Chronic Illness, Psychosocial Coping with

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Abstract

Improvements in health care technologies and treatments have resulted in increased life expectancies and improved disease management potential for individuals with chronic illnesses. To a great degree, quality of life may be determined by the ways they deal with the illness. Thus, identifying effective ways of coping with these diseases may lead to the development of efficacious interventions. Since 1980 there has been a substantial amount of research devoted to understanding the relation between coping with chronic illnesses and psychological adaptation. The majority of this research has used Lazarus and Folkman's Stress and Coping paradigm. Although there have been some consistent findings regarding general types of coping and their impact on psychological outcomes, particularly in the area of coping with pain, the enthusiasm for the empirical study of coping in general has dampened significantly over the course of the past several years. However, more recent studies have used idiographic and nomothetic designs that can more clearly elucidate the dynamic associations between stress, coping, and psychological adaptation to chronic illness. These advances hold a great deal of promise for the field of coping with chronic illness.

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1. Background
Improvements in health care technologies and treatments have resulted in increased life expectancies and improved disease management for individuals with chronic illnesses. To a great degree, quality of life for many individuals with these illnesses may be determined by the ways they deal with the illness. Thus, identifying effective and ineffective ways of coping with these diseases may lead to the development of more efficacious interventions for these individuals.

Since 1980 there has been a substantial amount of research devoted to understanding the relation between coping with chronic illnesses and psychological adaptation. Although there have been some consistent findings regarding coping and its impact on psychological outcomes, particularly in the area of coping with pain, the enthusiasm for the empirical study of coping in general has dampened significantly over the course of the past several years. Indeed, recent reviews of coping research have harshly criticized the literature, particularly assessment methodologies (see Coyne and Racioppo 2000). Thus, much of the initial promise for coping research to enhance clinical practice has not been realized.

2. Historical Perspective and Current Concepts of Coping

The psychological study of coping dates back to Sigmund Freud (1896/1966), who put forth the concept of defense mechanisms, defined as mental operations that kept painful thoughts and feelings out of awareness. The next major shift in the study of coping was brought about as a result of cognitive theories. The focus on intrapsychic processes that intervene between events and responses to events increased with the introduction of other cognitive theories such as Beck (1976). According to cognitive theories, cognitive coping mediated between stressful events and psychological and physical responses to stressful events. It was hypothesized that, by examining individual coping differences, a greater understanding of why people react differently to the same events would be achieved.

Research on stress and coping exploded with the work of Lazarus and Folkman (1984), who put forth the transactional stress and coping paradigm. According to Lazarus, coping refers to cognitive and behavioral efforts to manage disruptive events that tax the person’s ability to adjust (Lazarus 1981, p. 2). Chronic illness can pose a number of life stressors including loss of physical and social functioning, alterations in body image, managing difficult and complex medical regimens, and chronic pain. According to Lazarus and Folkman (1984) coping responses are a dynamic series of transactions between the individual and the environment, the purpose of which is to regulate internal states and/or alter person-environment relations. The theory postulates that stressful emotions and coping are due to cognitions associated with the way a person appraises or perceives his or her relationship with the environment. There are several components of the coping process. First, appraisals of the harm or loss posed by the stressor (Lazarus 1981) are thought to be important determinants of coping. Second, appraisal of the degree of controllability of the stressor is a determinant of coping strategies selected. A third component is the person’s evaluation of the outcome of their coping efforts and their expectations for future success in coping with the stressor. These evaluative judgements will lead to changes in the types of coping employed, as well as play a role in determining psychological adaptation. Two main dimensions of coping are proposed, problem-focused and emotion-focused coping. Problem-focused coping is efforts aimed at altering the problematic situation. These coping efforts include information seeking and problem solving. Emotion-focused coping are efforts aimed at managing emotional responses to stressors. Such coping efforts include cognitive reappraisal of the stressor and minimizing the problem.

How the elements of coping unfold over time is a key theoretical issue involved in studies of coping processes. Despite the fact that the theory is dynamic in nature, most of the research utilizing the stress and coping paradigm put forth by Lazarus (1981) has relied on retrospective
Towards the end of the twentieth century there has been an expansion in theoretical perspectives on cognitive coping. The literature on cognitive processing of traumatic life events has provided a new direction for coping research and broadened theoretical perspectives on coping methods of coping with chronic illness. According to cognitive processing theory, traumatic events can challenge people's core assumptions about them and their world (Janoff-Bulman 1992). The unpredictable nature of many chronic illnesses, as well as the numerous social and occupational losses, causes many individuals to question beliefs they hold about themselves. For example, the diagnosis of chronic obstructive pulmonary disease (COPD) can challenge a person's core beliefs about personal invulnerability. To the extent that a chronic illness challenges core beliefs, integrating the illness experience into their pre-existing beliefs should promote psychological adjustment. Cognitive processing has been used as the phrase to define cognitive activities that help people view undesirable events in personally meaningful ways and find ways of understanding the negative aspects of the experience, and ultimately reach a state of acceptance. Attempts to find meaning or benefit in a negative experience are ways patients may be able to accept the losses they experience. Focusing on the positive implications of the illness or finding personal significance of a situation are two ways of finding meaning in the illness. When considering meaning-making coping, one must distinguish coping activities that help individuals to find redeeming features in an event from the successful outcome of these attempts. For example, people who have a serious illness may report that as a result they have found a new appreciation for life or that they place greater value on relationships. Patients may also develop an explanation for the illness that is more benign (e.g., attributing it to God's will). While cognitive processing theory constructs have been applied to adjustment to losses such as bereavement (e.g., Davis et al. 1998), these constructs have received relatively little attention from researchers examining coping with chronic illness.

Another coping process that falls under the rubric of cognitive coping is social comparison. Social comparison (SC) is a common cognitive process whereby individuals compare themselves to others in order to obtain information about them (Gibbons and Gerrard 1991). According to SC theory, health problems increase uncertainty; uncertainty increases the desire for information and creates the need for comparison. Studies of coping with chronic illness have included social comparison as a focus. A certain type of SC, downward comparison, has been the focus of empirical study among patients with chronic illnesses such as rheumatoid arthritis (RA) (Tennen and Affleck 1997). Wills (1981) has suggested that people experiencing a loss can experience an improvement in mood if they learn about others who are worse off. Indeed, there is evidence to suggest that SC increases as a result of experiencing health problems (Kulik and Mahler 1997). One proposed mechanism for SC is that downward comparison impacts cognitive appraisal by reducing perceived threat. When another person's situation appears significantly worse, then the appraisal of one's own illness may be reduced (Aspinwall and Taylor 1993).

3. Assessment of Coping

3.1. General Coping Checklists

Folkman and Lazarus/Ways of Coping Checklist (WOC, Folkman and Lazarus 1980) has been one of the most widely used instruments to assess coping efforts. This instrument contains two major subscales, problem-focused and emotion-focused coping, as well as a number of subscales including wishful thinking, cognitive restructuring, information seeking, seeking support, self-
blame, and minimization. Instructions typically ask the individual to rate how he or she manages the stressor (Manne and Zautra 1989).

Another measure that has been used is the Coping Strategies Inventory (CSI, Tobin et al. 1989). The CSI distinguishes two dimensions of coping, engagement/disengagement strategies and focusing on the problem/focusing on emotions about the stressor. Problem-focused engagement is composed of problem-solving and cognitive restructuring; problem-focused disengagement is composed of problem avoidance and wishful thinking. Emotion-focused engagement is composed of social support and expressed emotion; emotion-focused disengagement is composed of social withdrawal and self-criticism.

Measuring meaning-making coping and other methods of cognitive processing has been done utilizing existing measures. Some aspects of meaning-making coping can be assessed using the cognitive reappraisal subscales of the COPE (Carver et al. 1989) and the Ways of Coping Checklist (Lazarus and Folkman 1984). Other means of measuring the process of meaning-making involve using measures of cognitive processing. For example, the Impact of Events scale (Horowitz et al. 1979) measures attempts to integrate a traumatic event with current schemas. Other studies have utilized questions tailored specifically for their population.

3.2. Illness-specific Checklists

The majority of illness-specific coping instruments have been designed to assess coping with pain associated with chronic illnesses such as rheumatoid arthritis (RA) and osteoarthritis (OA). Two instruments, the Vanderbilt Pain Management Inventory (VPMI) and the Coping Strategies Questionnaire (CSQ) have been the most widely used instruments. Both measures assess the degree to which patients employ a variety of cognitive and behavioral mechanisms to reduce the impact of painful episodes. Brown and Nicassio (1987) developed the VPMI to assess cognitive and behavioral pain-coping strategies. The 18-item VPMI has two subdimensions, active and passive pain coping. The CSQ comprises seven subscales measuring distinct coping strategies. Factor analyses of the CSQ in both RA and OA samples provide evidence for a two-factor solution, Coping Attempts and Pain Control and Rational Thinking (Keefe et al. 1987).

The Coping with Rheumatic Stressors (CORS, Lankveld et al. 1994) was specifically designed to measure stressor-specific coping in RA. This measure is unique in that it measures coping separately with three stressors, pain, limitations, and dependence. The three coping with pain scales are comforting cognitions, decreasing activity, and diverting attention. The three coping with limitation scales are optimism, pacing, and creative solution seeking. The two coping with dependence scales are making an effort to accept dependence and showing consideration.

3.3. Daily Diary Instruments

Only one instrument, the Daily Coping Inventory (Stone and Neal 1984), has been developed to assess daily coping. This inventory has been adapted for chronic pain coping by Affleck et al. (1992). Patients are asked whether or not they utilize each of seven categories of coping: (a) pain reduction attempt; (b) relaxation; (c) distraction; (d) redefinition; (e) vent emotions; (f) seek spiritual comfort; and (g) seek emotional support. These coping categories have been reduced using factor analyses to two factors, labelled emotion-focused and problem-focused coping (Affleck et al. 1999).

4. Studies Using the Stress and Coping Paradigm

4.1. Cross-sectional Studies
Early studies of coping using the stress and coping paradigm were cross-sectional and utilized retrospective checklists such as the WOC. The earliest studies divided coping into the general categories of problem- and emotion-focused strategies, and focused mostly on psychological outcomes, rather than pain and functional status outcomes.

Later studies have investigated specific types of coping. For example, Felton et al. (1984) examined two types of coping, wish-fulfilling fantasy, and information seeking, using a revision of the Ways of Coping Checklist. Wish-fulfilling fantasy was a more consistent predictor of psychological adjustment than information seeking. While information seeking was associated with higher levels of positive affect, its effects on negative affect were modest, accounting for only 4 percent of the variance. In a second study, Felton and Revenson (1984) examined coping of patients with arthritis, cancer, diabetes, and hypertension. Wish-fulfilling fantasy, emotional expression, and self-blame were associated with poorer adjustment, while threat minimization was associated with better adjustment. Scharloo et al. (1998) conducted a cross-sectional study of individuals with COPD, RA, or psoriasis. Unlike the majority of studies, illness-related variables such as time since diagnosis and the severity of the patient's medical condition were entered first into the equation predicting role and social functioning. Overall, coping was not strongly related to social and role functioning. Among patients with COPD, passive coping predicted poorer physical functioning. Among patients with RA, higher levels of passive coping predicted poorer social functioning.

Very few studies have examined coping with other chronic illnesses. Several studies have investigated the association between coping and distress among individuals with MS. Pakenham et al. (1997) categorized coping as either emotion- or problem-focused, and found that emotion-focused coping was related to poorer adjustment, while problem-focused coping was associated with better adjustment. In contrast, Wineman and Durand (1994) found that emotion- and problem-focused coping were unrelated to distress. Mohr et al. (1997) found that problem solving and cognitive reframing strategies are associated with lower levels of depression, whereas avoidant strategies are associated with higher levels of depression.

As previously noted, most studies have used instructions that ask participants how they coped with the illness in general, rather than asking participants how they coped with specific stressors associated with their illness. Van Lankveld et al. (1994) assessed how RA patients cope with the most important stressors associated with RA (pain, functional limitation, and dependence). When coping with pain was considered, patients with similar degrees of pain who used comforting cognitions and diverted their attention from the pain reported higher well-being. Limiting one's activity was associated with lower well-being. When coping with functional limitation was examined, patients who used pacing of their activity reported lower levels of well-being, and use of optimism was associated with higher well-being after functional capacity was controlled for in the equation. Finally, when coping with dependence was examined, only showing consideration was associated with higher well-being after functional capacity was controlled for in the equation.

4.2. Longitudinal Studies

Unfortunately, there have been relatively few studies that have employed longitudinal designs. Overall, passive coping strategies such as avoidance, wishful thinking, and withdrawal, as well as self-blame, have been shown to be associated with poorer psychological adjustment (e.g., Scharloo et al. 1999), and problem-focused coping efforts such as information seeking have been found to be associated with better adjustment (e.g., Pakenham 1999).

5. Studies of Coping with Chronic Pain
The majority of these studies have utilized longitudinal designs. For example, Brown and Nicassio (1987) studied pain-coping strategies among RA patients and found that patients who engaged in more passive coping when experiencing more pain became more depressed six months later than patients who engaged in these strategies less frequently. Keefe et al. (1989) conducted a six-month longitudinal study of the relationship between catastrophizing and depression in RA patients. Those patients who reported high levels of catastrophizing had greater pain, disability, and depression six months later. Other investigators (Parker et al. 1989) have reported similar findings. Overall, studies have suggested that self-blame, wishful thinking, praying, catastrophizing, and restricting activities are associated with more distress, while information seeking, cognitive restructuring, and active planning are associated with less distress.

As previously mentioned, several recent studies have employed prospective daily study designs in which participants complete a 30-day diary for reporting each day’s pain, mood, and pain-coping strategies using the Daily Coping Inventory (Stone and Neale 1984). These studies, which have been conducted with RA and OA patients, have shown that emotion-focused strategies, such as attempting to redefine pain to make it more bearable and expressing distressing emotions about the pain, predict increases in negative mood the day after the diary report. The daily design is a promising new method of evaluating the link between coping strategies and mood. More importantly, these studies can elucidate coping processes over time. For example, Tennen et al. (2000) found that the two functions of coping, problem- and emotion-focused, evolve in response to the outcome of the coping efforts. An increase in pain from one day to the next increased the likelihood that emotion-focused coping would follow problem-focused coping. It appeared that, when efforts to directly influence pain were not successful, participants tried to alter their cognitions and adjust rather than influence the pain.

6. Challenges to the Study of Coping with Chronic Illness

Recently, the general literature on coping has received a great deal of criticism from researchers (e.g., Coyne and Racioppo 2000). The main concern voiced in reviews regards the gap between the elegant, process-oriented stress and coping theory and the cross-sectional, retrospective methodologies that have been used to evaluate the theory. Although the theory postulates causal relations among stress, coping, and adaptation, the correlational nature of most empirical work has been unsuitable to test causal relations. In addition, retrospective methods require people to recall how they coped with an experience, and thus are likely to be influenced by both systematic and non-systematic sources of recall error. Coping efforts as well as psychological outcomes such as distress are best measured close to when they occur. Recent studies have used an approach that addresses these concerns. These studies have employed a microanalytic, process-oriented approach using daily diary assessments (e.g., Affleck et al. 1999). These time-intensive study designs allow for the tracking of changes in coping and distress close to their real-time occurrence and moments of change, are less subject to recall error, and capture coping processes as they unfold over time. The daily assessment approach also can evaluate how coping changes as the individual learns more about what coping responses are effective in reducing distress and/or altering the stressor. These advances may help investigators to more fully examine whether the methods used to cope with stressors encountered in the day-to-day experience of living with a chronic disease predict long-term adaptation. Unfortunately, this approach has only been utilized among individuals with arthritis and has not been applied to individuals dealing with other chronic illnesses.

Another key problem with coping checklists that has been noted in a number of reviews of the coping with chronic illness literature is the instructional format. The typical instructions used (e.g., ‘How do you cope with RA?’) are so general that it is not clear what aspect of the stressor the participant is referring to when answering questions. Thus, the source of the stress may differ
across study participants. There are problems even when the participant is allowed to define the stressor prior to rating the coping strategies used. The self-defined stressor may differ across participants, and thus the analyses will be conducted with different stressors being rated.

A third assessment problem regards the definition of coping. While Lazarus and Folkman (1984) regard only effortful, conscious strategies as coping, other investigators have argued that ‘automatic’ coping methods also fall under the definition of coping (Wills 1997). Indeed, some coping responses may not be perceived by the individual as choices, but rather automatic responses to stressful events. For example, wishful thinking or other types of avoidant types of coping such as sleeping or alcohol use may be categorized by researchers as a coping strategy, but not categorized as such by the individual completing the questionnaire because the individual did not engage in this as an effortful coping strategy. A related and interesting issue regards the categorization of unconscious defense mechanisms. Cramer (2000), in a recent review of defense mechanisms, distinguishes between defenses that are not conscious and unintentional and coping processes that are conscious and intentional. However, there has been an interest in repressive coping, suggesting that some researchers regard defensive strategies such as denial and repression under the rubric of coping. More clarity and consistency between investigators in the definition of coping, particularly when unintentional strategies are being evaluated, would provide more clarity for research.

A fourth assessment issue regards the distinction between ‘problem-focused’ and ‘emotion focused’ coping efforts. While researchers may categorize a particular coping strategy as problem-focused coping, the participant’s intention may not be to alter the situation, but rather to manage an emotional reaction. For example, people may seek information about an illness as a way of coping with anxiety and to alter their appraisal of a situation, rather than to engineer a change in the situation. The lack of an association between emotion-focused coping and psychological outcomes may, in part, be due to a categorization strategy that does not account for the intention of the coping. Studies utilizing these two categories to distinguish coping dimensions may wish to evaluate coping intention.

There are a number of additional methodological and conceptual challenges that are specifically relevant to studies of coping with chronic illness. First, relatively few studies control for disease severity in statistical analyses. Extreme pain or disability can result in both more coping attempts and more distress. Studies that do not take into account these variables may conclude mistakenly that more coping is associated with more distress. In addition, little attention has been paid to the effects of progressive impairment on the selection of coping strategies, and in the perceived effectiveness of those strategies. Chronic progressive illnesses may be expected to increase feelings of hopelessness. For example, Revenson and Felton (1989) studied changes in coping and adjustment over a six-month period and found that lower acceptance, more wishful thinking, and more negative affect accompanied increases in disability.

Another issue is the lack of longitudinal studies. Clearly, longitudinal studies would help the literature in a number of ways. First, this type of design might help clarify whether coping influences distress or whether coping is merely a symptom of distress, a criticism frequently raised in critiques of coping (e.g., Coyne and Racioppo 2000). Second, longitudinal studies may clarify the role of personality factors in coping. While some investigators suggest that personality factors play a limited role in predicting coping, other investigators argue that coping is a personality process that reflects dispositional differences during stressful events.

Although the lack of progress in the area of coping is frequently attributed to methods of assessment and design, the relatively narrow focus on distress outcomes may also account for some of the problem, particularly when coping with chronic illness is being evaluated. Chronic
illness does not ultimately lead to psychological distress for the majority of patients. Indeed, many individuals report psychological growth in the face of chronic illness, and are able to find personal significance in terms of changes in views of themselves, their relationships with others, and a changed philosophy of life (Tennen et al. 1992). While positive affect is included as an adaptational outcome in some studies (e.g., Bendston and Hornquist 1991), the majority of studies do not include positive outcomes. Positive affect will be a particularly important outcome to evaluate when positive coping processes such as cognitive reappraisal and finding meaning in the experience are examined, as these types of coping may play a stronger role in generating and maintaining positive mood than in lowering negative mood.

Finally, relatively few studies have focused solely on coping and distress and have not taken into account potential moderators such as level of pain, appraisals of controllability, gender, and personality. A careful evaluation of potential moderators will provide both researchers and clinicians with information about which circumstances particular coping strategies are most effective.

7. Conclusions

As Lazarus points out in his commentary in American Psychologist, ‘A premise that occurs again and again ... is that for quite a few years research has disappointed many who had high hopes it would achieve both fundamental and practical knowledge about the coping process and its adaptational consequences. I am now heartened by positive signs that there is a growing number of sophisticated, resourceful, and vigorous researchers who are dedicated to the study of coping’ (Lazarus 2000). It is clear that, despite the multiple methodological problems that this area of research has faced in the past, a heightened awareness of these limitations has led to the application of sophisticated methods that might assist this field in fulfilling the high hopes for this field of research. If investigators in the field of coping with chronic illnesses can adapt daily-diary methods to their populations, focus on specific stressors related to the illness when instructing participants to answer coping questions, include coping appraisals and the perceived efficacy of coping efforts, and carefully delineate illness-related, contextual, and dispositional moderators, the findings may lead to the development of effective interventions for clinicians hoping to improve the quality of life for these individuals.

Cross References

Chronic Illness: Quality of Life
Chronic Pain: Models and Treatment Approaches
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Illness Behavior and Care Seeking
Illness: Dyadic and Collective Coping
Pain, Health Psychology of
Pain, Management of
Rheumatoid Arthritis: Psychosocial Aspects
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References


