Coping with a diagnosis of multiple sclerosis


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Abstract (Document Summary)

There are indications that the manner in which individuals attempt to cope with MS may be one of the determinants of presence or absence of depressive symptoms (Brooks & Matson, 1982; Devins & Seland, 1987). Coping generally refers to the strategies individuals use to minimize the negative impact of life stressors on their psychological well-being ([Coyne, J.C.], Aldwin, & Lazarus, 1981; Lazarus & Folkman, 1984; Pearlin & Schooler, 1978). A large body of research has shown that, for individuals with and without chronic illness, the use of emotion-focused coping strategies (e.g., strategies aimed at managing emotional reactions to stressful situations) is associated with higher levels of depressive symptomatology (Billings & Moos, 1981, 1984; Bombardier, D'Amico, & [Jordan, J.S.], 1990; Coyne et al., 1981; Holahan & Moos, 1987; Rosenstiel & Keefe, 1983; Sullivan & D'Eon, 1990). The relation between problem-focused coping (e.g., strategies directly aimed at managing the stressful situation) and depression has been less clear (Lazarus, 1993; Coyne & Gottlieb, in press).

The method of assessing coping during the early stages of illness also deserves consideration. The bulk of research on coping and emotional distress has proceeded by requiring participants to complete checklist measures of coping and self-report measures of depressive symptomatology. However, reliance on checklist measures to assess coping has recently been the target of pointed criticism (Coyne & Gottlieb, in press; Stone, Greenberg, Kennedy-Moor, & Newman, 1991; Sullivan & D'Eon, 1990; Tunks & Bellissimo, 1988). [Stone, A.A.] et al. (1991) have argued that many of the items included in checklist measures of coping are not applicable to many of the stresses that individuals experience. It has also been argued that checklist coping scales frequently contain items that are confounded with symptoms of depression thus rendering observed relations between coping and depression difficult to interpret (Stanton, Danoff-Burg, Cameron, & Ellis, 1994; Sullivan & D'Eon, 1990).

The finding that avoidance and denial strategies are associated with reduced likelihood of depression contrasts with the findings of several investigations showing that in community and clinical samples, avoidance and denial strategies are associated with increased risk for depression (e.g., Feifel, Strack, & Nagy, 1987; [Folkman] et al., 1993; Folkman & Lazarus, 1986; Lazarus, 1993; [Quinn] et al., 1987). However, the avoidance and denial strategies reported by patients in this study differ qualitatively from strategies described in checklist coping scales used in previous research. For
example, items such as "I tried to reduce tension by taking more tranquillizing drugs" (Billings & Moos, 1984) reflect efforts to avoid or escape a distressing situation once coping efforts have failed. In the current study however, patients' reports that they "tried not to think about it" appear to reflect efforts to 'regulate' the stress of illness onset. As suggested by Shontz' (1975), avoidance and denial may become maladaptive only when these strategies interfere with illness prevention or health promoting behaviours (e.g., physician visits, dietary changes), interfere with adaptive compensatory behaviour (e.g., refusing to use a cane to manage gait instability) or when they increase the frequency or intensity of intrusive thoughts (Mullen & Suls, 1982; Roth & Cohen, 1986; Suls & Fletcher, 1985).

Full Text (5231 words)

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Abstract

This study examined the relation between coping and depression in a sample of 50 (38 women, 12 men) individuals recently diagnosed with multiple sclerosis (MS). A semi-structured interview was used to assess how individuals coped with the onset of disabling illness, and to assess depressive symptomatology. According to DSM-III-R criteria, 18 participants were diagnosed with major depression, 11 were diagnosed with adjustment disorder with depressed mood, and 21 did not satisfy the criteria for any affective disorder. Interview results indicated that nondepressed participants were more likely to use present focus and avoidance/denial strategies to deal with illness onset than participants with major depression or adjustment disorder. Discussion addresses why these strategies may be an adaptive means of dealing with the onset of MS.

Numerous investigations have shown that individuals diagnosed with chronic illness are at high risk for the development of depressive symptoms (see Rodin, Craven, & Littlefield, 1991, for a review). There are also indications that coping may be an important determinant of depression in individuals with chronic illness (Felton, & Revenson, 1984; Folkman, Chesney, Pollack, & Coates, 1993; Lazarus & Folkman, 1986; Quinn, Fontana, & Reznikoff, 1987; Rosenstiel & Keefe, 1983). The primary aim of the present research was to examine the relation between coping and depression in individuals recently diagnosed with multiple sclerosis.

MULTIPLE SCLEROSIS AND DEPRESSION

Multiple sclerosis (MS) is the most common neurological illness affecting young and middle aged adults. MS is characterized by the demyelination of nerve fibre tracts in the central nervous system leading to a variety of sensory and motor disturbances. These may include weakness, fatigue, loss of coordination, loss of sensation, incontinence, sexual dysfunction, and visual problems (Sibley, 1990). While the exact nature and rate of physical deterioration is difficult to predict, the natural course of MS is reflected in the progressively decreased capacity for physical activity (Sibley, 1990; Weinshenker & Ebers, 1987).

Although there have been few controlled studies, research suggests that the degree of depressive symptomatology in MS patients is higher than that observed in the general population (Dalos, Rabins, Brooks, & O'Donnell, 1983; McIvor, Riklan, & Reznikoff, 1984). Studies using standard diagnostic criteria for depression have reported prevalence rates of depression in samples of MS patients ranging from 25% to 54% (Joffe, Lippert, Gray, Sawa, & Horvath, 1987; Minden, Orav, & Reich, 1987; Minden & Schiffer, 1990; Sullivan, Weinshenker, Mikail, & Edgley, 1995).

Studies examining the disease-related correlates (e.g., disease severity, illness duration) of depression in patients with MS have yielded equivocal findings. While some studies have reported a positive correlation between disease severity and depressive symptoms (McIvor et al., 1984; Zeldow & Pavlou, 1984), other studies have failed to demonstrate this relation (Dalos et al., 1983; Maybury & Brewin, 1984). Most studies have failed to show a significant relation between illness duration and depressive symptoms (McIvor et al., 1984; Minden et al., 1987; Whitlock & Siskind, 1980). Due to the lack of systematic relation between disease-related variables and depression in patients with MS, there has been increased interest in examining the potential role of psychosocial factors in determining risk for depression (Devins & Seland, 1987).

COPING WITH MULTIPLE SCLEROSIS

There are indications that the manner in which individuals attempt to cope with MS may be one of the determinants of presence or absence of depressive symptoms (Brooks & Matson, 1982; Devins & Seland, 1987). Coping generally
refers to the strategies individuals use to minimize the negative impact of life stressors on their psychological well-being (Coyne, Aldwin, & Lazarus, 1981; Lazarus & Folkman, 1984; Pearlin & Schooler, 1978). A large body of research has shown that, for individuals with and without chronic illness, the use of emotion-focused coping strategies (e.g., strategies aimed at managing emotional reactions to stressful situations) is associated with higher levels of depressive symptomatology (Billings & Moos, 1981, 1984; Bombardier, D'Amico, & Jordan, 1990; Coyne et al., 1981; Holahan & Moos, 1987; Rosenblum & Keefe, 1983; Sullivan & D'Eon, 1990). The relation between problem-focused coping (e.g., strategies directly aimed at managing the stressful situation) and depression has been less clear (Lazarus, 1993; Coyne & Gottlieb, in press).

It has been suggested that the stresses associated with the onset of a debilitating illness may differ in significant ways from the day-to-day stresses of a long-standing illness (Lyons, Sullivan, Ritvo, & Coyne, 1995; Shontz, 1975). For example, the diagnosis of MS is likely to signal major changes in lifestyle including threats of reduced physical abilities, loss of employment, financial insecurity, loss of independence and changes to interpersonal roles (Edgley, Sullivan & Dehoux, 1991; Lyons et al., 1995). The individual diagnosed with MS must struggle with the reality of being diagnosed with an incurable debilitating disease, even though in the early stages of the illness, the individual may suffer from little or no functional impairment (Matson & Brooks, 1977; Brooks & Matson, 1982; Shontz, 1975). The early stages of MS are marked by the threat of loss, while in more advanced stages of the illness, coping with actual loss may become the primary focus (Lyons et al., 1995; Sullivan, Edgley, Mikail, Dehoux & Fisher, 1993).

Shontz (1975) described a pattern of response to the onset of debilitating illness characterized by competing tendencies to confront and to retreat from the reality of disability. In Shontz' model, denial is considered an adaptive strategy if it prevents the individual from becoming overwhelmed with the stress of illness and disability. Denial may function as a regulating mechanism allowing for the gradual management of threat (Horowitz, 1976; Roth & Cohen, 1986; Shontz, 1975). In the early stages of illness, denial may provide the individual with the needed time to assimilate threatening information about illness and disability, and consider alternatives for coping. Shontz' (1975) position on the adaptive value of denial contrasts with that of more recent models that suggest that avoidance and denial are maladaptive methods of dealing with stress (e.g., Lazarus & Folkman, 1984).

Little is known about the strategies that individuals invoke to deal with the onset of multiple sclerosis, or how these strategies influence the probability of the precipitation of a major depressive episode. The elucidation of a relation between coping and depression following the diagnosis of MS may have significant clinical implications. Determination of coping strategies that are associated with depression may permit early identification of individuals at risk for development of depression. In turn, the early identification of individuals who are at risk for developing major depression would allow for a more proactive approach to treatment, allowing for timely implementation of interventions aimed at facilitating adjustment to disability.

The method of assessing coping during the early stages of illness also deserves consideration. The bulk of research on coping and emotional distress has proceeded by requiring participants to complete checklist measures of coping and self-report measures of depressive symptomatology. However, reliance on checklist measures to assess coping has recently been the target of pointed criticism (Coyne & Gottlieb, in press; Stone, Greenberg, Kennedy-Moor, & Newman, 1991; Sullivan & D'Eon, 1990; Tunks & Bellissimo, 1988). Stone et al. (1991) have argued that many of the items included in checklist measures of coping are not applicable to many of the stresses that individuals experience. It has also been argued that checklist coping scales frequently contain items that are confounded with symptoms of depression thus rendering observed relations between coping and depression difficult to interpret (Stanton, Danoff-Burg, Cameron, & Ellis, 1994; Sullivan & D'Eon, 1990).

Interview methods of assessing coping have been advocated as one way of circumventing the shortcomings of checklist coping scales (Coyne & Downey, 1991; Coyne & Gottlieb, in press). It has been suggested that through carefully conducted interviews, the issues of confounded or redundant measurement can be minimized, and that interview methods may be less constrained by theory-driven apriori determination of relevant coping dimensions (Coyne & Gottlieb, in press). Additionally, it has been suggested that interview methods are less likely to be influenced by error variance contributed by items that bear little relation to the stressor that is being studied (Brown & Harris, 1978; Coyne & Gottlieb, in press).

The present study examined the relation between coping and depression in individuals recently diagnosed with MS. On the basis of Folkman and Lazarus' (1984) model of stress and coping, the prediction was that reports of avoidance or denial strategies would be more common in individuals with a diagnosis of major depression than in nondepressed individuals, and that the use of active cognitive or behavioral problem-focused coping strategies (e.g., information...
seeking, positive thinking) would be more common in nondepressed than depressed individuals. On the basis of Shontz’ (1975) model of adaptation to chronic illness, the prediction was that reports of avoidance or denial strategies would be less common in individuals with a diagnosis of major depression than in nondepressed individuals.

METHOD

Participants

Participants were 50 (12 men, 38 women) consecutive referrals to the MS Clinic of the Ottawa General Hospital. All participants were “new” cases of MS. New cases were defined as individuals who had not received a diagnosis of MS prior to evaluation at the MS Clinic (f.1). Diagnoses of MS were made according to the Poser, Paty, Scheinberg, McDonald, Davis, Ebers, Johnson, Sibley, Silberberg & Tourtellotte, (1983) criteria by one of four neurologists. Thirty three patients were married, 16 were single, and 1 was divorced. At the time of the evaluation, 26 patients were employed; the remainder were either on leave due to illness (n = 10) or had not been gainfully employed prior to the diagnosis of MS (n = 14). Thirty patients completed at least 12 years of education. The mean age of the sample was 36.2 years (SD = 8.8) with a range of 21 to 58 years.

Measures

Neurological Impairment. At the time of diagnosis, neurologists completed the Expanded Disability Status Scale (EDSS; Kurtzke, 1983). The EDSS is a structured neurological evaluation that yields a score from 0 to 10 with higher numbers reflecting increasing severity of neurological impairment associated with MS. Scores between 0 and 5 reflect increasing degrees of neurological involvement but not sufficient to significantly interfere with ambulation, scores greater than 5 indicate increasing impairment sufficient to require the use of an assistive aid for ambulation (i.e., cane, wheelchair), and a score of 10 indicates death due to MS. EDSS scores were only available on 45 patients.

Semi-structured coping interview. Participants responded to the following questions: When you were diagnosed with MS, how did you react?, What were the few months like after diagnosis?, If you met someone who had just been diagnosed with MS, what advice would you give them on how to deal with MS?, Is that how you've tried to deal with MS?, How else have you tried to deal with MS?. These questions were derived from extensive pilot testing and our previous research on coping with symptoms of MS (Lyons et al., 1995; Sullivan et al., 1993; Sullivan, Edgley & Dehoux, 1990).

Participants' responses were unitized on the basis of thematic content by two different judges who were blind to the experimental hypotheses. The two judges read transcripts of all participants' responses and coded responses into one of 6 coping categories; 1) information seeking ("I tried to find out everything I could about MS"; "I got all the information I could get from my doctor"), 2) seeking support ("I wanted to meet other people who had MS"; "I discussed it a lot with my husband"), 3) positive focus ("I tried to keep a positive attitude"; "I focused on all the good things in my life"), 4) avoidance/denial ("I tried not to think about it"; "I just went on as if nothing had changed"), 5) present focus ("I decided to take one day at a time"; "I tried to think only of what I had to do today"), and 6) negative focus ("I was shocked, I was a complete mess for weeks"; "I couldn't keep it out of my mind"). Coping categories were derived on the basis of their relevance to current models of coping with stress (e.g., Lazarus & Folkman, 1984; Billings & Moos, 1984; Shontz, 1975) as well as their ability to encompass the range of responses that individuals provided to the semi-structured interview. Percentage agreement values for the two judges' classification of coping strategies were, respectively, 1) 75%, 2) 78%, 3) 85%, 4) 80%, 5) 83%, and 6) 77%. Disagreements were resolved through discussion.

Depression. Structured interview was used to assess depressive illness (Diagnostic Interview Schedule, Affective Disorders; Robins, Helzer, Croughan, & Ratcliff, 1981) and diagnoses were made according to DSM-III-R criteria (APA, 1987). The Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) was used as a self-report measure of depressive symptom severity.

Procedure

All new patients referred to the MS Clinic of the Ottawa General Hospital over a two-year period were contacted by the clinic coordinator and asked to participate in the research. Over 90% of patients who were contacted agreed to participate. A project assistant then contacted patients to arrange a clinical interview that was conducted by one of three clinical psychologists. Participants were evaluated by a clinical psychologist approximately 8 weeks following diagnosis of MS.
RESULTS

Prevalence and Severity of Depression

At the time of the evaluation, 18 of the 50 patients (36%) met the DSM-III-R criteria for major depression, 11 patients (22%) met the criteria for adjustment disorder with depressed mood, and 21 patients (42%) showed no evidence of depression. A one-way analysis of variance on BDI scores revealed a significant effect for diagnostic category, F (2, 47) = 4.5, p < .01. Multiple comparisons (Student Newman-Keuls) revealed that patients with major depression scored significantly higher (M = 17.9; SD = 7.5) on the BDI than patients with no depression (M = 9.7; SD = 7.9), p < .05. BDI scores for patients with adjustment disorder (M = 12.6; SD = 12.6) did not differ significantly from scores for patients with major depression or no depression.

Diagnosis of depression did not vary significantly as a function of age F (2, 47) = .34, ns, gender, X² = 1.4, ns, marital status, X² = 1.5, ns, or employment status, X² = .40, ns. Patients with depression, adjustment disorder and no depression did not differ significantly with respect to severity of neurological impairment as measured by EDSS scores, F (2, 42) = .50, ns (for a more detailed discussion of relation between MS and depression in this sample, see Sullivan, Weinshenker, Mikail, & Bishop, 1995; Sullivan et al., 1995). The mean EDSS score was 2.1 indicating that most participants were experiencing mild neurological symptoms with little or no functional impairment.

Coping and Depression

Total number of coping strategies reported during the semi-structured interview did not differ significantly for patients with major depression (M = 2.8; SD = 1.2), adjustment disorder (M = 3.1; SD = 1.7), or no depression (M = 3.1, SD = 2.1), F (2, 47) = .12, ns. The percentage of patients reporting using different coping strategies to deal with their illness is displayed in Table 1. A series of Chi Square analyses were performed on these data to determine whether the likelihood of using a particular coping strategy varied as a function of diagnosis of depression. As shown in Table 1, the most frequently reported coping strategy was positive focus (n = 30). However, positive focus did not vary significantly with diagnostic status. Information seeking, which would be considered an example of a problem-focused coping strategy, was reported by approximately 30% of participants, but again, did not vary significantly with diagnostic status. Patients who were not depressed were significantly more likely to use present focus strategies than patients with major depression or adjustment disorder, X² = 5.8, p < .05. Patients who were not depressed were somewhat more likely than patients with adjustment disorder or major depression to use avoidance/denial strategies to deal with their illness, X² = 5.4, p < .06. No other differences approached statistical significance.

A stepwise discriminant function analysis was conducted to determine the unique contribution of each coping strategy to the classification of diagnosis of depression. For this analysis, each coping strategy was dummy coded as 0 or 1 to indicate the absence or presence of the coping strategy, respectively. Present focus entered in the first step of the analysis and contributed significantly to the classification of diagnosis of depression, Wilks Lamda = .82, equivalent F (2, 42) = 4.55, p < .01. No other variable contributed significantly to the classification of diagnosis of depression beyond the variance accounted for by present focus.

DISCUSSION

The findings of the present study indicate that there is a significant relation between the coping strategies individuals use to deal with the onset of MS and depressive symptomatology. Individuals who reported using strategies that were classified as present focus (i.e., "I decided to take one day at a time", "I tried to think only of what I had to do today"), and avoidance/denial ("i.e., I tried not to think about it") were less likely to be diagnosed with depression than individuals who did not use these strategies. The results of the discriminant function analysis showed that avoidance and denial strategies did not contribute to the prediction of diagnosis of depression independent of the variance accounted for by present focus. These results suggest that present focus and avoidance/denial may reflect a similar underlying coping dimension characterized by efforts to focus on current concerns and to divert attention away from more unpleasant aspects of living with a chronic illness.

Focussing on current concerns and diverting attention away from the stresses of chronic illness may represent a particularly adaptive approach to coping a diagnosis of MS. Given that the early stages of MS are typically associated with minimal physical disability, present focus may allow individuals to continue to attend to day-to-day responsibilities...
in a manner similar to how they proceeded through daily life prior to the diagnosis of MS. By focussing on day-to-day responsibilities and challenges, individuals may create a stimulus situation that appears more manageable. In addition, present focus may maximize the probably that individuals will perceive themselves as able to function effectively in spite of their illness. In contrast, a past or future focus may foster the development of depressive symptoms by highlighting the losses that the individual has experienced or the losses that the individual may experience in the future.

The finding that avoidance and denial strategies are associated with reduced likelihood of depression contrasts with the findings of several investigations showing that in community and clinical samples, avoidance and denial strategies are associated with increased risk for depression (e.g., Feifel, Strack, & Nagy, 1987; Folkman et al., 1993; Folkman & Lazarus, 1986; Lazarus, 1993; Quinn et al., 1987). However, the avoidance and denial strategies reported by patients in this study differ qualitatively from strategies described in checklist coping scales used in previous research. For example, items such as "I tried to reduce tension by taking more tranquillizing drugs" (Billings & Moos, 1984) reflect efforts to avoid or escape a distressing situation once coping efforts have failed. In the current study however, patients' reports that they "tried not to think about it" appear to reflect efforts to 'regulate' the stress of illness onset. As suggested by Shontz' (1975), avoidance and denial may become maladaptive only when these strategies interfere with illness prevention or health promoting behaviours (e.g., physician visits, dietary changes), interfere with adaptive compensatory behaviour (e.g., refusing to use a cane to manage gait instability) or when they increase the frequency or intensity of intrusive thoughts (Mullen & Suls, 1982; Roth & Cohen, 1986; Suls & Fletcher, 1985).

It is interesting to note that the severity of MS symptoms was not a significant determinant of depression. The restricted range of EDSS scores in the present study accounts, at least in part, for the failure to observe a relation between MS symptoms and depression. But more importantly, the lack of a relation between neurological impairment and depressive symptoms suggests that depressive symptoms observed in recently diagnosed MS patients cannot be explained solely as a reflection of the expression of neurological disease activity. The results of the present study indicate that the manner in which individuals attempt to cope with MS may be a more important determinant of diagnosis of depression than the severity of MS symptoms they are experiencing.

It is important to emphasize caution in interpreting the findings of the present study. Inferences about causal direction of relations between coping and depression must be viewed as speculative given limitations inherent in cross-sectional correlational designs. It has been argued in past research that depression may lead to a particular style of coping as opposed to the view espoused in this paper, that coping is causally related to depression. There are grounds, however, for favouring the latter interpretation of the present findings. Depressed participants were not more likely than nondepressed participants to engage in negative focus strategies as would have been expected if increased negativity and hopelessness associated with depression were the primary basis of observed findings. Second, nondepressed individuals did not use fewer coping strategies than depressed nor were they less likely to use what would be considered to be 'effortful' strategies such as information seeking.

From a clinical perspective, the results of the present study suggest that teaching individuals to focus on present day-to-day concerns, and to turn their attention away from the more threatening aspects of illness and disability may be useful components of programs aimed at facilitating adjustment to the onset of MS. The findings of the present study may be generalizable to other chronic illnesses insofar as they share characteristics of MS. For individuals with persistent pain disorders who are experiencing high levels of physical distress, or for individuals diagnosed with life threatening illnesses such as cancer, it may be more difficult to use present focus strategies. Constant reminders of deteriorating health or functional loss may require developing strategies aimed at restructuring meaningful activities, relationships or life values in order to minimize the negative emotional impact of illness (Lyons et al., 1995). This line of reasoning suggests that the contextual determinants of different chronic illnesses may have bearing on what is and what is not an effective coping strategy.

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Footnote

(1) Although patients included in this study received a diagnosis of MS only 8 weeks earlier, patients reported that they had experienced symptoms of MS for some time prior to diagnosis. On average, patients reported that symptoms of MS began 2.7 years prior to diagnosis (SD = 3.7). Time since symptom onset did not vary significantly as a function of depression, F (2, 45) = .15, ns.

[Table]

<table>
<thead>
<tr>
<th>Type of Coping Strategy</th>
<th>Major Adjustment</th>
<th>Not</th>
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<td>Depression Disorder</td>
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(n = 18) (n = 11) (n = 21)
Information Seeking 38% (7) 63% (4) 28% (6) .15

Seeking Support 44% (8) 27% (3) 14% (3) .11

Avoidance/Denial 50% (9) 36% (4) 76% (16) .06

Positive Focus 55% (10) 64% (7) 62% (13) .88

Present Focus 16% (3) 27% (3) 52% (11) .05

Negative Focus 61% (11) 64% (7) 38% (8) .24

Note. Values in parentheses represent the actual number of participants reported different coping strategies. Values under the heading p represent the probability values associated with chi square analyses.