N=62,644; prevalence 13.5%) the found proportions are substantially higher.

As shown as in Figure 5c, the pattern for total mood disturbance (POMS-TMD) was comparable to that of HADS-D, showing a significant increase from T1 to T2, and from T1 to T3. No clinical cut-offs or norm data are available for the POMS-SF. As can be observed in Figure 5d, POMS subscale fatigue (POMS-fatigue) exhibited pattern unlike the other measures, showing an increase at T2, T3, and T4 in comparison to T1, with no signs of recovery.

Predictors of psychological distress and adjustment

Consistent with the second aim of this study, a next series of analyses was conducted to identify pre-treatment variables that may predict individual differences in psychological adjustment over the course of BMT/SCT treatment. Tables 2, 3, 4, 5 and 6 present the correlations between demographic, medical and pre-treatment psychosocial variables and psychological distress (HADS-A, HADS-D, POMS-TMD, IES-R, and POMS-fatigue) at the 4 time points (IES-R was administered at T4 only) An overview of the main findings presented in these tables will be set out below.

Demographic and Medical variables. At T1 men showed significantly higher scores on HADS-D (t= 2.24, df= 60, p<.05). No other gender differences were observed. Furthermore, analyses showed a borderline significant association between marital status (married/cohabiting vs. single) and POMS-fatigue at T4 (t=1.91, df= 44, p=.06). No associations were found with other demographic or medical variables (type of transplant).

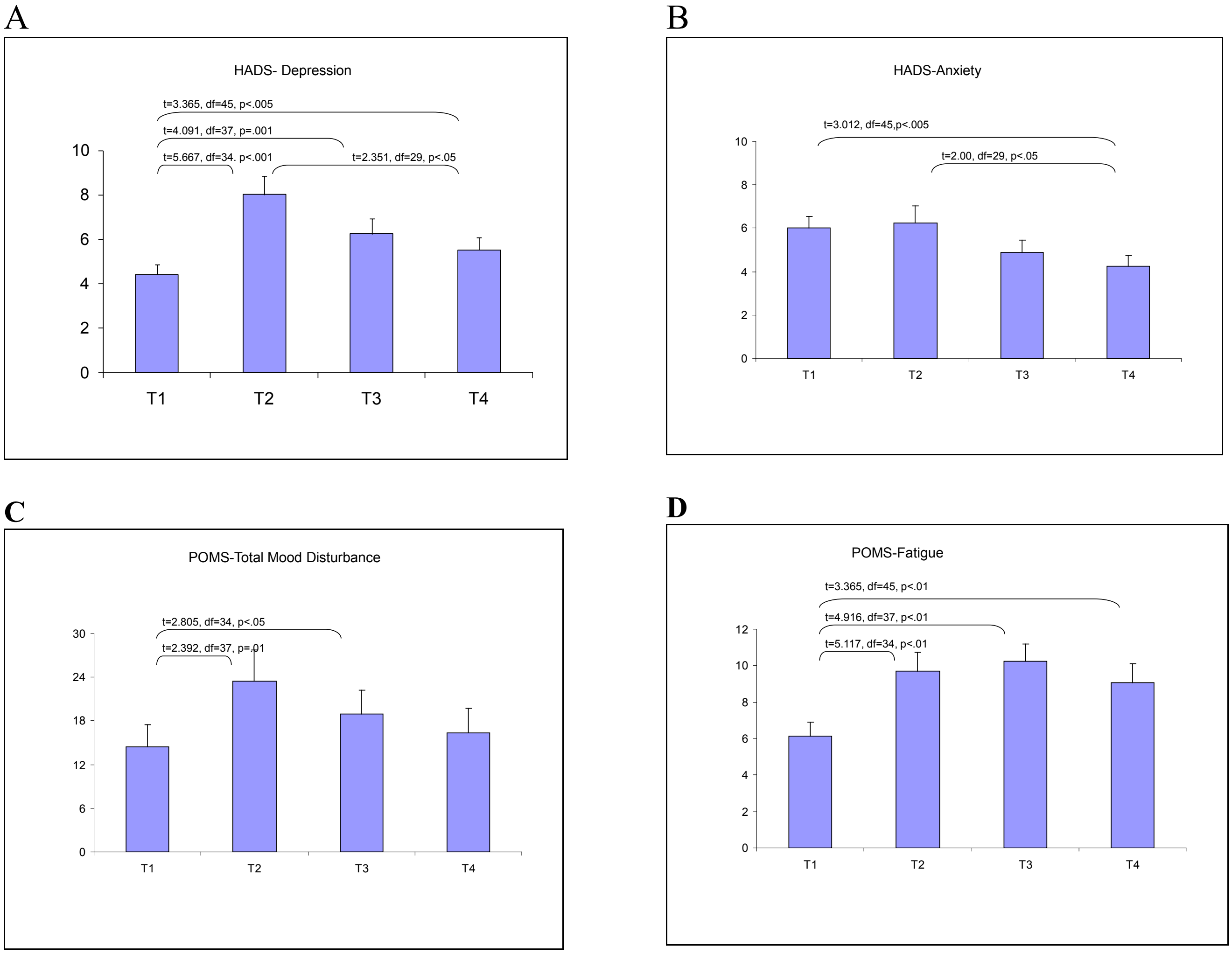

Figure 5 Psychological distress at admission (T1), before discharge (T2), 1 week post discharge (T3) and 120 days post transplant (T4).Bars indicate mean, vertical lines indicate S.E. Mean. P-values reflect results of paired t- tests (2-sided)

Illness perceptions. As shown in Tables 2 to 6, illness perceptions (IPQ-R) showed consistent associations with distress outcomes, in particular at T1 and T4. Associations were found with the IPQ-R subscales ‘emotional representations’ (the impact of illness on emotional well-being), ‘illness coherence’ (extent to which the patient understands the illness), and ‘psychological causal attributions’ (the extent to which patients believe psychological factors, like stress and worry, are potential causes of their illness). Partial correlation analyses revealed that these associations between illness perceptions and distress remained significant after correction for age and gender (please see Appendix 15, page 57 for an overview).

Psychological state at admission. As can be seen in Tables 2 to 6, psychological state at admission (HADS-D, HADS-A, POMS-TMD and POMS-SF subscales) appeared to be a strong predictor of distress at subsequent time points, with most correlations ranging between .40 and .60. The only exception was HADS-D at T3, which was not predicted by initial levels of distress (see Table 2). Psychological state at admission also predicted post-traumatic stress symptoms (i.e., intrusions, avoidance behaviours and hyper-vigilance) at T4. Partial correlation analyses revealed that these associations remained significant after correction for age and gender (please see Appendix 15, page 57 for an overview).

Informational coping style as a predictor of psychological adjustment.

The third aim of the current study was to determine if informational coping style predicted psychological adjustment. Scores on the TMSI monitoring and blunting scale, as well as the difference score of these scales (monitoring score minus blunting score) were used as independent variables and correlated with distress and fatigue measures at the 4 time points. As can be seen in Tables 2 to 5, monitoring was not a significant predictor of distress, whereas a modest positive association was found between blunting and anxiety at T1 and T4. The latter finding indicates that a blunting coping style was associated with lower reported anxiety at these time points. However, consistent positive associations (with 6 out of 16 tested correlations reaching statistical significance) were found between the monitoring-blunting difference and measures of distress. These findings indicate that patients who displayed a stronger tendency to monitoring than to blunting reported higher levels of distress at T1 and T4. As with previous analyses, these associations remained unaltered after controlling for age and gender.

To further scrutinize the finding that informational coping style predicted HADS-A and POMS-TMD at T1 and T4, Hierarchical Linear Regression analyses were performed to determine to what extent informational coping style was an independent predictor. In this analysis the variables that predicted anxiety and POMS-TMD at T1 and at T4 (derived from Table 3 and Table 4, respectively) were entered first in one block. These parameters were: age, gender, illness representations and attributions (if significantly correlated with dependent variables), and anxiety or TMD at T1. In a subsequent step informational coping style (i.e., monitoring score, blunting score or difference score) was entered, and the incremental variance explained (R^2-change) determined. The results demonstrated that none of the informational coping measures predicted any of the distress outcomes (anxiety, depression, POMS-MD, IES subscales) at T1 or at T4 after correcting for illness representations and attributions; for all analyses the R^2-change was <.04 (F(1,56) <2.8, p>.09).

Does informational coping style mediate the association between illness perceptions and adjustment?

For mediation (Barron & Kenny, 1986) it is necessary to show that; 1) the independent variable (illness perception) must be associated with the dependent variable (distress); 2) the independent variable must be associated with the mediator (informational coping style); 3) the selected mediator is associated with the dependent variable; and 4) the association between the independent and the dependent variable diminishes after accounting for the mediator. The correlation analyses presented in Tables 2 to Table 6 satisfied criteria 1 and 3, as both the illness perceptions and informational coping style (the putative mediator) predicted measures of distress, in particular HADS-A and POMS-TMD (note: linear regression analyses, replacing Pearson's r by standardized regression coefficient β, gave identical results). With regard to criterion 2, regression analysis yielded only 2 significant associations between IPQ-R and TMSI; 'personal control' was significantly associated with monitoring (β=.28, $F_{(1,59)}$ =4.91, p<.05), while emotional illness representations was associated with the TMSI difference score (β=.30, $F_{(1,59)}$ =5.95, p<.05). These findings indicate only weak support for criterion 2, and therefore no further analyses were performed to test criterion 4.

Table 2.
Associations between HADS-D at T1 to T4 with demographic, medical and psychological factors at T1. Values represent Pearson's correlation coefficients

	HADS-D			
	T1(N=62)	**T2(N=35)**	**T3(N=39)**	**T4(N=46)**
Demographic variables				
Age	.13	–.03	.04	.09
Sex [a]	**-.33***	-.20	-.12	**-.29***
Marital status [a]	.10	–.03	–.01	.14
Education [a]	–.17	–.18	–.09	–.20
Ethnicity [a]	.13	.21	.28	.07
Transplant type				
Transplant (autologous, allogenic) [a]	–.17	–.00	–.03	–.23
Illness attributions (IPQ-R)				
illness representation: timeline (acute, chronic)	.21	–.17	–.17	.26
illness representation: timeline (cyclical)	**.30***	.10	.20	**.34***
illness representation: consequences	**.30***	.12	.18	.27
illness representation: personal control	–.09	.03	.21	.05
illness representation: treatment control	**–.31***	–.12	–.15	**–.32***
illness representation: illness coherence	**–.35****	–.16	–.28	–.22
illness representation: emotional representations	**.53****	**.35***	–.04	**.32***
causal attributions: psychological	**.34****	.14	–.12	**.38***
causal attributions: risk factors	**.31***	–.03	.13	**.32***
causal attributions: immunity	.16	.11	**.39***	**.33***
causal attributions: accident or chance	**.26***	–.12	–.04	.24
Psychological state at entry (T1)				
HADS-Depression time 1	---	**.58****	**.37***	**.64****
HADS-Anxiety time 1	**–.68****	**.48****	.13	**.63****
POMS TMD time 1	**.74****	**.57****	.31	**.52****
POMS Depression time 1	**.70****	**.59****	.27	**.43****
POMS Anger time 1	**.58***	**.57****	.09	**.37***
POMS Tension time 1	**.59***	**.41***	.17	**.34***
POMS Confusion time 1	**.63***	**.51****	.30	**.39****
POMS Fatigue time 1	**.41***	**.52****	.28	**.31***
POMS Vigour time 1	**–.48***	–.24	–.30	**–.56****
Informational coping style(TMSI)				
Monitoring	.16	.22	.11	.26
Blunting	–.23	–.05	–.09	–.01
Monitoring minus Blunting	**.29***	.24	.14	.24

* p<.05 (2- tailed)
** p≤.01 (2- tailed)
[a] Spearman correlation coefficient was computed for these variables

Table 3.

Associations between HADS-A at T1 to T4with demographic, medical and psychological factors at T1. Values represent Pearson's correlation coefficients

	HADS-A			
	T1(N=62)	**T2(N=35)**	**T3(N=39)**	**T4(N=46)**
Demographic variables				
Age	.03	–.05	–.20	–.12
Sex [a]	–.13	.01	–.20	–.20
Marital status [a]	.00	.00	.16	.19
Education [a]	–.05	–.28	–.17	.04
Ethnicity [a]	–.13	.10	.31	.16
Transplant type				
Transplant (autologous, allogenic) [a]	–.10	–.04	–.24	–.09
Illness attributions (IPQ-R)				
illness representation: timeline (acute, chronic)	.25	–.08	–.06	.02
illness representation: timeline (cyclical)	.15	.09	.28	.25
illness representation: consequences	**.31***	.25	.03	.27
illness representation: personal control	.01	.02	.30	.26
illness representation: treatment control	–.26	–.07	–.10	–.11
illness representation: illness coherence	**–.31***	–.18	–.31	–.21
illness representation: emotional representations	**.71****	**.53****	.23	**.36***
causal attributions: psychological	**.50****	.30	**.36***	**.34****
causal attributions: risk factors	.22	–.13	.22	**.31***
causal attributions: immunity	.24	.16	.28	**.49****
causal attributions: accident or chance	.17	–.05	–.08	.12
Psychological state at entry (T1)				
HADS-Depression time 1	**.68****	**.59****	**.39***	**.49****
HADS-Anxiety time 1	---	**.72****	**.43****	**.63****
POMS TMD time 1	**.79****	**.58****	**.52****	**.50****
POMS Depression time 1	**.77****	**.55****	**.42***	**.46****
POMS Anger time 1	**.68****	**.63****	**.35***	**.41****
POMS Tension time 1	**.73****	**.44****	**.47****	**.38***
POMS Confusion time 1	**.65****	**.44****	**.38***	**.40****
POMS Fatigue time 1	**.31***	**.35***	**.44****	**.31***
POMS Vigour time 1	**–.50****	**–.43***	–.28	**–.39****
Informational coping style(TMSI)				
Monitoring	.20	.17	.26	.20
Blunting	**–.28***	–.14	–.22	**–.30***
Monitoring minus Blunting	**.35***	.27	**.34***	**.37***

* p<.05 (2- tailed)

** p≤.01 (2- tailed)

[a] Spearman correlation coefficient was computed for these variables

Table 4.

Associations between POMS-TMD at T1 to T4 with demographic, medical and psychological factors at T1. Values represent Pearson's correlation coefficients

	POMS-TMD			
	T1(N=62)	**T2(N=35)**	**T3(N=39)**	**T4(N=46)**
Demographic variables				
Age	.00	.02	–.10	–.25
Sex [a]	–.24	–.09	–.17	–.16
Marital status [a]	.10	–.11	–.06	.16
Education [a]	–.01	–.26	–.01	.06
Ethnicity [a]	–.05	.16	.16	–.05
Transplant type				
Transplant (autologous, allogenic) [a]	–.18	–.21	–.24	–.05
Illness attributions (IPQ-R)				
illness representation: timeline (acute, chronic)	.23	.03	–.06	.01
illness representation: timeline (cyclical)	.20	.12	.04	.15
illness representation: consequences	**.33***	.13	.11	.17
illness representation: personal control	–.04	–.01	.09	.13
illness representation: treatment control	**–.27***	–.24	–.23	–.28
illness representation: illness coherence	**–.49****	–.24	–.34	–.39
illness representation: emotional representations	**.67****	**.44***	.27	.44
causal attributions: psychological	**.39****	.15	–.06	.33
causal attributions: risk factors	.24	–.02	.12	.23
causal attributions: immunity	**.31***	.06	.27	**.46****
causal attributions: accident or chance	.22	–.06	.05	.22
Psychological state at entry (T1)				
HADS-Depression time 1	**.74****	**.63****	.27	**.53****
HADS-Anxiety time 1	**.79****	**.62****	.23	**.56****
POMS TMD time 1	**---**	**.57****	**.48****	**.55****
POMS Depression time 1	**.88****	**.52****	**.39***	**.48****
POMS Anger time 1	**.74****	**.54****	**.49****	**.47****
POMS Tension time 1	**.86****	**.45****	**.42***	**.39****
POMS Confusion time 1	**.86****	**.43***	.31	**.46****
POMS Fatigue time 1	**.61****	**.56****	**.35***	**.37***
POMS Vigour time 1	**–.66****	**–.35***	–.23	**–.42****
Informational coping style(TMSI)				
Monitoring	.22	.13	.21	.24
Blunting	–.12	–.08	–.15	–.16
Monitoring minus Blunting	**.27***	.17	.26	**.32***

* p<.05 (2- tailed)

** p≤.01 (2- tailed)

[a] Spearman correlation coefficient was computed for these variables

Table 5.

Associations between IES-R at T4 with demographic, medical and psychological factors at T1. Values represent Pearson's correlation coefficients

	IES-R (measured at T4, N=46)			
	Avoidance	**Intrusion**	**Hyper-arousal**	**Total Score**
Demographic variables				
Age	–.14	–.19	–.17	–.19
Sex [a]	–.06	–.01	–.05	–.01
Marital status [a]	.02	–.02	.04	.01
Education [a]	–.30	–.03	–.16	–.19
Ethnicity [a]	–.13	.03	.10	–.01
Transplant type				
Transplant (autologous, allogenic) [a]	.03	–.07	–.05	–.05
Illness attributions (IPQ-R)				
illness representation: timeline (acute, chronic)	.05	–.07	.04	.01
illness representation: timeline (cyclical)	.18	–.03	.29	.15
illness representation: consequences	.12	.10	.21	.15
illness representation: personal control	.05	.03	.00	.04
illness representation: treatment control	–.10	–.11	–.25	–.16
illness representation: illness coherence	–.30	**–.35***	**–.43***	**–.39***
illness representation: emotional representations	**.50****	**.42***	**.38***	**.50****
causal attributions: psychological	.11	.02	.02	.06
causal attributions: risk factors	.18	.02	.18	.14
causal attributions: immunity	.32	**.38***	**.34***	**.39***
causal attributions: accident or chance	.10	**.39***	.24	.27
Psychological state at entry(T1)				
HADS-Depression time 1	**.41***	**.34***	**.53****	**.47****
HADS-Anxiety time 1	**.71****	**.45****	**.53****	**.65****
POMS TMD time 1	**.45****	**.42****	**.52****	**.52****
POMS Depression time 1	**.38***	**.31***	**.33***	**.39***
POMS Anger time 1	**.41***	**.42****	**.49****	**.49****
POMS Tension time 1	**.45****	**.39***	**.35***	**.46****
POMS Confusion time 1	.29	.28	**.47***	**.38***
POMS Fatigue time 1	.23	**.36***	**.43***	**.37***
POMS Vigour time 1	**–.35***	–.24	**-.46****	**–.38***
Informational coping style(TMSI)				
Monitoring	.07	.11	.11	.11
Blunting	.10	–.01	–.10	–.02
Monitoring minus Blunting	.01	.11	.16	.08

* p<.05 (2- tailed)

** p≤.01 (2- tailed)

[a] Spearman correlation coefficient was computed for these variables

Table 6.

Associations between POMS-fatigue at T1 to T4 with demographic, medical and psychological factors at T1. Values represent Pearson's correlation coefficients

	POMS-Fatigue			
	T1(N=62)	**T2(N=35)**	**T3(N=39)**	**T4(N=46)**
Demographic variables				
Age	–.01	–.01	.05	–.20
Sex [a]	–.03	–.04	–.10	–.18
Marital status [a]	**.32***	–.06	.05	**.31***
Education [a]	.07	–.20	.19	–.02
Ethnicity [a]	.04	.06	–.04	–.03
Transplant type				
Transplant (autologous, allogenic) [a]	–.06	–.21	–.01	.06
Illness attributions (IPQ-R)				
illness representation: timeline (acute, chronic)	.01	.14	–.15	–.05
illness representation: timeline (cyclical)	.15	.02	–.02	.09
illness representation: consequences	.10	–.01	.07	.10
illness representation: personal control	.08	–.07	–.16	.03
illness representation: treatment control	–.14	–.25	**–.36***	–.14
illness representation: illness coherence	–.15	–.05	–.10	–.16
illness representation: emotional representations	.14	.19	.10	.26
causal attributions: psychological	.20	.10	–.12	.23
causal attributions: risk factors	.03	–.05	–.04	.07
causal attributions: immunity	.21	–.06	.04	.23
causal attributions: accident or chance	.02	–.17	.03	.23
Psychological state at entry(T1)				
HADS-Depression time 1	**.38****	**.37***	.23	**.34***
HADS-Anxiety time 1	**.29***	**.43***	.21	**.37***
POMS TMD time 1	**.57****	.33	.26	**.34***
POMS Depression time 1	**.26***	**.36***	.27	.25
POMS Anger time 1	**.26***	.13	.11	.24
POMS Tension time 1	**.28***	**.36***	.23	.22
POMS Confusion time 1	**.44***	.25	.13	.28
POMS Fatigue time 1	---	.28	.12	**.36***
POMS Vigour time 1	**–.42****	–.14	–.22	–.23
Informational coping style				
Monitoring	–.07	.02	–.08	.19
Blunting	.09	–.06	–.15	–.11
Monitoring minus Blunting	–.12	.07	.02	.24

* p<.05 (2- tailed)

** p≤.01 (2- tailed)

[a] Spearman correlation coefficient was computed for these variables

Discussion

It is known that patients undergoing BMT/SCT experience considerable levels of distress (Hjermstad *et al.*, 1999; Fife *et al.*, 2000). The current study aimed to characterize the dynamics of this distress over the course of BMT/SCT treatment until 120 days post-treatment. A second aim was to determine which pre-treatment demographic, medical and psychosocial factors predicted psychological distress post-treatment. These exploratory analyses included an assessment of illness perceptions and attributions as a predictor of distress. Third, the present study specifically investigated to what extent informational coping style (i.e., monitoring vs. blunting) predicted treatment-related distress. Fourth, exploratory analyses were included to determine a possible mediation of informational coping (monitoring, blunting) in the association between illness perception and psychological adjustment.

With regard to the first aim, the results showed that HADS-D, HADS-A, and POMS-TMD all peaked at T2 and then gradually declined. However, even at T4 the reported depression and mood disturbance were still above the levels reported at T1. Fatigue exhibited a different pattern than the other measures, showing a significant increase (as compared to T1) at T2 to T4 with no signs of recovery. The results confirmed previous reports (Hjermstad *et al.*, 1999; Keoch, O'Riordan, McNamara, Duggan, & McCann, 1998) by showing that the levels of depression during and after treatment are quite substantial. For example, at the time of discharge 62.9% of patients scored above the HADS-D clinical threshold (HADS-D≥8), which is 5 times larger than found in the general population (11.4%; Crawford *et al.*, 2001). Even when raising the clinical cut-off to 11 (the HADS-D cut-off for moderate to severe depression), as suggested by Crawford *et al.* (2001), 34.2% of the patients remained within the clinical range. Using the same elevated cut-off the proportions for other time points ranged between 9.7% at T1 and 10.4% at T4 (general population 3.6%; Crawford *et al.*, 2001). A review by Hjermstad & Kaasa (1995) demonstrated that distress in BMT patients also exceeds what is found among other cancer populations. Clearly, depression in this vulnerable population warrants adequate attention for assessment and intervention. This finding is particularly relevant in the light of earlier research showing that although health care providers (e.g., nurses, doctors) perform reasonably well in detecting anxiety in their patients, they tend to be less sensitive identifying depression (Trask *et al.*, 2002). Clinical levels of depression may thus be under reported and, as a consequence, under-referred to psychological services.

The findings for HADS-A showed a different pattern than those for HADS-D. Although HADS-A levels similarly reached a peak at T2 and then gradually declined, the percentage of cases above the clinical cut-off (HADS-A ≥ 8) was similar or even below to that found in the general population. At T2 this proportion was 28.6% (33.2% in the general population; Crawford, Henry, Crombie & Taylor, 2001) and as low as 17.4% at T4. While these findings appear counter-intuitive considering the medical threat, it is in line with the results reported in a review of 7 studies (Sherman *et al.*, 2004). This review indicated that the proportion of patients with above-threshold HADS-A ranges between 20% and 34%[2]. Possibly these low levels of anxiety reflect the ability of health care professionals to identify anxiety in patients and respond appropriately.

Analysis of the dynamics of reported fatigue over the course of treatment revealed that fatigue increased significantly compared to reported levels at T1. For example, post-hoc analyses of individual items show that at T3, 38.4% of the participants indicated feeling ‘quite a bit’ to ‘extremely’ exhausted, and 46.2% gave similar ratings for the adjective ‘fatigued’. Moreover, at T4, 41.3% of the participants still indicated they were ‘quite a bit’ to ‘extremely’ exhausted, and 34.8% had similar scores for the adjective ‘fatigued’ (post-hoc analyses data not presented in results section). These findings confirm that fatigue remains a significant long-term complaint for patients (Neitzert *et al.*, 1998). Finally, POMS-TMD showed a pattern

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[2] note: one study by Keogh et al. (1998) found that 61% of patients reported above threshold anxiety. Their finding substantially deviates from all other published results, and is therefore regarded as a non-representative

similar to that of HADS-D, peaking at the time of discharge. Although no normative data exist for the POMS-SF, it appears safe to conclude that the amount of total mood disturbance and fatigue is substantial in this population.

In summary, the high proportion of clinical depression warrants close monitoring of this problem in patients. Moreover, the results provide an argument to extend psychosocial care (monitoring and intervention) to extended periods post-treatment when patients recover at home.

What factors predict individual differences in adjustment after BMT/SCT treatment?

Analyses of the present data showed that demographic factors (age, education level, ethnicity) and treatment factors (e.g., allograft, autograft) were not strong predictors of distress in this sample. The cancer literature yields inconsistent results with regard to gender differences with a majority of studies finding no gender differences (Massie, 2004). For example, Zabora *et al.* (2001), did not observe any gender differences in distress in a sample of 9000 male and female cancer patients. Likewise, in the current study no consistent pattern was found with regard to gender differences, although two significant findings (HADS-Depression, POMS-TMD) suggest that men had significantly higher levels of depression at admission. It is possible that the two significant correlations merely represent a type-1 error due to multiple testing. However, even if the found correlations were not spurious, this still implies that gender is not a major predictor of treatment related distress.

Despite the common understanding that allogenic transplant, as compared to autologous transplant, has a much higher transplant related (i.e., < 3months) mortality (allogenic 18% vs. autologous 4%) and a lower one-year survival rate (allogenic 64% vs. autologous 86%) (Arora *et al.*, 2005), treatment modality did not predict distress. This suggests that the perception of illness is more influential to well-being than the medical reality.

This idea was confirmed by analyses of illness perceptions: strong associations were found for three cognitive and emotional attributions of illness; (1) not understanding the nature of their illness ('illness coherence'); (2) feeling that one's psychological make-up and experiences could have caused the disease ('psychological attributions'); and (3) experiencing high emotional impact of the illness ('illness representations'). Thus, it seems warranted for future research on interventions to focus on the role of illness perceptions on the development of psychological distress, e.g., in case a patients exhibits strong dysfunctional beliefs regarding their own past behaviours or psychological make-up as a cause of their illness, stress-reduction could be achieved by an intervention providing detailed information about the nature and known causes of a patient's illness to correct irrational beliefs or possible self-blame.

To what extent does informational coping style (i.e., monitoring, blunting) predict distress and fatigue?

The third aim of this study was to investigate whether informational coping style predicted distress during and after treatment. The analyses employed three coping parameters that were derived from the TMSI; the total score on both monitoring and blunting subscales, and the difference score of these scales (monitoring score minus blunting score). Although there is an ongoing debate about the appropriateness of employing such a difference score, we have included it for completeness. The difference-score provides a measure of *preferential* coping style. For example, a person who engages in both monitoring **and** blunting (i.e., a high score on both subscales) would score similar to a person who scores low on both subscales, which in both cases would be close to zero. In contrast, a person who strongly prefers one coping style over another will score at the extreme ends of this difference score. The calculation of the difference score has been recommended by Miller (1988), who proposed it as a means of differentiating 'real' monitors and 'real' blunters. Some researchers (c.f., Bijttebier, Vertommen, & Vander Steene, 2001) have argued that the subscales are uncorrelated and therefore represent independent constructs. In their view, calculating a difference score would be like subtracting "apples and oranges". The current TMSI data confirmed that the monitoring and blunting subscales were uncorrelated (r=.16, p>.1). Notwithstanding these psychometric arguments, the current results showed that preferential coping style showed a more consistent association with psychological distress than either subscale (see Tables 3 and 4). The negative correlations indicated that it were the preferential 'blunters' who reported lower levels of distress. Thus, the current results, as well as the results of others (Lerman *et al.*, 1996; Nordin, Lidén, Hansson, Rosenquist, & Berglund, 2002), clearly showed that the concept of preferential coping style has predictive utility and should, on empirical grounds, not be dismissed therefore.

In summary, the present results are in line with the existing theory that a 'monitoring' coping style is associated with increased distress and a 'blunting' coping style is protective (Miller, 1995). Monitoring has been described as an adaptive strategy when individuals perceive themselves as having control. However, when undergoing BMT transplantation, an experience whereby the patient is largely out of control, a blunting style may protect the individual by enabling them to 'switch off', and redirect their attention away from the threat. Although these patients may, at face value, appear 'in denial' (Van Zuuren *et al.*, 1996; Miller, 1992), it is important for health care professionals to be aware of the (short term) benefits of this coping style during this critical time. Future research is required to determine the longer term effects of a preferential blunting coping style, for example, through following patients up over longer periods than normally reported (e.g., 12 months). At present very little is know about the long term benefits of this coping preference (Miller, 1992; Devins, Mendelssohn, Barré, & Binik (2003).

The current study used the TMSI as a measure of informational coping style, which seemed more appropriate than MBSS in a hospital population. It has been argued that the MBSS scenarios (e.g., 'imagine being held hostage by a group of armed terrorists') are not appropriate for use in a severely ill population, and that patients might get annoyed over the irrelevant hypothetical character of the MBSS items (Steptoe, 1989). Furthermore, Van Zuuren, de Groot, Mulder, & Muris (1996) have mentioned that coping style is largely situation dependent and assessing it across different situations might lead to invalid findings. Moreover, it has been established that the blunting subscale of the MBSS has poor psychometric quality and therefore produces unreliable findings (Van Zuuren *et al.*, 1996; Muris, Van Zuuren, de Jong, Merkelbach, & Hanewald, 1994).

Whereas initial analyses demonstrated informational coping style to be a significant predictor of distress, results of a subsequent linear regression analysis showed that it had limited predictive value above and beyond other predictors. This observation raises the possibility that patients with a certain coping style (monitoring or blunting) are more distressed before the onset of their BMT/SCT treatment. For example, some studies have reported that monitoring may be associated with increased trait anxiety (Steketee, Bransfield, Miller & Foa, 1989), depression (Miller *et al.*, 1988), and psychiatric problems (Steptoe & O'Sullivan, 1986). The current results support this interpretation, showing lower anxiety and total mood disturbance in blunters at T1. In addition, regression analyses showed that when controlling for the effects of pre-treatment anxiety and mood, the predictive utility of the TMSI for later distress diminished.

This study also observed significant associations between illness perceptions and treatment related distress. Illness attributions are known to determine coping behaviours (Hagger & Orbell, 2003). Hence, it is possible that coping style mediated the links between illness perceptions and distress. Mediational analysis (Barron & Kenny, 1986) did not confirm this hypothesis. To summarize, the current results indicate that informational coping style is a predictor of distress in BMT/SCT patients, and that this informational coping style is largely unaffected by illness perceptions and attributions. However, analyses also indicate that informational coping style is related to pre-treatment distress. This finding implies that the link between coping and post-treatment distress may be confounded, at least in part, by pretreatment distress (i.e., anxiety, mood disturbance).

Strengths and limitations of the present study

The present study has several methodological strengths. First, to the author's best knowledge this is the first longitudinal study to investigate the association between informational coping style and psychological distress in BMT/SCT treatment using well validated and reliable psychological measures. Moreover, the study provides information about both short-term (T1-T3) and longer-term distress (T4) in BMT/SCT patients. The literature assessing pre-treatment distress is sparse (Fife *et al.*, 2000) and therefore the assessment of pre-treatment distress provided a potentially valuable contribution. Assessment of pre-treatment distress levels also affords a reference for the levels of subsequently reported distress.

Another strength is that the current study included men and women, a wide age range, and both types of transplant (i.e., allogenic and autologous). This makes it likely that that the findings can be generalized to the wider patient population. Generalizability is further confirmed by analyses showing little to no relationship between these variables and degree of distress. Lastly, this prospective study collected data directly from participants, which has clear benefits over observer assessments (i.e., through interviews by clinicians or nursing staff) (Fife *et al.*, 2000).

The study also has several limitations. First, there were missing data due to attrition related to the impact of treatment and severity of illness. Therefore, there is a need to be cautious when interpreting the data, although the power analyses revealed that the sample was large enough to yield statistically meaningful results. Unfortunately, it was not always possible to obtain a complete data set for each of the 62 participants. Reasons were that some patients were at times too ill to complete the questionnaires; some were transported to another hospital after their stem cell infusion, and some were simply not approached in time. One patient preferred only to participate for the pre-treatment data collection. Sadly, eight participants died at various points in time throughout the data collection. For the last data collection at T4, 7 of the 55 remaining participants (12.7%) did not return their questionnaires. Reasons were not asked for, but it may be that these participants attempted to 'get on with life' after the treatment and did not want to be reminded of their illness experience. If this is the case, there may be a bias of self-selection for the last data collection. An independent samples t-test revealed that patients who were lost to the T4 follow up did not significantly differ from the participants that remained in the study on demographic and psychological variables measured at T1. In any case, missing data is a known problem in longitudinal research, particularly in vulnerable populations like BMT/SCT patients.

A second limitation is the relatively short duration of follow-up. Most longitudinal studies follow participants up to at least a year post-transplant, yet this was impossible due to researcher time constraints. Plans to submit a proposal to follow these participants in the future have been drawn up but have yet to be submitted for funding.

A third limitation concerns the multiple tests that were performed to analyze the data, which incurs a risk for type 1 error (i.e., falsely rejecting the null-hypothesis). To reduce this risk it is not uncommon to use adjustment methods, such as the 'Bonferroni adjustment for multiple testing', which aims to decrease type 1 error by decreasing the total alpha. However, one problem with such approaches is that they inevitably increase the chances for type 2 error, and hereby increase the risk for failing to detect relevant associations. In line with the recommendation by Perneger (1998) it was, therefore, decided not to apply correction for multiple testing. It is acknowledged that this choice implies that a (small) proportion of the current findings may be spurious. Lastly, it needs to be mentioned that the T1 data collection was scheduled shortly after admission in hospital, sometimes within half a day after admission. The timing of this data-collection may have impacted on the results by measuring not only anticipation of the upcoming onset of treatment, but also other factors, e.g., adjusting to a new environment, being away from home and family, not sleeping in one's own bed, etc. Therefore, the T1 data collection should not been regarded as a baseline, but rather as a reference to which subsequent data collection time points can be compared.

Conclusion and clinical implications

In conclusion, several clinical implications can be derived from the results of the current study, which may help future patients and the health care professionals involved with their care. First, it is important to understand the role of pre-treatment psychological factors on patients' psychological responses to the transplant. With understanding of the impact of pre-treatment factors such as coping style, illness perceptions, and psychological 'unwell-being', it may be possible to more effectively help patients through their transplant experience and to improve longer term physical and psychological functioning. Through careful pre-treatment psychological screening and assessment for anxiety, depression, coping style and illness perceptions, health care professionals involved with the patient may be able to intervene directly. Examples of pre-BMT/SCT interventions may be tailored information provision, training patients to use self-regulatory skills to manage illness/treatment related anxiety, providing BMT/SCT specific psycho-education, and CBT. Alternatively, a referral to additional services may be made. Also, by being aware of pre-treatment distress, health care professionals can adequately inform patients about the likelihood that these symptoms will improve within the months after their treatment but that they still might need attention. Lastly, considering the long term psychological after effects of BMT/SCT treatment, there is a clear need to psychologically follow-up patients who have already received BMT/SCT treatment to ascertain their long term psychological well-being and intervene where needed.

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Appendix 1

Executive Summary

This literature review and main study were conducted by Josja Eggen and presented as part of a thesis for submission to the school of Psychology, University of Birmingham, for the Doctorate in clinical Psychology

Literature Review

The impact of monitoring coping style on psychological adjustment in people with a real or potentially life threatening illness

Being affected by a life threatening illness has important consequences for someone's physical, emotional and psychological wellbeing. Research has shown both short-term and long-term beneficial psychological and physical benefits of informational preparation in threatening medical situations such as surgical procedures and high risk treatments. However, it has also been demonstrated that a considerable amount of patients still reports feeling dissatisfied about informational preparation, hence the question remains on how the optimal level of information provision for individual patients can be determined. Another question is which patient factors influence satisfaction with informational preparation? Previous literature suggests that an informational coping style seems may play a role in how a patient responds to information provision (Fallowfield, 1995; Steptoe 1991). Miller (1987) has distinguished two individual informational coping styles: 'monitoring' and 'blunting'. Monitoring involves the extent to which an individual has an attentional bias for negative, potentially painful or dangerous aspects of information or a situation, whereas blunting involves the extent to which an individual distracts themselves from the threatening information or situation. Monitoring has been described as an adaptive strategy when individuals perceive themselves as having control. However, when confronted with the loss of control as is the case in many serious illnesses, a monitoring coping style may be maladaptive in that it may make the individual more vulnerable to distress because they are focusing on the threat, but they are also amplifying it, resulting in a vicious circle leading to high levels of distress (Monitoring Process Model; Miller, 1995). Previous research on the interaction between informational coping style and informational preparation in cancer have shown that generally speaking, patients cope better when information provision is tailored to their informational coping style (Miller, 1995).

A preliminary investigation of the literature showed that there are a number of empirical studies investigating the relationship between monitoring coping style and psychological adjustment in threatening medical situations. It seemed worthwhile to systematically review the most recent literature in order to bring to light any emerging patterns which may have implications for the medical context or method in which the tailoring of information to the coping style of the individual is most beneficial, and to make recommendations for future research.

Main Paper

Psychological Adjustment and Coping Style in Patients Undergoing BMT/SCT

Background and Objectives

With the development of improved cancer treatments, remission and survival rates have increased over the past decade. As a result, more investments are made in research that focuses on quality of life and psychological adjustment in cancer patients. Stem Cell Transplantation (SCT) and Bone Marrow Transplantation (BMT) are the only curative options in many blood cancers. SCT/BMT is combined with the delivery of high doses of chemotherapy and radiotherapy and is therefore a very intensive treatment, during which the patient may feel very ill and which requires prolonged hospitalization, often in isolation.

Previous research has demonstrated that SCT/BMT causes considerable psychological distress in both patients and their carers. Furthermore, it has been demonstrated that distress during treatment is predictive of long term emotional and physical well-being. Information provision is a common component of many rehabilitative interventions, however is delivered in a standard, 'one size fits all' format. Miller (1987, 1995) has argued that tailoring of information to the informational coping style of the patient is necessary to avoid information related distress. She argued that individual's differ in their tendency to either actively seek ('monitor') or avoid ('blunt') potentially stressful health related information. The first, *monitoring*, involves the extent to which an individual actively scans for negative, potentially painful or dangerous aspects of information or situation, whereas *blunting* involves the extent to which an individual distracts themselves from the threatening information or situation. Thus, whether someone is distressed by certain information does not depend on the content of the information or the situation per se, but on how the individual processes it according to their individual informational coping style.

To summarise, BMT/SCT patients are expected to experience considerable levels of distress prior to and during their transplant, which may influence their need for information provision and pre-treatment preparation. As provision of information is mostly delivered in a standard way, it can be expected that informational coping style will affect treatment related psychological distress.

The present study is the first longitudinal study to investigate the association between informational coping style and psychological distress and fatigue in BMT/SCT treatment and has three aims. The first aim is to evaluate the degree of psychological distress in patients prior to BMT/SCT treatment compared to post treatment and normative data. Secondly, the present study aimed to examine which pre-treatment demographic, medical and psychosocial factors predicted psychological distress and adjustment after the BMT/SCT. Thirdly, the present study aimed to examine to what extent informational coping style (i.e., monitoring, blunting) predicts post distress and fatigue in patients. Fourthly, to explore a possible mediation of informational coping (monitoring, blunting) in the association between illness perception and psychological adjustment

\Details of the study

Participants

Sixty-two participants (aged 20-70) with various haematological cancers who were scheduled to undergo BMT/SCT treatment opted to take part in the study. Inclusion criteria included (a) being a potential transplant candidate, (b) being over 18 years of age, (c) no previous transplant and (d) fluency in the English language. These participants completed various self-report measures of distress, informational coping style, post-traumatic stress symptoms and illness perceptions.

Method

The design for the study was a prospected longitudinal design with four data collection time points; (a) on day of admission, (b) after transplant, 0-2 days prior to discharge from hospital, (c) one week post-discharge in outpatient clinic, and (d) 120-days post transplant. Adjustment was operationalized as low HADS-anxiety, HADS-depression, POMS-fatigue, POMS total mood disturbance and IES total score. Predictor variables were demographic, medical and pre-treatment psychosocial factors, including illness perceptions, informational coping style.

Further Information and References

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The literature review and main study findings are reported in detail in the following:

Eggen, J.K. (2008). *What is the impact of monitoring coping style on psychological adjustment in people with real or potentially life threatening illness?*
Clin.Psy.D. Volume 1. Birmingham, School of Psychology, University of Birmingham

Eggen, J.K. (2008). *Psychological Adjustment and Coping Style in Patients Undergoing BMT/SCT.*
Clin.Psy.D. Volume 1. Birmingham, School of Psychology, University of Birmingham

Appendix 2

Schematic overview of the included studies

	Author	Medical context	Design	Sample size	Population (specified)	Support for MPM model	Aims of the study	Findings
1	Andrewes, Camp, Kilpatrick, & Cook, 1999	Treatment	Cohort	N=100	Patients undergoing presurgical monitoring for epilepsy Gender information N/A	MPM+	To examine whether patients in high information preparation group experience less anxiety about the procedure than in the low information group. To examine whether monitors are less anxious than blunters after the intervention	Overall, information provision is beneficial to these patients. Pre-test monitors higher anxiety than pre-test blunters Monitors more in need of support Monitors used more problem focused coping Blunters more denial avoidant coping Power too low to make any prediction about interaction over time
2	Andrykowski et al., 2002	screening	Cohort	N=100	Women with suspected ovarian cancer	MPM+	To identify the psychological variables that explain differences in psychological response to Benign Breast Biopsy both initially and across time	Interaction between informational coping style and distress under conditions of low optimism

3	Andrykowski, Boerner, Salsman, & Pavlik, 2004	screening	Cohort	N=540	Women with suspected ovarian cancer	MPM+	To identify psychological variables that explain differences in psychological response to abnormal screening result	Monitors with low dispositional optimism respond with stronger distress to abnormal test result than when optimism is high
4	Barnoy. Bar-Tal, & Zisser. 2006	treatment	Cross-sectional	N=196	98 same sex couples of which one is a cancer patient and the other the main caregiver. Mixed sample of mainly sex-nonspecific cancers.	Gender specific MPM +/-	To examine the influence of correspondence of informational coping style on psychological well-being in marital couples of which one is a cancer patient and the other the main care giver.	For female patients, correspondence in monitoring, for males, correspondence in blunting with their partner associated with better wellbeing. Correspondence in blunting associated with caregiver's worse psychological wellbeing.
5	Brown & Bedi. 2001	Treatment	Cross-sectional	N=85	75% male and 25% female cardiac rehabilitation patients	MPM+/-	To examine to what extent informational coping style is associated with well-being in recent cardiac patients	Blunting positive associated with positive affect and negative with negative affect. No significant relationship for monitoring. Relationship between blunting and positive or negative affect only in situations when there was low outcome expectations, high pessimism and low self-efficacy.
6	Christensen, Moran,	Treatment	Cross-	N=51	30 (59%)male and	MPM+/-	To examine whether	Monitoring partially associated

	Lawton. Stallman, & Voigts, 1997		sectional		21 (41%) female hemodialysis patients	Some findings in favour, others not. No support found for maladaptive coping strategies of monitors	monitoring is associated with poorer adherence. To examine the possibility that relationship between monitoring and adherence is mediated by avoidance and disengagement, or by perceived control in monitors	with adherence either directly or via perceived control. (2 out of 3 adherence variables significant) Partial support for model that perceived control mediating relationship monitoring and adherence. Significant correlation between monitoring and lower perceived control and higher trait anxiety:
7	Constant, Castera, Quintard. Bernard, de Ledighen, Couzigou, & Bruchon-Schweitzer, 2005	treatment	Cross-sectional	N=185	60% male and 40% female chronic Hepatitis C patients	MPM+	To examine whether monitoring coping style was associated with greater perceived severity or chronic hepatitis C	Monitoring positively correlated with perceived severity for men, but not for women. Blunting negative significant relationship with perceived severity Significant correlation monitoring and anxiety Significant correlation between monitoring and perceived severity overall (men and women)

8	Devins, Mendelssohn, Barré, & Binik (2003)	Treatment	RCT	N=297	179 (60.3%) male and 118 (39.7%) female patients with progressive chronic kidney disease needing dialysis	MPM-	To examine whether psycho-educational intervention affects time to dialysis, anxiety and depression. To examine whether informational coping style mediates time to dialysis. To examine whether monitors benefit more from PPI than blunters	PPI extended time to dialysis. Monitoring no effect on beneficial effect of PPI on the delay of dialysis. Medium and high levels of blunting associated with shortened time to dialysis.
9	Lerman et al., 1996	screening	RCT	N=239	Women with suspected breast cancer	MPM+	To examine psychological variables and educational level that might moderate the impact of breast cancer risk counselling on breast cancer specific distress and general distress in women with a family history of cancer	Monitors display become more distressed over time on general distress regardless of getting counselling or not. No effect for disease specific distress
10	Miller, Rodoletz, Schroeder, Mangan, Sedlacek, 1996	Treatment	Cross-sectional	N=176	101 HPV positive women with suspected cervical cancer and 75 HIV positive men	MPM+	To examine whether high monitors have more intrusive thoughts than low monitors, to examine whether this then prompts to avoidant ideation and ultimately to denial and	High monitors in both samples characterized by elevated levels intrusive ideation compared to low monitors. **HPV and HIV sample:** Association between high monitoring and intrusive

							disengagement behaviours	ideation. Intrusive ideation associated with avoidant ideation and denial/disengagement. no association between monitoring and depression
11	Nordin et al., 2002	screening	Cohort	N=63	58 female, 5 male 71 % breast cancer 8% ovarian cancer 21% colorectal cancer	MPM+	To investigate the relationship between coping styles in individuals attending genetic counselling and psychological distress, risk perception and satisfaction with counselling	Significant correlation of monitoring and HADS anxiety and depression before counselling and worry before and after counselling. Counselling more beneficial for monitors than for non-monitors
12	Ong, Visser. van Zuuren, . Rietbroek. Lammes & de Haes, 1999	treatment	Cross-sectional	N=137	83% female and 17% male gynaecological and medical oncology patients	MPM-	To examine the relationship between informational coping style and information and decision making preference. quality of life, communicative behaviours and global affect during an initial oncology consultation. To evaluate validity of shortened TMSI	Monitoring related to preference for information. good or bad, and to participation in decision making Monitoring positively related to patients' question asking and dominance during the consultation. but not significant No relationship between monitoring or blunting and

								Quality of life, disease specific distress, generic quality of life.
13	Petersson, Nordin, Glimelius, Brekkan, Sjoden and Berglund, 2002	treatment	RCT	N=442	41% male and 59% female newly diagnosed cancer patients. 223 breast, 86 colorectal, 15 gastric and 118 prostate patients.	MPM+/-: For prostate MPM+ and for breast MPM -	To investigate the extent to which MBSS can be used to differentiate patients who would benefit from rehabilitation intervention with strong information component and who not	No interaction informational coping style and anxiety and depression Prostate cancer monitors: rehabilitation with info component decreases subjective distress. Breast cancer monitors: rehabilitation did not decrease subjective distress. Intervention not of influence on how blunters are doing in either group
14	Pieterse, Van Dulsem, Ausems, Schoenmaker, Beemer, & Bensing, 2005	Screening	Cohort	N=200	91% female and 18% male patients in a mixed sample of suspected cancer (63% breast cancer 20% colon cancer 5% ovarian cancer 6% other medical cancers)	MPM+/-	To examine whether a monitoring coping style is related to an increased preference for generic and disease specific information during genetic counselling	Monitoring coping style positively related with a higher perceived importance of generic and cancer specific issues of concern during counselling (e.g., info on procedural aspects of the counselling, determinants of susceptibility to developing cancer). Positive but not significant

								relationship between monitoring and psychological distress before counselling
15	Schwartz et al.. 1995	screening	Cross sectional	N=103	Women with suspected ovarian cancer	MPM+	To explore interrelations between monitoring, increased levels of perceived risk, intrusive ideation and psychological distress in women at risk for ovarian cancer	Relationship between monitoring and heightened levels of perceived risk for ovarian cancer, intrusive thoughts and psychological distress
16	Sheehan, Sherman, Lam & Boyages, 2007	treatment	Cross-sectional	N=123	Women with breast cancer who have undergone reconstruction (59% immediate, 41% delayed)	MPM+/-	To examine the moderating effect of informational coping style on post decisional regret. To examine whether increased regret, psychological distress, low statisfaction with information are associated with monitoring coping style	No significant correlation between monitoring and decision regret. Moderating effect of monitoring coping style on the relationship between anxiety and regret: Relationship between anxiety and regret stronger in low monitors. No significant effects of monitoring on relationship between regret and information satisfaction, depression, or stress
17	Tercyak et al.. 2001	screening	Cohort	N=107	Women with suspected ovarian cancer (BRCA1 and 2	MPM+	To explore the relationship between attentional coping style and distress in	Monitors more anxious at each time point in the study. Relationship monitoring and

					gene)		women awaiting test results after genetic testing for breast cancer gene and immediate impact postdisclosure	predisclosure anxiety Carriers more distress post disclosure than non carriers; no effect for coping style
18	Timmermans, Van Zuuren, Van der Maazen, Leer, & Kraaimaat, 2007	treatment	Cohort	N=116	51% male and 49% female, 52% curative and 48% palliative cancer patients – type not defined	MPM+/-	To examine how patients' informational coping style are reflected during the consultation with their consultant and how they affect their evaluation of the consultation. To examine whether patients' disease status influenced the effects of their informational coping style	Monitoring was positively correlated and blunting negatively correlated to asking questions during consultation. In palliative group monitoring effect enhanced: 6 weeks after consultation high monitors compared to low monitors more doubts about treatment decision. Other way around for high and low blunters.
19	Van Vliet, Grypdonck, Van Zuuren, Winnubst, & Kruitwagen, 2004	Treatment	Cohort	N=260	129 male (50%) and 131 female (50%) patients undergoing gastrointestinal endoscopy for suspected cancer	MPM-	To examine whether preparing patients in concordance with their coping style has positive effects on experience than control group, less distress, less anxiety, less pain, and more satisfaction with the procedure	High M: Participants in the extensive info or basic info conditions not less anxious than monitors in the control condition Low M: Participants in the intervention group not less anxious than in the control group
20	Warburton et al., 1997	screening	Cross sectional	N=249	200 (80.3%) men and 49 (19.7%) women	MPM-	To examine degree of emotional distress in all	No significant interaction between monitoring or

					with suspected HIV		four combinations of high/low monitoring and high/low blunting in individuals undergoing testing fro HIV	blunting on distress measures Significant interaction between monitoring, blunting, prediction of results and emotional distress
21	Williams-Piehota et al., 2004	screening	RCT	N=500	Women with suspected breast cancer	MPM+	To examine whether attentional coping style matching health messages are more effective in motivating for screening mammography than mismatched messages	Monitors reported more worry about developing breast cancer than than blunters Least distress in blunters receiving a matched message, highest distress in monitors receiving mismatched message Blunters more likely to get mammogram when matched message

Appendix 9

Demographics Form

DATE:..................

1) NAME

First.................................... Middle Initial..

Last...

2) DATE OF BIRTH...Age:......................

3) SEX: ☐ Male ☐ Female

4) MARITAL STATUS:

☐ Married ☐ Divorced/Separated ☐ Widow(er)

☐ Single ☐ Cohabiting/unmarried couple

5) DO YOU HAVE CHILDREN?

☐ No ☐ Yes if Yes, how many? ....

6) WHAT IS YOUR ETHNIC BACKGROUND

☐White British	☐White Irish	☐White other	☐Asian Indian
☐Asian Pakistani	☐Asian Bangladeshi	☐Asian Other	☐Black British
☐Black Caribbean	☐Black African	☐Black Other	☐Chinese

Other Ethnic group...........................

7) WHAT IS YOUR EDUCATIONAL LEVEL

☐ No diploma ☐ Secondary school ☐ Undergraduate ☐ Graduate

8) TYPE OF TRANSPLANT

☐ Autologous ☐ Allogenic

MEDICAL STATUS/DIAGNOSIS..

....

Study number
(office use only)

Appendix 10

Consent form

University Hospital
Birmingham
NHS Foundation Trust

CONSENT FORM

Title of Project:

Psychological adjustment and coping style in patients undergoing Bone Marrow/Stem Cell Transplant.

Name of Researcher: Josja Eggen

I confirm that I have read and understand the information sheet dated August 2006 (version1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from University Hospital Birmingham, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records

I agree to my GP being informed of my participation in the study.
I agree to take part in the above study.

Name ________________ Signature__________ Date __________

Researcher __________ Signature __________ Date__________

Name of Person taking consent (if different from researcher): __________

Signature__________ Date__________

Appendix 11

Participant Information Sheet

University Hospital **NHS**
Birmingham
NHS Foundation Trust

Patient Information Sheet

Part 1

Study title:

Psychological adjustment and coping style in patients undergoing Bone Marrow Transplant.

You are being invited to take part in a research study. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study if you wish.

The information sheet consists of two parts:

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please feel free to ask us if there is anything that is not clear or if you would like more information. The contact phone number is written in the back under 'investigator contact information'. We will contact you in the next couple of days to ask you whether you would like to take part. Thank you for taking the time to read this.

The purpose of the study
In this research we want to examine psychological adjustment and wellbeing in cancer patients undergoing a Bone Marrow Transplant. It is known from previous research that many patients who undergo a Bone Marrow Transplant suffer from feelings of anxiety, worry, frustration and stress during and after treatment. Although

such feelings are entirely normal, some patients cope better than others. Because no patient is the same and it may be difficult to discuss these issues, care staff in hospital do not always recognise patients' difficulties. In the past there have been attempts to develop screening methods to identify patients who would benefit from support for dealing with such difficulties. However, what we don't know yet, is what such a screening should-or should not- entail to identify patients who could benefit from additional support. Through this research we aim to find out:

a) How patients are feeling before they start their Bone Marrow Transplantation treatment and afterwards
b) Which factors are predictive of psychological adjustment after Bone Marrow Transplant
c) Whether certain personal coping style is associated with psychological adjustment before and after Bone Marrow Transplant

Why have I been chosen?
You may have been admitted into hospital to undergo a Bone Marrow Transplant in the near future because you are suffering from a haematological type of cancer (e.g. Hodgkin's disease, or myeloma). In this case, you have been chosen to help us to identify which factors are associated with psychological adjustment after Bone Marrow Transplant and to help us develop a screening method to identify patients who would benefit from additional support.

Do I have to take part?
You do not have to take part. This is entirely your decision. If you do decide you would like to take part in the study, you will be given this information sheet to keep and you will be asked to sign a consent form. You will still be free to withdraw from the study at any moment without any reason. The decision to withdraw at any time will not affect your treatment in any way.

What will happen to me if I take part?
If you agree to take part in the study, you will be asked to do the following:

1) First, we will schedule two separate appointments with you to complete some questionnaires. Results from these questionnaires will tell us for example whether you are experiencing feelings of worry, or how you think about your current illness. These questionnaires are not 'tests', they only ask you about your opinion. The appointments should take place before you start your Bone Marrow Transplant treatment regimen. We have arranged a room on the ward where you can sit quietly without being disturbed. If you are feeling poorly, we can also visit you in your room so you can complete the questionnaires there. The time to fill out these questionnaires should take no more than 30 minutes per session.

2) After you have received your treatment, we will contact you again to make an appointment to visit you for a third and final time. This visit will probably take place shortly before you leave hospital. You will again be asked to fill out some

questionnaires, but this time there are only a few. This visit will take no more than 15 minutes. The staff on the ward will tell us when we can contact you to make the appointment for the final visit.

What do I have to do?

You will be asked to fill out questionnaires on three separate sessions. Two of these sessions take place before you undergo your bone marrow treatment and the final session will be scheduled shortly before you leave hospital.

What are the possible disadvantages and risks of taking part?

There is no immediate health risk involved with participating in this study and your normal treatment will take place as normal. However, it may be possible that the questions in the questionnaires make you think about your illness which has the risk of eliciting negative, sad or anxious feelings during the session or afterwards.

What are the possible benefits of taking part?

For you personally, there will not be a short time benefit associated with participating in this study. However, your participation may benefit future patients like yourselves because

a) standardised screening methods are in place to identify patients who are suffering from feelings of anxiety, sadness and/or frustration.

b) we can improve and tailor our support programs to the individual patient in order to achieve better patient care.

What happens when the research study stops?

Your medical care is independent of this study and your consultant will continue to provide the care for your current illness.

What if there is a problem?

If you are unhappy or unsure about anything that happens during the study, please feel free to contact the researchers at any time. They will do their best to address any complaint you may have. Their contact details are printed below. If you feel unable to do this, or are not satisfied with the response that you are receiving in reaction to your concerns, the normal NHS complaint procedures apply.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. All the information that leaves the hospital will have your name and address removed so you cannot be identified. If you consent to take part in the study, your GP and other doctors treating you will be notified of your participation in the study. By signing the consent form you are agreeing for this to be done.

Contact Details
Josja Eggen, School of Psychology, University Of Birmingham.
Phone [redacted]. Alternate phone number: [redacted]

For concerns or complaints with regard to the study please contact Professor David Horne at [redacted]

Part 2

What will happen to the results of the research study?
The researcher of this study plans to submit the findings to a peer reviewed scientific journal for publication. We will also produce an information sheet for participants of the study with the main findings. You can fill out an opt-in slip after the last session letting us know you would like to receive the results of the study. Your identity will not be revealed in neither publication nor patient report.

What will happen if I don't want to carry on with the study?
Nothing. The only thing we ask you to do is to let the researcher know you no longer want to participate. You don't have to give them a reason. This decision will not effect your treatment in any way.

Who is organising and funding the research?
This research is conducted as part of Josja Eggen's Doctoral research and is hence not funded.

Who has reviewed the study?
The scientific study review has been undertaken by the school of Psychology at the University of Birmingham. It has been approved by the Central office for Research Ethics Committees (COREC).

Appendix 12

120 day follow-up letter

Josja Eggen
Cancer Psychology Service
Cancer Centre
3rd Floor
Queen Elizabeth hospital
Edgbaston
Birmingham
B15 2HT

Birmingham 1st February 2008 2007

Dear

You may remember taking part in the study

'Psychological adjustment and coping style in patients undergoing Bone Marrow Transplant'

In this study we wanted to examine psychological adjustment and wellbeing in cancer patients undergoing a Bone Marrow Transplant by following them up from their transplant until 120 days post transplant.

As it is now approximately 4 months since you have had your transplant, we would be grateful if you could complete the enclosed last set of questionnaires and return them to us in the enclosed pre-addressed and stamped envelope.

After I have received most of the responses back from the participants, I will write to you again with a summary of the findings. Please complete and return the slip enclosed to indicate if you would appreciate to receive a summary.

Thank you very much for your cooperation.

Best Wishes

Josja Eggen
Clinical Psychologist in Training and Chief Researcher
University Hospital Birmingham and University of Birmingham
[redacted] (secretary)

Appendix 13

GP letter

University Hospital NHS
Birmingham
NHS Foundation Trust

Our Ref:JE/JE

Date:

Re: DOB:

Dear Dr

Your patient ....has been invited and has decided to take part in a research study with the title:

Psychological adjustment and coping style in patients undergoing Bone Marrow Transplant.

In the following section a brief summary of this study will be given.

The purpose of the study
In this research we want to examine psychological adjustment and wellbeing in cancer patients undergoing a Bone Marrow Transplant. It is known from previous research that many patients who undergo a Bone Marrow Transplant suffer from feelings of anxiety, worry, frustration and stress during and after treatment. Although such feelings are entirely normal, some patients cope better than others. Because no patient is the same and it may be difficult to discuss these issues, care staff in hospital do not always recognise patients' difficulties. In the past there have been attempts to develop screening methods to identify patients who would benefit from support for dealing with such difficulties. However, what we don't know yet, is what such a screening should-or should not- entail to identify patients who could benefit from additional support. Through this research we aim to find out:

a) How patients are feeling before they start their Bone Marrow Transplantation treatment and afterwards
b) Which factors are predictive of psychological adjustment after Bone Marrow Transplant
c) Whether certain personal coping style is associated with psychological adjustment before and after Bone Marrow Transplant

Participation
The total duration your patient will be participating in this study will be approximately 6 weeks, depending on time of admission in hospital. During this time he/she will participate in:

1) two separate sessions to complete questionnaires. The time to fill out these questionnaires should take no more than 30 minutes per session.

2) a third session prior to discharge to complete questionnaires. This session will take place shortly before discharge from hospital. This visit will take no more than 15 minutes.

Risks
There is no health risk involved with participating in this study and normal treatment will take place as normal. However, it may be possible that the questions in the questionnaires elicit negative, sad or anxious during the session or afterwards. It may also be possible for your patient to feel fatigued after completing the questionnaires.

After the study
Medical care is independent of this study and your patient's consultant will continue to provide the normal care.

Confidentiality
All the information about your patient's participation in this study will be kept confidential and treated according to the Data Protection Act.

If you have comments or queries with regard to your patient's participation in his study, please do not hesitate to contact me on the phone number below.

Contact Details
Josja Eggen, School of Psychology, University Of Birmingham.
Phone [redacted]

Prof David Horne, School of Psychology, university of Birmingham
Phone [redacted]

Yours Sincerely,

Josja Eggen
Chief Researcher

Appendix 15

Partial correlations (illness perceptions, psychological state at admission with adjustment)

Correlations

Control Variables			HADS anxiety T1	HADS anxiety T2	HADS anxiety T3	HADS anxiety T4
Sex & age	Marital	Correlation	.049	.173	.292	.223
	educational level	Correlation	-.048	-.304	-.215	.013
	ethnicity	Correlation	-.162	.008	.231	.026
	transplant type	Correlation	-.003	-.075	-.382*	-.119
	IPQ timeline	Correlation	.262*	-.010	.053	.024
	IPQ consequences	Correlation	.307*	.254	-.051	.217
	IPQ personal control	Correlation	.017	-.045	.192	.280
	IPQ treatment control	Correlation	-.284*	-.188	-.267	-.106
	IPQ illness coherence	Correlation	-.297*	-.234	-.333*	-.173
	IPQ timeline cyclical	Correlation	.147	.152	.342*	.266
	IPQ emotional	Correlation	.698**	.493**	.218	.324*
	IPQ psych attribute	Correlation	.496**	.366*	.405*	.302*
	IPQ lifestyle	Correlation	.191	-.041	.317	.319*
	IPQ cause: immunity	Correlation	.238	.170	.270	.483**
	IPQ cause: chance	Correlation	.127	-.044	-.056	.150
	HADS depression T1	Correlation	.677**	.626**	.464**	.481**
	HADS anxiety T1	Correlation	1.000**	.716**	.463**	.616**
	POMS TMD T1	Correlation	.792**	.612**	.560**	.504**
	POMS depression T1	Correlation	.767**	.620**	.522**	.462**
	POMS anger T1	Correlation	.577**	.443**	.155	.427**
	POMS tension T1	Correlation	.741**	.527**	.534**	.342*
	POMS confusion T1	Correlation	.645**	.484**	.401*	.371*
	POMS fatigue T1	Correlation	.287*	.246	.307	.318*
	POMS vigor T1	Correlation	-.515**	-.524**	-.432**	-.380*
	monitoring	Correlation	.170	.165	.233	.174
	blunting	Correlation	-.290*	-.159	-.268	-.332*
	monitoring-blunting	Correlation	.333**	.273	.348*	.369*

*. Correlation is significant at 0.05 level

**. Correlation is significant at 0.01 level

Correlations

Control Variables			HADS depression T1	HADS depression T2	HADS depression T3	HADS depression T4
Sex & age	Marital	Correlation	.183	.185	.193	.246
	educational level	Correlation	-.159	-.203	-.094	-.190
	ethnicity	Correlation	.081	.122	.168	-.006
	transplant type	Correlation	-.064	-.073	-.118	-.143
	IPQ timeline	Correlation	.185	-.145	-.122	.181
	IPQ consequences	Correlation	.289*	.034	.177	.236
	IPQ personal control	Correlation	-.054	.025	.145	.141
	IPQ treatment control	Correlation	-.323*	-.205	-.266	-.272
	IPQ illness coherence	Correlation	-.319*	-.153	-.260	-.107
	IPQ timeline cyclical	Correlation	.290*	.157	.262	.346*
	IPQ emotional	Correlation	.522**	.300	-.034	.242
	IPQ psych attribute	Correlation	.334*	.164	-.024	.291
	IPQ lifestyle	Correlation	.235	-.037	.175	.256
	IPQ cause: immunity	Correlation	.144	.106	.357*	.318*
	IPQ cause: chance	Correlation	.200	-.097	.009	.296
	HADS depression T1	Correlation	1.000**	.572**	.407*	.582**
	HADS anxiety T1	Correlation	.677**	.482**	.184	.588**
	POMS TMD T1	Correlation	.720**	.572**	.371*	.491**
	POMS depression T1	Correlation	.678**	.617**	.391*	.394**
	POMS anger T1	Correlation	.462**	.427*	-.024	.402**
	POMS tension T1	Correlation	.580**	.423*	.282	.268
	POMS confusion T1	Correlation	.611**	.499**	.324	.323*
	POMS fatigue T1	Correlation	.397**	.452**	.165	.333*
	POMS vigor T1	Correlation	-.497**	-.327	-.418*	-.516**
	monitoring	Correlation	.107	.166	.082	.223
	blunting	Correlation	-.227	-.069	-.089	.003
	monitoring-blunting	Correlation	.238	.204	.118	.195

*. Correlation is significant at 0.05 level

**. Correlation is significant at 0.01 level

Correlations

Control Variables			POMS fatigue T1	fatigue_pomsb	fatigue_pomsc	fatigue_poms120
Sex & age	Marital	Correlation	.328*	-.061	.072	.306*
	educational level	Correlation	.072	-.204	.206	-.067
	ethnicity	Correlation	-.037	.010	-.182	-.084
	transplant type	Correlation	-.076	-.241	-.058	.019
	IPQ timeline	Correlation	.016	.152	-.182	-.003
	IPQ consequences	Correlation	.111	-.023	.044	-.032
	IPQ personal control	Correlation	.084	-.065	-.142	.015
	IPQ treatment control	Correlation	-.142	-.251	-.354*	-.180
	IPQ illness coherence	Correlation	-.155	-.046	-.080	-.176
	IPQ timeline cyclical	Correlation	.147	.017	-.035	.098
	IPQ emotional	Correlation	.136	.192	.088	.254
	IPQ psych attribute	Correlation	.199	.095	-.137	.230
	IPQ lifestyle	Correlation	.035	-.068	-.103	.060
	IPQ cause: immunity	Correlation	.211	-.063	.026	.218
	IPQ cause: chance	Correlation	.013	-.186	.009	.187
	HADS depression T1	Correlation	.397**	.383*	.196	.348*
	HADS anxiety T1	Correlation	.287*	.428*	.192	.369*
	POMS TMD T1	Correlation	.589**	.330	.233	.312*
	POMS depression T1	Correlation	.274*	.368*	.249	.212
	POMS anger T1	Correlation	.261*	.131	.080	.214
	POMS tension T1	Correlation	.291*	.380*	.202	.156
	POMS confusion T1	Correlation	.450**	.252	.095	.254
	POMS fatigue T1	Correlation	1.000**	.280	.115	.372*
	POMS vigor T1	Correlation	-.424**	-.143	-.210	-.248
	monitoring	Correlation	-.077	.016	-.114	.150
	blunting	Correlation	.085	-.068	-.144	-.158
	monitoring-blunting	Correlation	-.121	.069	-.009	.235

*. Correlation is significant at 0.05 level

**. Correlation is significant at 0.01 level

Correlations

Control Variables			POMS TMD T1	TMD_pomsb	TMD_pomsc	TMD_poms120
Sex & age	Marital	Correlation	.198	.188	.223	.200
	educational level	Correlation	-.015	-.277	-.037	.008
	ethnicity	Correlation	-.119	.041	.028	-.069
	transplant type	Correlation	-.087	-.273	-.364*	-.113
	IPQ timeline	Correlation	.227	.076	.019	.034
	IPQ consequences	Correlation	.263*	.105	.010	.022
	IPQ personal control	Correlation	-.003	-.064	.013	.151
	IPQ treatment control	Correlation	-.304*	-.353	-.371*	-.296
	IPQ illness coherence	Correlation	-.458**	-.264	-.283	-.340*
	IPQ timeline cyclical	Correlation	.217	.189	.168	.187
	IPQ emotional	Correlation	.644**	.375*	.189	.389**
	IPQ psych attribute	Correlation	.369**	.231	.040	.268
	IPQ lifestyle	Correlation	.192	.044	.181	.254
	IPQ cause: immunity	Correlation	.295*	.074	.233	.466**
	IPQ cause: chance	Correlation	.195	-.040	.094	.270
	HADS depression T1	Correlation	.720**	.622**	.320	.527**
	HADS anxiety T1	Correlation	.792**	.594**	.266	.545**
	POMS TMD T1	Correlation	1.000**	.574**	.495**	.549**
	POMS depression T1	Correlation	.867**	.587**	.497**	.474**
	POMS anger T1	Correlation	.658**	.309	.226	.519**
	POMS tension T1	Correlation	.850**	.512**	.468**	.318*
	POMS confusion T1	Correlation	.846**	.444**	.301	.416**
	POMS fatigue T1	Correlation	.589**	.390*	.170	.387**
	POMS vigor T1	Correlation	-.682**	-.462**	-.396*	-.410**
	monitoring	Correlation	.161	.091	.155	.207
	blunting	Correlation	-.139	-.089	-.181	-.218
	monitoring-blunting	Correlation	.228	.152	.232	.324*

*. Correlation is significant at 0.05 level

**. Correlation is significant at 0.01 level

Correlations

Control Variables			IES avoidance	IES intrusion	IES hyperarousal	IES total score
Sex & age	Marital	Correlation	-.008	-.060	.018	-.023
	educational level	Correlation	-.334	-.068	-.200	-.236
	ethnicity	Correlation	-.209	-.018	-.011	-.107
	transplant type	Correlation	-.035	-.131	-.205	-.126
	IPQ timeline	Correlation	.098	-.011	.097	.067
	IPQ consequences	Correlation	.075	.061	.144	.099
	IPQ personal control	Correlation	.029	-.010	-.021	.004
	IPQ treatment control	Correlation	-.125	-.143	-.287	-.195
	IPQ illness coherence	Correlation	-.330	-.395*	-.465**	-.432*
	IPQ timeline cyclical	Correlation	.185	-.016	.299	.161
	IPQ emotional	Correlation	.509**	.443*	.381*	.519**
	IPQ psych attribute	Correlation	.120	.029	.024	.073
	IPQ lifestyle	Correlation	.221	.068	.205	.187
	IPQ cause: immunity	Correlation	.319	.396*	.339	.400*
	IPQ cause: chance	Correlation	.092	.402*	.214	.264
	HADS depression T1	Correlation	.441*	.395*	.558**	.516**
	HADS anxiety T1	Correlation	.726**	.474**	.538**	.674**
	POMS TMD T1	Correlation	.465**	.451**	.523**	.541**
	POMS depression T1	Correlation	.394*	.342	.328	.410*
	POMS anger T1	Correlation	.424*	.452**	.490**	.513**
	POMS tension T1	Correlation	.465**	.418*	.331	.474**
	POMS confusion T1	Correlation	.303	.304	.478**	.394*
	POMS fatigue T1	Correlation	.235	.361*	.430*	.373*
	POMS vigor T1	Correlation	-.364*	-.267	-.486**	-.409*
	monitoring	Correlation	.061	.117	.084	.099
	blunting	Correlation	.077	-.046	-.135	-.020
	monitoring-blunting	Correlation	.002	.132	.162	.099

*. Correlation is significant at 0.05 level

**. Correlation is significant at 0.01 level