SUPPORTIVE AND UNSUPPORTIVE PROCESSES
WITHIN THE STRESS AND COPING CONTEXT

by

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This dissertation comprises three studies, and includes interview and questionnaire data from 446 people coping with different stressful life events, and 87 providers. Data were gathered from a community sample, undergraduates, and people with Myalgic Encephalomyelitis (M.E.) and their close others. The primary aims were to document exchanges between providers and recipients, and develop a framework within which to understand supportive and unsupportive behaviors. Five sets of antecedents were studied, including personality dimensions, need for assistance, symptoms, perceived causes of chronic illness, and constraints (attributions for unhelpful actions and factors that prevented more supportive exchanges). Three sets of consequences (number and type of responses, and awareness of unhelpful actions) and two moderating variables (stressor characteristics and source of support) were also investigated. Consistent with the traditional model of social support, different forms of emotional assistance were regarded as helpful across the three studies. Avoidance, provision of unwanted information, and minimization and maximization were considered to be universally unhelpful. In line with the specificity model, other forms of support, such as tangible and informational assistance, were mentioned as especially helpful or unhelpful depending upon characteristics of the stressor (such as physical incapacitation, controllability, or trajectory). Across the three studies, respondents mentioned attributions for unsupportive behaviors that emphasized causes that were benign such as ignorance/lack of knowledge or
understanding, emotional difficulties, additional stressors, and overprotectiveness. Such benign attributions were offered to close others and relatives more often than to distant others, and were not specific to situations with which providers had little familiarity. Approximately half of recipients reported that they did not say or do anything in response to unwanted actions by providers, which is consistent with the notion that many people coping with stressful life events may be reluctant to share their negative feelings with others. When they were not reticent, participants' responses were consistent with maintenance of harmony or conflict avoidance perspectives. Thus, recipients said that they discussed the issue rationally, downplayed the problem, blocked communication, or agreed with providers. Few recipients indicated that they attempted to maintain freedom and autonomy through screaming or acting in a hostile manner toward providers. Limitations, practical implications, and areas for future research were discussed.
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Supportive and Unsupportive Processes
Within the Stress and Coping Context

Chapter 1
Introduction

Social support research has traditionally emphasized the protective functions of relationships, that is the beneficial aspects of interacting with people in one's social network (see Cohen & Wills, 1985, for a review). Findings have generally supported the notion that social relationships moderate the effects of stressful life events (Kessler, Price, & Wortman, 1985; Lin, Simeone, Ensel, & Kuo, 1979; see Cohen & Syme, 1985, for a review). However, it is evident that not all interpersonal exchanges, or even support attempts, are appreciated by people coping with stressful life events (Cutrona, Cohen, & Igram, 1990; Dunkel-Schetter & Wortman, 1982; Lehman, Ellard, & Wortman, 1986). Another, albeit smaller, literature has begun to explore various aspects of negative interactions (e.g., Coyne, Wortman, & Lehman, 1988; Wortman & Lehman, 1985). These include people's unsuccessful efforts to help others (e.g., Dakof & Taylor, 1990; Dunkel-Schetter & Wortman, 1982; House, 1981; Lehman et al., 1986; Thoits, 1982; Wortman & Lehman, 1985), active criticism or rejection of others (e.g., Coyne et al., 1988; Lehman & Hemphill, 1990), and loss of mastery associated with excessive support provision (e.g., Perloff, 1987). The importance of investigating such issues is highlighted by the fact that negative social interactions are more highly related to adaptational outcomes than are positive interactions (e.g., Rook, 1984). This thesis seeks to advance
the latter tradition by examining not only supportive but also unsupportive processes toward people coping with stressful life events.

This dissertation comprises three studies that were conducted to examine connections between pre-behavioral, interpersonal, and post-behavioral processes between providers and recipients. "Providers" are defined as others who offer helpful and unhelpful actions to someone coping with a stressful life event, whereas "recipients" are those who receive such actions. Three distinct aspects of supportive and unsupportive exchanges are examined (see Figure 1). First, "antecedents" are those cognitive, motivational, and emotional processes that precede supportive and unsupportive behaviors. For example, a provider may think that the recipient does not want to be reminded about his or her difficulties, or a provider may experience distress at the prospect of interacting with the recipient. Second, "helpful and unhelpful behaviors" are those specific exchanges that occur between providers and recipients. For example, a provider may listen to the concerns of a recipient, or a provider may give advice on how to cope with a particular problem. Third, "consequences" refer to post-behavioral processes of a cognitive, behavioral, emotional, or interpersonal nature. For example, after receiving an action that is perceived as unhelpful, a recipient may respond by discussing the issue rationally with the provider or by avoiding future interactions with this person. Each of these three components of the support process will be discussed below, along with two potential moderating variables (source of support and stressor characteristics). First, however, the focus of this
dissertation and its goals will be presented in more detail.

**Scope of the Present Investigation**

One may investigate an issue from different levels of analysis. For example, Bronfenbrenner (1977, 1979) stresses the immediate household (microsystem), larger social systems (exosystem), and cultural beliefs and values (macrosystem). Although all levels are important for a complete understanding of the positive and negative sides of social exchange, the scope of inquiry in the present investigation is restricted to an examination of supportive and unsupportive interactions at the micro level of analysis. Specifically, individual and dyadic influences are examined, along with contextual factors and moderating variables that may affect the success or failure of supportive efforts.

Although the present framework (antecedents, behaviors, and consequences) is presented in a linear fashion, that is, with one discrete variable leading to other variables, one at a time, this has been done strictly for the purpose of clarity. The present set of studies is based upon the assumption that interpersonal processes are cyclical and nonlinear. That is, person A's perceptual processes and behavior influence person B's perceptual processes and behavior which, in turn, influence person A's perceptual processes and behavior, and so on (Watzlawick, Jackson, & Beavin, 1967). The pattern is theoretically continuous, with neither a beginning nor an end. Given the impracticality of investigating all aspects of this cycle at once, a decision was made to examine the process at one slice in time. Participants were asked to discuss the most important examples, ensuring that respondents discussed
psychologically meaningful interactions.

Antecedents, behaviors, and consequences may be punctuated very differently depending upon whose impressions are being collected. One person's "behavior" may be another's "consequence." Consider a maritally distressed couple in which the husband contributes passive withdrawal while the wife contributes nagging criticism. The husband believes that he withdraws only because his wife nags, whereas she explains her criticism of him as a result of his withdrawal. In essence, his view of the disagreements is that "I withdraw because you nag," whereas she believes "I nag because you withdraw." Although there may be agreement with respect to the behaviors that are exchanged between spouses, the partners may punctuate the sequence of events differently (Watzlawick et al., 1967). Once started, the cycle may be self-perpetuating unless or until one or both of the partners alter their own behavior.

The purpose of this dissertation is to examine supportive and unsupportive processes that occur between providers and recipients. Because the literature on negative aspects of social exchanges is in its infancy, this research is necessarily exploratory. It aims to integrate information from providers and recipients about beliefs and experiences prior to, during, and subsequent to the helpful and unhelpful exchanges. This thesis also presents an organizational framework based upon integration of research that has previously been conducted.

It is recognized that certain variables may be influential at more than one stage in the process. For example, personality factors are undoubtedly important in determining the manner in which an individual perceives a situation ("antecedents"), acts
toward someone coping with a stressful life event ("behaviors"),
and responds to another person who has offered unhelpful actions
("consequences"). To avoid redundancies, each variable will be
discussed in the most relevant section.

Perceived and Received Support

There are two separate research traditions within the
social support literature. The first, perceived or available
social support, emphasizes people's perceptions about whether
they are loved, valued, and esteemed by others (Pierce, Sarason,
& Sarason, 1992). The second, received support, includes
resources that are provided to the recipient regardless of how
the support is interpreted (Barrera, 1986). Dunkel-Schetter and
Bennett (1990) refer to these as cognitive and behavioral
support, respectively. The conceptual distinction between these
two constructs is supported by empirical evidence (Wethington &
Kessler, 1986). Studies examining the relations between
perceived support and supportive behaviors have reported
nonexistent (Lakey & Heller, 1988) or weak (Cutrona, 1986)
associations.

Although both aspects of support are important, the present
set of studies focuses exclusively on received support, on
interpersonal interactions or the behavioral component of
support. This is because perceived support is apt to be more
inaccurate than received support with respect to quantity and
quality of social resources (Dunkel-Schetter & Bennett, 1990).
Thus, the amount of support that is anticipated may be more or
less than actually materializes, and its effectiveness may also
be discrepant with expectations. There is some evidence which
suggests that people coping with stressful life events may
overestimate the amount of support believed to be available (e.g., Peters-Golden, 1982). Providers may be ineffective because of intrapersonal (Wortman & Lehman, 1985) or interpersonal distress (Lehman et al., 1986), poor understanding of effective responses (Lehman & Hemphill, 1990), and misconceptions about the support process (Silver & Wortman, 1980; Wortman & Silver, 1989). Recipients' lack of awareness of these factors may lead them to inaccurately estimate support that is forthcoming.

Individual difference variables may be implicated in both the cognitive and behavioral aspects of support, but they may be particularly important with respect to the former component (Lakey & Cassady, 1990). This is because it is more difficult to distort an event that has actually happened than it is to distort the perception of availability during times of crisis. Thus, disconfirmation of one's views may occur with received support, whereas one's perceptions of available support are often not subject to empirical validation in the same way. Moreover, perceived support is related to a negative recipient outlook bias (Vinokur, Schul, & Caplan, 1987), which may influence ratings of mental health. This latter possibility may account for the fact that there is often a stronger association between perceived than received support and measures of psychological adjustment (Barrera, 1981; Sarason, Pierce, & Sarason, 1990; Wethington & Kessler, 1986). Moreover, to the extent that current views of available support are based on past experiences (Cutrona, 1986), it is perhaps prudent to measure such experiences directly via actual interactions.

A final reason for the emphasis upon received support in
the present set of investigations is that much of our understanding of social support has relied on findings from perceived support. Pearlin and McCall (1990) have noted that the social and interactional character of support has either been ignored altogether or largely taken for granted. One aim of this dissertation is to address this issue by investigating supportive and unsupportive behaviors among people coping with different types of stressful life events.

**Behaviors: Helpful and Unhelpful Exchanges**

Previous social support studies have tended to emphasize general questions about, for example, the extent to which respondents feel loved. As a result, very little is known about specific interactions that occur between providers and recipients during stressful life events, and this lack of knowledge has impeded (1) progress linking support to health outcomes and (2) the development and implementation of effective strategies to help someone cope with stressful life events (Lehman et al., 1986). Some recent studies have attempted to fill these gaps by investigating specific behaviors from the recipient’s point of view (e.g., Dakof & Taylor, 1990; Martin, Davis, Baron, Suls, & Blanchard, 1994).

An examination of both the helpful and unhelpful aspects of social exchanges is important for at least two reasons. First, studies have noted that unsupportive elements of interpersonal relationships are strongly and consistently negatively associated with mental health outcomes (Fiore, Becker, & Coppel, 1983; Rook, 1984). Second, unsupportive behaviors are unfortunately not rare occurrences. For example, Davidowitz and Myrick (1984) found that, among the bereaved, the majority of
statements (80%) were considered unhelpful from the recipient's point of view. Despite these findings, surprisingly few researchers have investigated the negative side of relationships.

The little research that has been conducted has documented particular exchanges that occur between providers and recipients (e.g., Dakof & Taylor, 1990; Lehman & Hemphill, 1990; Martin et al., 1994). For example, Lehman et al. (1986) reported specific behaviors that were regarded as especially helpful or unhelpful by bereaved individuals interviewed 4-7 years after the loss of their spouse or child in a motor vehicle accident. Support attempts most frequently mentioned as helpful were contact with a similar other and provision of emotional support; those most frequently mentioned as unhelpful were giving advice and encouraging recovery. Data obtained via this methodology are informative because participants describe, in their own words, issues of importance to them.

The present research attempts to advance the literature in this area in several ways. Previous research has focused almost exclusively on the recipient's point of view. The paucity of data available from the provider's perspective includes behavioral intentions to assist someone in hypothetical scenarios (e.g., Dunkel-Schetter & Skokan, 1990; Lehman et al., 1986) rather than reports of actual support interactions. This thesis continues to chart out the territory of supportive and unsupportive behaviors within the context of coping with stress, but extends the literature by examining providers as well as recipients.

In an attempt to further understanding in this research
area, contextual factors potentially related to helpful and unhelpful actions will be explored. These factors or processes may exist prior to the acts (i.e., "antecedents") or following the acts (i.e., "consequences"). In fact, although we have a basic understanding of the types of helpful and unhelpful exchanges that occur, we know virtually nothing about the context within which they transpire. However, understanding of context is vital because (1) behavior does not occur in isolation; (2) the same behavior may spring from different origins; and (3) different results may be produced by the same causes (Watzlawick et al., 1967). Thus, a mere examination of supportive and unsupportive acts is problematic. At best it may yield an incomplete understanding and at worst erroneous conclusions.

Justification for an initial attempt at examining these issues rests on the assumption that social support is a dynamic process that comprises an interwoven sequence of events rather than merely supportive and unsupportive actions offered in a vacuum (Watzlawick et al., 1967). Work that has focused on the more dynamic aspects of support processes has been exclusively theoretical (e.g., Coyne et al., 1988). This dissertation is an initial attempt to map out the terrain surrounding helpful and unhelpful actions, a necessary prerequisite for further empirical and theoretical development.

Antecedents

Within the context of the present research, antecedents reference cognitions, affective states, personality and situational factors that temporally precede the offering of supportive or unsupportive actions. Antecedents, then, refer
specifically to the factors that may contribute to what providers say or do. Based upon previous theorizing (e.g., Dunkel-Schetter & Skokan, 1990; House, 1981), this dissertation focuses on five main categories of variables that may lead providers to offer particularly helpful or unhelpful actions.

First, dispositional characteristics provide a backdrop against which specific behaviors occur or are interpreted. The relatively enduring ways that people view and respond to environmental stimuli will undoubtedly impact upon their interactions with others. Providers' personalities, therefore, may predict their particular helpful and unhelpful exchanges with recipients. For instance, Agreeable individuals are characterized by interpersonal trust and consideration of others (Wiggins, 1995), and are apt to offer nurturant behaviors (Alden, Wiggins, & Pincus, 1990). Extraverts tend to experience positive emotions, be sociable, and engage in high levels of activity (Costa & McCrae, 1985). Previous research has shown that Extraversion is positively related to social support (Connell & D'Augelli, 1990; Duckitt, 1984). Neuroticism, the tendency to experience emotional distress, may be negatively associated with social support behaviors (Duckitt, 1984), and positively related to the use of regressive or coercive tactics in interpersonal relationships (Buss, 1992). Because Conscientiousness and Openness to Experience have been relatively less studied in personality research (Marshall, Wortman, Vickers, Jr., Kusulas, & Hervig, 1994), particularly in the area of social support, only tentative predictions may be offered. People high on Openness tend to be philosophical, abstract-thinking, and imaginative (Trapnell & Wiggins, 1990).
Therefore, it is expected that helpful and unhelpful actions may relate to the use of novel or unconventional strategies toward recipients. Because they are undisciplined, forgetful, and disorganized (Trapnell & Wiggins, 1990), those low on Conscientiousness may not offer helpful actions because their good intentions are not realized. In order to obtain a comprehensive understanding of associations between personality and helpful and unhelpful behaviors, the five dimensions of personality (Nurturance, Dominance, Neuroticism, Conscientiousness, and Openness to Experience) will be correlated with measures of social support.

Second, prior to engaging in support attempts, the potential provider must perceive a need for assistance by the recipient (Latane & Darley, 1970). Interestingly, previous researchers have not assessed the ways in which support providers become aware that need exists. It is possible that potential providers may become aware of need by asking or being asked by recipients, but at times this may be difficult for one or both of the parties to do (Silver, Wortman, & Crofton, 1990). Recipients may not want to risk rejection or highlight their victimization status, whereas providers may resist asking recipients either because they are concerned about making the potential recipient feel bad or they may not want to invest the time and energy needed to follow through with the request if an affirmative response is obtained. Because of these potential problems, providers and recipients may not be completely candid with one another. In such situations, providers may rely on less direct indicators of need. For example, providers may perceive need by relying on nonverbal signs of distress such as
crying, movement of facial muscles, adoption of certain body postures, or alterations in behavior (such as the recipient withdrawing from a particular situation). Because nonverbal factors are highly subject to interpretation, they may yield less accurate information than that obtained from verbal communication (Watzlawick et al., 1967). Providers may also assess need on the basis of beliefs about the coping process (Wortman & Silver, 1989), through disclosure from a mutual friend, or the like.

Third, perceptions of symptoms may also be associated with supportive and unsupportive behaviors. Providers and recipients will be asked to report on physical (Goldstein, 1992; Komaroff & Buchwald, 1991) and psychological (Derogatis & Melisaratos, 1983) symptoms experienced by recipients. The logic is that recipients who have an abundance of symptoms will be unable to accomplish much, and will need more assistance from those in their social network than those who endorse fewer complaints. Based upon the foregoing, it is assumed that (1) providers who indicate fewer symptoms than their yoked recipients will view the stressful life event as being less serious than the person coping with the stressor, and that (2) the size of discrepancy between a provider's and recipient's symptom reporting is a measure of magnitude of congruence of perceived seriousness. Incongruence scores will be analyzed in connection to supportive and unsupportive actions. It is hypothesized that (1) reports of more physical symptoms will be related to more helpful and less unhelpful actions and (2) greater discrepancies between providers and recipients for physical symptoms will be associated with more unhelpful actions and fewer helpful actions
by providers from the recipients' point of view. With respect to psychological symptoms, providers may offer primarily supportive actions if they believe the psychological symptoms are due to stresses and limitations imposed by the illness. On the other hand, providers may offer primarily unsupportive behaviors, or no actions at all, if they believe that the psychological symptoms are due to recipients' lack of effort.

Fourth, providers' views regarding the cause of an illness may be important in leading to a greater understanding of why they say or do what they do. Guided by the research of Weiner and his colleagues (Schmidt & Weiner, 1988; Weiner, 1985; Weiner, Perry, & Magnusson, 1988), an examination of attributions and their relations to supportive and unsupportive behaviors will be undertaken. According to attribution theory, the perceived cause of a negative life event may influence providers' subsequent affective reactions and behavioral responses. For example, Weiner et al. (1988) found that physically-based stressful life events were perceived as onset-uncontrollable, and elicited pity, no anger, and judgments to help. In contrast, mental-behavioral events were perceived as onset-controllable, and elicited little pity, much anger, and lack of assistance. However, Weiner et al. (1988) did not include support providers of actual people coping with stressful life events, and instead relied on respondent's views of hypothetical people coping with one of a number of negative life experiences.

Rather than investigating people's views of several stigmas, and comparing mean ratings between event types, individuals with differing views within a single chronic illness
category will be examined. Specifically, close others (providers) of people with Myalgic Encephalomyelitis (M.E.), an illness characterized by extreme levels of fatigue and flu-like symptoms, will be asked about their views regarding the suspected etiology of their close other's illness. Because of ambiguity regarding the onset and course of M.E., it is anticipated that different providers may consider the illness to be caused by factors ranging from psychological, physical, environmental, and biological. Furthermore, it is proposed that such views may be associated with reported behavior toward people with the illness. Thus, it is anticipated that providers' beliefs that M.E. is primarily caused by psychological factors will be related to fewer supportive actions, and more unsupportive actions, whereas beliefs that the illness is largely due to physical causes will be associated with more supportive actions and fewer unsupportive actions.

Fifth, antecedents will be measured by examining the constraints that have some bearing on providers' subsequent unhelpful actions or lack of helpful behaviors. Previous research suggests that providers may be influenced by several factors such as ignorance or paucity of information about the appropriate course of action (Peters-Golden, 1982), lack of experience with the stressor (Lehman & Hemphill, 1990), interpersonal anxiety (Wortman & Lehman, 1985), lack of resources such as time or money (Darley & Batson, 1973; Hobfoll, 1989), discrepant coping styles of providers and recipients (Lane & Hobfoll, 1992), and expectancy of negative consequences (Fichten & Bourdon, 1986). Nonetheless, it is not clear whether providers and recipients view such factors as being important in
preventing providers from acting in more favorable ways. In an attempt to determine constraints that are operating on providers, people coping with stressful life events and their close others (such as partners, close friends, or relatives) initially will be asked why they believe providers said or did the unhelpful things that they did. Constraints will be assessed more directly by asking respondents what they think prevented providers from acting in a way that recipients would have preferred. Such a question will prompt respondents to think back to the things that were happening before the upsetting exchanges occurred.

Consequences

Social interaction theorists (e.g., Gottman, Notarius, Gonso, & Markman, 1976) have emphasized the need to investigate not only the supportive and unsupportive acts and their precipitants, but also the recipient’s response. Despite its importance, there have been few studies that have examined this latter issue. To the extent that behaviors are often repeated within the communication process, and certain actions constrain the range of subsequent responses, a reciprocal cyclical process or pattern may develop across time (Patterson & Reid, 1970).

The little research that has focused on recipient’s reactions to supportive and unsupportive behaviors has emphasized the physical and psychological consequences of support receipt (see Hobfoll & Parris Stephens, 1990, for a review). For example, considerable research has documented the beneficial long-term effects of support upon health (Gore, 1978; House, Umberson, & Landis, 1988). A recent review pointed out that there is substantial evidence documenting higher mortality
rates among people lowest in social integration (House, Landis, & Umberson, 1988). Similarly, social support processes are related to immune functioning (Baron, Cutrona, Hicklin, Russell, & Lubaroff, 1990), well-being (Turner, 1981), satisfaction (Hobfoll, Shoham, & Ritter, 1991), and psychological symptomatology (Sandler & Barrera, 1984), to name a few.

Despite the emphasis upon physical and psychological effects of support (House, 1981), there are certain consequences that have been less thoroughly investigated. Consequences in the present set of studies include those interpersonal, perceptual, and behavioral responses that unfold subsequent to helpful or unhelpful actions. Three main issues to be examined here include (1) the proportion of participants who have received unhelpful actions that respond in some manner to the person who has offered them, (2) the types of responses that are made by recipients, and (3) awareness by providers that their behavior was unappreciated. Awareness comprises two related issues: (1) the point at which providers became aware of the unhelpfulness of their actions, and (2) the manner in which that awareness was obtained.

The first issue concerns whether or not recipients said anything in response to the unhelpful actions. This is potentially important because it offers insight into the amount of information that providers have regarding the unhelpfulness of their actions. There is some evidence that people coping with stressful life events may be reluctant to share their negative feelings with others (Dunkel-Schetter, 1984; Lehman & Hemphill, 1990), and this tendency may be exacerbated when recipients are to communicate with someone whose actions are
unappreciated. If recipients fail to communicate with their significant others, then providers may be poorly informed about the unhelpfulness of their actions, and such negative exchanges may then be more likely to occur in the future.

Recipients who indicate that they did or said something in response to the providers' unhelpful or upsetting actions will be asked to describe exactly how they responded. This question examines whether recipients' responses are generally appropriate or inappropriate to the situation (Barrera, 1981; Coyne et al., 1988; Dakof & Taylor, 1990). For example, previous research in the area of interpersonal conflicts has determined that people may respond to dyadic problems in numerous ways. Perhaps the most socially sanctioned of these is rational discussion (Straus, 1979). In fact, therapists of maritally distressed patients often prescribe interventions to enhance verbal exchanges between partners, such as communication training and clarifying one's feelings and opinions (Schmaling, Fruzzetti, & Jacobson, 1989).

 Nonetheless, it is clear that, particularly in conflictual relationships, negative responses are also likely. These may include complaining, arguing, demanding and, in extreme circumstances, violence (Pan, Neidig, & O'Leary, 1994). Moreover, people coping with stressful life events may respond to criticism of others by withdrawing physically (Burchill & Stiles, 1988). This is particularly true if there has been a cycle of interactions in which providers respond to distress of recipients with annoyance and unsupportive actions (Coyne, 1976). In addition to physical avoidance, recipients may engage in psychological avoidance by explicit rejection, avoidance of
confrontation, or ignoring what the provider has said or done (Jung, 1989).

Various theoretical perspectives may be useful in elucidating post-behavioral processes; a summary of equity, reactance, and threat to self-esteem theories is offered below. Given that there are no well developed perspectives to account for helpful and unhelpful actions, it is not the goal of the present set of studies to test specific predictions from these theories. Rather, the present set of studies is necessarily exploratory, and the different perspectives are utilized as frameworks within which to better understand the support process. Using the theories as a guide, I consider possible responses to interactions that may occur between providers and recipients.

Equity theories are based on assumptions that the lack of equity in interpersonal relationships leads to discomfort, which may be restored by altering inputs or outputs, or by cognitively distorting them (e.g., Walster, Walster, & Berscheid, 1978). Such a formulation emphasizes negative reactions to aid (Fisher, Nadler, & Whitcher-Alagna, 1982), that is, feelings and responses that occur as a result of disproportionate inputs of providers relative to recipients. In essence, equity theory expects unfavorable reactions to being overbenefited, and efforts to restore equity or leave the relationship. Equity theories, however, fail to explain exactly how recipients respond in order to establish parity. That is, what type of behaviors will recipients perform? One goal of the present set of investigations is to document specific actions that recipients engage in subsequent to receiving unhelpful exchanges
Reactance theory (Brehm, 1966) is perhaps more relevant for close relationships in which one individual is coping with a negative life experience. The theory posits that perceived reduction in freedom of choice results in a negative psychological state. People are then motivated to restore such freedom by engaging in the threatened behavior, or by altering perceptions and judgments. For example, intrusiveness on the part of an overinvolved provider may lead the recipient to preserve autonomy by "refusing to be pushed around" and engaging in the undesired behavior anyway (Coyne et al., 1988). Reactance theory, then, emphasizes recipient behaviors that map directly onto those statements or actions by providers.

Fisher et al. (1982) have developed a comprehensive threat to self-esteem model to account for recipient reactions to assistance. Briefly, the model assumes that dependency relations have potential for self-threat, and that there is a mixture of beneficial and negative features of support. For example, instrumental aid may be obtained at the expense of independence. Furthermore, reactions to aid are determined by its predominantly supportive or threatening aspects. Of particular interest to the present set of studies, negative or defensive responses to assistance may be obtained when there are certain aid-related conditions, such as negative donor attributes and motivation, inability to reciprocate, threat to autonomy, and aid that implies the loss of important freedoms. Again, however, the specific manner in which participants may respond is not addressed by the model, and is a focus of investigation in the present set of studies.
Few researchers have investigated directly awareness of the supportiveness of particular behaviors. However, interaction-based approaches to social support may help to shed some light on these processes. Although providers and recipients may agree about the supportiveness of certain behaviors (Lehman et al., 1986), this is not always the case. For example, Melamed and Brenner (1990) studied couples in which one of the spouses had rheumatoid arthritis (RA), and noted that a substantial percentage of partners disagreed about supportiveness of a variety of actions. Similarly, support providers may believe that efforts of cheerfulness and compliments about patient’s appearance would be supportive, even though the patients themselves may disagree (Peters-Golden, 1982). These findings suggest that a subset of providers may be unaware that their actions were unhelpful in the first place.

The third issue, development of awareness at some point in the support process, will be examined in two ways. First, people with M.E. and their close others will be asked to think back to the most upsetting exchange between them. Then, respondents will be asked when, if at all, awareness was obtained. Responses to such a question will be important to assist in our understanding of the manner in which the support process unfolds. For instance, providers may recognize immediately after saying or doing the unhelpful things that their actions were unappreciated. Then, they may use this awareness as a guide to their future behavior, or believe that such things needed to be said or done, even though they were not appreciated by the recipient. Alternatively, providers may not recognize that what they said or did was unhelpful, and may
arrive at such an understanding only after an intervening period of time.

Providers may make inferences about the appropriateness of their behaviors in a number of ways. To further our understanding in this area, a second question will be asked regarding how providers became aware that their actions were unhelpful or upsetting. In order to answer this question, providers may rely on statements made by recipients, nonverbal indicators, or obtain information from a third party. Each of these will be discussed in turn.

Research has indicated that disclosure about a traumatic event may have beneficial effects (Pennebaker, 1989). However, for various reasons, people coping with stressful life events may find it difficult to talk about their problems, and in some cases discussion may have deleterious effects (Costanza, Derlega, & Winstead, 1988). Recipients may be particularly hesitant to talk to providers about the unhelpful things that have been said or done by the latter because of the appearance of being ungrateful for successful supportive efforts, tensions inherent in face-to-face interactions, and discouragement of open communication that may occur when recipients attempt to discuss their thoughts and feelings (Wortman & Lehman, 1985).

If providers are unable to obtain useful information from verbal statements by recipients to assess awareness of the unhelpfulness of their actions, they may rely on nonverbal strategies. Nonverbal behavior and communication involve the intentional sending of various messages to another individual by means of symbols or signs (Wiener, Devoe, Rubinow, & Geller, 1972). Although nonverbal communication may comprise a number
of components, providers and recipients, who are unlikely to be experts in this area, probably will only be cognizant of a subset of strategies that influence actions. Nonverbal behaviors that may be used to gain awareness include gestures (movement of the body, or any part of it, that is considered expressive of thought or feeling), facial expressions, physical proximity between one person and another, and eye contact (Siegman & Feldstein, 1987).

A third way in which providers may assess that their actions were unappreciated is by talking with mutual friends. Copers may be reluctant to reveal this information directly to providers, as the former may want to avoid the negative social consequences that may ensue (Lehman & Hemphill, 1990). Moreover, such information is inconsistent with the positivity bias that is inherent in social interactions (Taylor, Falke, Mazel, & Hilsberg, 1988). Nonetheless, recipients of unhelpful actions may be willing to disclose their dissatisfaction to other people who did not offer the unhelpful actions. In some instances, particularly among family members, the confidant may report back to providers that their actions were unappreciated. Therefore, awareness is obtained through discussion with a third party, and not with the recipient directly (see Taylor, Aspinwall, Giuliano, & Dakof, 1993, for data on a related topic, "storytelling").

The negative interaction (i.e., "unhelpful actions") itself may offer clues to providers about the unhelpfulness of behaviors. However, if providers do not attend closely to the responses to their actions, and engage in a superficial analysis of exchanges, providers may not yield any useful information
from them. These latter possibilities suggest practical implications; in such situations it may be important for professionals to inform providers and recipients about the development of problematic exchanges, and about the implementation of more effective strategies.

**Moderating Variables**

Thus far, discussion has emphasized variables that fit into one of the three categories of antecedents, behaviors, or post-behavioral consequences. However, there are other variables that cut across these categories, and may moderate their relations. Two variables, source of support and stressor characteristics, are postulated to affect the relations between the antecedent and behavioral components (see Figure 1).

**Relationship between provider and recipient.** There is evidence that source of support plays an important role in the support process. For instance, data suggest that type of relationship between providers and recipients is associated with the latter's response to negative life events (Coyne & DeLongis, 1986). Thus, spouses may protect one another from the deleterious effects of stressful life events, and the presence of other intimate relationships does not seem to be able to compensate for the absence of a close partner (Brown & Harris, 1978). Social support from family versus friends is distinguishable, has different correlates, and is worthwhile to measure separately (Procidano & Heller, 1983).

Close relationships are often characterized by conflictual affective bonds. Thus, most anger that adults experience in their daily lives is with blood relatives, followed by their partners (Fitz & Gerstenzang, 1978). Argyle and Furnham (1982,
investigated different relationship types, and noted distinctive patterns of satisfaction and conflict. Thus, the spouse was characterized by the highest levels of both conflict and satisfaction than more distant relationships. The ratio of conflict to satisfaction was greater in less voluntary relationships, such as with relatives.

The above research, despite documenting the importance of different types of relationships, fails to examine the specific exchanges that occur between providers and recipients, and how such behaviors are associated with attributions for the unhelpful behavior. The little research that is available is consistent with the notion that behaviors offered, and recipient's perceptions of them, differ according to relationship between provider and recipient. Thus, Dakof and Taylor (1990) and Martin et al. (1994) noted that esteem/emotional support was most common in close relationships, whereas information and advice were more often offered by medical care experts. Among older adults, instrumental support was primarily offered by children, whereas emotional support was more typically offered by spouses or friends (Rook, 1987). Finally, Primomo, Yates, and Woods (1990) studied women with chronic illnesses, finding that they perceived more support from their partner than from any other source. Whereas family members provided more affective support than friends or others, friends provided more affirmation than family or others.

Lehman and Hemphill (1990) asked people with multiple sclerosis (MS) to indicate unhelpful actions that were offered to them and their attributions for these actions. The researchers found that by far the most common attribution for
unhelpful support attempts was a class of benign attributions, such as lack of knowledge or understanding of the illness and attempts to be helpful. At a broad conceptual level, source of support provider (e.g., relatives, close others, or more distant others) may be an important variable to account for such benign interpretations. It is reasoned that recipients may offer benign interpretations for those who are generally supportive or emotionally close to them, while not extending such views to more distant others. Such a rationale is an extension of findings among maritally distressed and nondistressed couples. For example, Bradbury and Fincham (1992) found that benign attributions were offered by maritally nondistressed couples, whereas maladaptive attributions were offered by distressed couples, and that pejorative attributions were related to higher rates of negative behavior.

The above findings will be extended in the present set of studies by examining different relationships in order to obtain a range of closeness. Different types of relationships varying along the closeness dimension may be associated with discrepant views regarding why unhelpful actions were offered. Recipients may be unwilling to entertain negative thoughts about close others because of fear of rejection or alienation (Wortman & Lehman, 1985); such issues are much less likely to be of concern in an emotionally distanced relationship.

Stressor characteristics. Previous researchers have noted possible reciprocal links between social support and stressors (Thoits, 1982), and the interdependence of stress and support processes (Eckenrode & Gore, 1981). Many negative life events disrupt or reduce the availability of support. For example,
bereavement often involves the loss of a potential provider. Cessation of a romantic relationship may entail not only loss of a former source of support, but also disruption of the entire social network (Shinn, Lehmann, & Wong, 1984). Work stress, particularly loss of a job, may undermine the presence of opportunities for support. In fact, all events on Holmes and Rahe's (1967) list of stressful life events have direct or indirect implications for social support.

Events that are judged as highly stressful constitute a loss or threat of a loss (see Hobfoll, 1989, for a review). Moreover, negative life events often involve sequences of events in which multiple losses occur (Wortman & Silver, 1987). One distinction between minor and major stressors is that the latter challenge the stability of the individual's presumptive world (Janoff-Bulman & Timko, 1987). The present set of studies examines significant stressors, as opposed to hassles or problems associated with everyday life.

Specificity models propose that different life experiences require different types of support because they pose different coping requirements (Cohen & McKay, 1983). Although well-intentioned, others' efforts may be seen as aversive to recipients because of a lack of congruence between support offered and the individual's current needs (Lehman et al., 1986).

According to Cohen and McKay's (1983) stressor-support specificity model of the buffering hypothesis, negative life events involving resource deficits require tangible support such as money, transportation, or assistance with everyday tasks. In contrast, stressors in which emotional difficulties are due to
interpretations of the situation require appraisal support. Stressors associated with attributions of failure are offset by esteem support.

The limited data that are available tend to support a specificity model. For example, Gottlieb (1978) found that emotional support was perceived as most helpful for problems of an emotional nature, and instrumental support and active helping behaviors were most helpful for financial problems. Similarly, practical assistance was most helpful for diabetics (Dunkel-Schetter, Blasband, Feinstein, & Bennett Herbert, 1992), the chronically ill (Lehman & Hemphill, 1990), and headache patients, but not irritable bowel syndrome patients (Martin et al., 1994). In contrast to the bereaved and cancer patients, few people with MS mentioned contact with similar others as especially helpful, perhaps because they were exposed to others with more advanced cases of the illness, thus providing a threatening view of the future (Lehman & Hemphill, 1990).

In terms of unhelpful actions, minimization and trivialization appear to be important for people experiencing threats/losses such as cancer patients (Dakof & Taylor, 1990; Dunkel-Schetter, 1984), the bereaved (Lehman et al., 1986) and MS patients (Lehman & Hemphill, 1990), but not those facing challenges such as diabetics (Dunkel-Schetter et al., 1992). Diabetics were unique in reporting that attempts to show love and concern through offerings of restricted foods, and reprimands from deviating from diet, were unappreciated (Dunkel-Schetter et al., 1992). The bereaved's focus on others' encouragements of recovery and advice-giving may be specific to stressors in which the perceived trajectory is positive, which
would explain fewer endorsements among cancer and MS samples (Lehman & Hemphill, 1990).

Cutrona and Russell (Cutrona, 1990; Cutrona & Russell, 1990) extended the specificity model by identifying four dimensions with which to categorize stressful life events. These include desirability, controllability, duration of consequences, and life domain affected by the event. When an event is controllable, problem-focused coping (Lazarus & Folkman, 1984) in the form of informational support may be beneficial because it emphasizes instrumental action that is needed in order to rectify the situation.

In contrast to specificity models, traditional models assume that interpersonal relationships are generally helpful, and that their absence is detrimental (Cohen & Wills, 1985). There is also empirical support for this viewpoint. In a review of behaviors perceived as helpful and unhelpful across four groups, Goldsmith (1992) reported that all samples found direct expressions of love/concern to be helpful. This conclusion is echoed by Wortman and Lehman (1985), who emphasize the importance of avoiding responses that close off further attempts at discussion, which trivialize or dismiss the victim’s feelings, or which imply that the victim is coping poorly. Esteem/emotional support is particularly important for serious events and life-threatening illnesses (Martin et al., 1994). Not surprisingly, research has found rude/insensitive remarks (Goldsmith, 1992) and various forms of minimization or trivialization (Lehman & Hemphill, 1990) to be generally unhelpful.

The above review emphasizes that there is evidence for both
specificity and traditional models of social support processes. However, it is not known which types of social support are consistent with specificity or traditional models when people are coping with a variety of negative life circumstances. Therefore, one goal of the present set of studies is to document consistencies and inconsistencies in reports of supportive and unsupportive behaviors across a range of stressful life events.

**Summary**

In sum, this thesis seeks to advance research in the area of supportive and unsupportive behaviors by examining not only the helpful and unhelpful actions that are exchanged from providers to recipients, but also the context within which they occur. The studies that comprise this dissertation emphasize the cyclical, nonlinear nature of interpersonal processes. Antecedents are those cognitive, motivational, and emotional processes that precede supportive or unsupportive actions. Consequences, in contrast, are post-behavioral processes of a cognitive and interpersonal nature. Two moderating variables of potential importance, source of support and stressor characteristics, will also be examined. A framework within which these variables may be understood, and the inter-relationships between them, is proposed.
Chapter 2
Study 1

Study 1 explores both the beneficial and detrimental functions of social interactions as perceived by those who have experienced a stressful life event. In previous investigations, respondents who have experienced events such as bereavement (Davidowitz & Myrick, 1984; Lehman et al., 1986; Rigdon, Clayton, & Dimond, 1987), cancer (Dakof & Taylor, 1990; Dunkel-Schetter & Wortman, 1982), irritable bowel syndrome or recurrent headache (Martin et al., 1994), and MS (Lehman & Hemphill, 1990) have been asked to indicate the things others have said or done that were especially helpful or unhelpful. Lehman and Hemphill (1990) and Goldsmith (1992) noted that some things were viewed as generally helpful or unhelpful across different samples while other things were specific to certain types of stressful circumstances. Nonetheless, the research area still lacks a taxonomy of helpful and unhelpful actions across a broad range of events. Thus, one goal of Study 1 was to sample respondents having experienced any of a wide spectrum of negative life experiences. Specifically, a large group of people were asked to indicate the most stressful event that had occurred to them, thus enabling analyses of the perceptions of helpful and unhelpful actions by others both within and across life event categories.

In order to obtain a range of event types, participants were recruited in two ways. First, members of the community who visited the Department of Psychology at the University of British Columbia during an Open House were asked to complete a questionnaire on social support. Additional respondents
included volunteers from an introductory social psychology class.

Traditional approaches to social support have assumed that interpersonal relationships are universally beneficial (Cohen & Wills, 1985; House, 1981). For example, social support is thought to be central in protecting people from the negative effects of stress (see Kessler et al., 1985, for a review). Furthermore, the absence of significant relationships is generally considered deleterious, leading to disease vulnerability, immune function difficulties, and enhanced mortality (House et al., 1988; Pennebaker, Kiecolt-Glaser, & Glaser, 1988). Specificity models, in contrast, propose that the effectiveness of supportive actions will vary according to the situational demands of the stressor (e.g., Cutrona, 1990). For example, someone whose physical functioning is compromised will benefit from tangible assistance to a greater extent than someone who is well physically.

In the present study, the possibility of combining traditional and specificity models was investigated. It was reasoned that although some types of actions may be perceived by recipients as helpful or unhelpful regardless of the type of stressor, the beneficial or detrimental effects of other actions may depend upon the stressful life event experienced. It was anticipated that emotional support would be highly valued by recipients, irrespective of the type of stressful event experienced. Two specific forms of emotional support, listening to others and providing a nonjudgmental environment, would likely validate the concerns and beliefs of the recipient. Additionally, talking with others about traumatic experiences is
usually regarded by both professionals and laypeople as generally important in facilitating psychological adjustment in coping with undesirable life events (Pennebaker, 1989; Wortman & Lehman, 1985).

In contrast, some actions were expected to be viewed as uniformly unhelpful or upsetting. For example, previous research has indicated that various forms of minimization (e.g., "Your situation is not as bad as it could be") tend to be distressing to recipients (Lehman et al., 1986). Likewise, recipients typically consider others' views that suggest that the recipient is to blame for his or her victimization to be unhelpful. Although blaming statements are generally seen in a negative way, people experiencing certain types of stressful life events may be particularly prone to being exposed to such statements. For instance, people are likely to be held culpable for outcomes primarily when they are able to alter them through effortful responses (Brickman et al., 1982). Therefore, others may say or do things that are regarded as especially unhelpful by recipients because such actions implicitly or explicitly indicate that the person was responsible for his or her predicament (e.g., Dakof & Taylor, 1990; Jung, 1989). It was anticipated that, because events such as relationship problems and work or school stress are often regarded as being influenced by the person involved, reports of unhelpful actions that focus on the recipient's contribution to the event may be most likely in such cases. In contrast, events that are much less likely to be influenced by volition, such as bereavement, were expected to lead to fewer reports of unhelpful social interactions in the form of victim blaming.
Another set of actions was expected to be perceived as differentially helpful or unhelpful depending upon the stressor. For example, although the provision of practical assistance may be especially helpful to the physically-ill (Dakof & Taylor, 1990; Lehman & Hemphill, 1990), these actions may be considered condescending to recipients without such physical restrictions. Similarly, respondents experiencing events that are perceived as controllable or associated with a positive course are expected to perceive informational support as being helpful, whereas those experiencing events associated with a lack of control or an unfavorable course may view such assistance as unhelpful (Buunk, Collins, Taylor, VanYperen, & Dakof, 1990; Hemphill & Lehman, 1991). This is because, in the case of events that are subject to personal control, information may provide the necessary prerequisite for effective action or, with respect to stressful events that have a favorable trajectory, informational support may give recipients hope of a positive outcome (Albert, 1977).

Attributions for Unhelpful Social Interactions

In an attempt to discover how unhelpful support attempts are interpreted, Lehman and Hemphill (1990) examined MS recipients' attributions by asking respondents why they thought support providers acted as they did. Results indicated that recipients tended to make benign attributions, even for support attempts that seemed especially rude and inappropriate. For example, people with MS reported that others said or did unhelpful things because of a lack of knowledge or understanding about the illness, in an attempt to be helpful, or due to interpersonal discomfort. It was proposed that people
experiencing stressful life events, such as MS, feel vulnerable within their social network (owing to their victimization) and hence may be loath to criticize others' unhelpful actions. That is, people coping with chronic illness may be motivated to believe that support providers are basically good people because holding such beliefs may be less threatening to the stability of the relationship.

Because the Lehman and Hemphill study was limited to those with MS, it is unclear whether people coping with other life stressors would also make benign attributions, or whether such responses are specific, for example, to chronic illnesses, or to stressful life events with which potential providers have little familiarity. That is, recipients may be likely to offer benign attributions (e.g., others lack knowledge or experience) primarily in situations that support providers are unlikely to encounter on a regular basis. The present study examines this possibility with the inclusion of a wide range of life events.

Another possible explanation for the large number of benign attributions offered in the Lehman and Hemphill (1990) study involves the preamble to the unhelpful question. Prior to indicating the things others said or did that were unhelpful, participants read the following statement: "Sometimes, in trying to help, people may say or do things that are not in fact helpful." Thus, respondents may have inadvertently been discouraged from reporting unhelpful actions by others that were not intended to be helpful, precisely those actions expected to be perceived by the recipient in the most negative and critical terms. In order to widen the scope of unhelpful behaviors that may be reported, this study omitted the preamble, focusing not
only on "support attempts that fail" but also including negative or upsetting "exchanges" or "actions" that are not necessarily meant to be helpful.

**Responses to Unhelpful Social Interactions**

Unhelpful actions are rarely discrete events. Rather, they are likely to occur within the context of a relationship that unfolds over time (Coyne et al., 1988). The pattern of repeated exchanges that occurs between persons across time has largely been ignored in the stress and coping literature. Instead of viewing social support as consisting of an interwoven sequence of behaviors, researchers have investigated actions at one slice in time (Coyne & Holroyd, 1982), an approach that fails to examine the antecedents and consequences of behavior.

This study examines the bidirectional exchange that occurs between recipients and potential supporters by asking respondents how they reacted to others' unhelpful interactions. Utilizing this approach allowed an examination of the following questions: What percentage of recipients respond at all to another's unhelpful actions? Are recipients' responses generally conducive to ameliorating unhelpful actions in the future (e.g., rational discussion, request for a different type of support; see Barrera, 1981 and Dakof & Taylor, 1990, for discussions), or are they more likely to exacerbate communication difficulties and further unhelpful exchanges (e.g., screaming, avoiding; see Coyne et al., 1988, for a discussion)?
Issues to be Explored in Study 1

1.) Respondents coping with one of a number of stressful life events will report supportive and unsupportive behaviors that are at times consistent with the specificity model and at other times consistent with the traditional model.

2.) Investigate whether benign attributions for unhelpful actions are offered primarily for stressors with which providers have inadequate familiarity, or whether such attributions are more general across stressful life events.

3.) Examine if recipients' responses to unhelpful actions are likely to ameliorate or exacerbate problems with providers.

**Method**

**Sample**

Participants were obtained via two methods. One hundred and thirty-two respondents (70% of the total sample) were volunteers who attended the University of British Columbia's "Open House." This was a three-day event in which people from the community visited participating university departments. It is impossible to calculate the response rate for this sample because visitors were simply given the opportunity to participate in the study with a sign posted outside of a large room. Fifty-six volunteer students in a social psychology class (30% of the total sample) also participated in the study for extra course credit. The total sample (188 people) comprised 73% females and 27% males. Participants ranged in age from 13 to 78 years (M = 31 years). Fifty-eight percent of respondents were single, 23% married, 10% divorced, 5% separated, 4% common law, and 2% were widowed.
Procedure

Participants were informed that the researchers were interested in learning as much as possible about how people deal with stressful life circumstances, with an emphasis upon interpersonal aspects of coping. Questionnaires were completed individually, and participants were assured of their anonymity. Subsequent to completing the questionnaire, each respondent was given a debriefing sheet describing the research in detail and was thanked for their participation.

Measures

The questionnaire contained several open-ended questions asking people to indicate their most stressful life experience, other people's responses to them, and their reactions to others' responses. First, participants were asked: "Think about the one most stressful event that has occurred to you (for example, the death of a loved one, a personal injury or illness, loss of a job). Please give a brief account of this event." Then, respondents were asked, "Thinking back, what did others say or do that you found especially helpful in coping with this stressful event?" Following this question, participants were asked, "What did others say or do that you found especially unhelpful or upsetting?" Attributions for the unhelpful actions were assessed by asking respondents, "For each of the unhelpful actions described above, why do you think the person did or said them?" Participants then answered the following question: "At the time, did you do or say something (to the person) in response to the person's unhelpful or upsetting actions?" If respondents answered in the affirmative, they were asked to describe how they responded to each of the unhelpful or
upsetting actions. The questionnaire concluded with demographic questions (gender, age, and marital status).

**Category Codes**

Category codes for the open-ended questions were formed by: (1) a consideration of categories from previous research (Dakof & Taylor, 1990; Lehman & Hemphill, 1990; Lehman et al., 1986) and (2) an examination of a random sample of responses from the current participants. Response categories were rated by three or four independent raters. Inter-rater reliabilities were calculated as the percentage of answers agreed upon by at least two-thirds or three-fourths of the raters (in the case of the three and four person rating teams, respectively). Agreements on the event, helpful, unhelpful, attribution, and response questions were 90%, 83%, 86%, 80%, and 86%, respectively. Categories are listed in Tables 1 through 4.

**Results**

**Event Categories**

Respondents reported stressful life events that were classified into one of six categories: (1) bereavement (55 respondents, or 29.3% of the total sample); (2) divorce/relationship problems (49, or 26.1%); (3) work or school stress (39, or 20.7%); (4) close other’s injury, illness, or suicide attempt (19, or 10.1%); (5) one’s own illness or injury (13, or 6.9%); and (6) one’s own psychological problems (13, or 6.9%).

**Helpful Responses**

Ninety-four percent of participants reported at least one especially helpful action by others (see Table 1). Each response category was coded dichotomously as to whether or not
participants mentioned it. Then, event types were treated as discrete categories, and the dichotomized responses were cross-tabulated within them. Chi-squares were then performed on each of the response codes across event types. This procedure was utilized for the helpful, unhelpful, attributions for unhelpful actions, and response questions. Such actions were classified under one of three major headings. The majority of the sample reported that some form of emotional support (75.5%) was considered to be especially helpful, followed by some form of informational (29.3%) and some form of tangible (17.6%) support. Emotional support was not differentially reported across event types, $X^2(5) = 5.37$, ns. Thus, emotional support appears to be universally beneficial regardless of the type of adversity with which one is coping. In addition, various forms of informational support were reported differentially across stressful life events, $X^2(5) = 22.94$, $p < .001$; respondents who had experienced work or school stress (51.3%), illness or injury (38.5%), or relationship problems (36.7%) reported a preponderance of helpful actions that took the form of providing various types of information. In contrast, people experiencing bereavement (10.9%) reported informational support much less frequently. Such a finding makes sense given that the former types of stressors tend to be modifiable and under the respondent’s control to a greater extent than the latter event. Thus, informational support is regarded as helpful primarily when actions may be taken to modify one’s situation. Moreover,
informational support appears to be valued more often when events have a favorable trajectory than when they do not.

Various forms of tangible support were differentially reported as helpful across event types, $X^2(5) = 18.93$, $p < .005$; such answers were provided primarily by recipients suffering from psychological problems (46.2%), or those coping with a physical illness or injury (46.2%). Tangible support sometimes took the form of financial aid, for example, after experiencing job loss. When the stressful event was physically-based, such as hyperthyroidism, practical assistance (e.g., helping with cleaning, cooking, and childcare) was regarded as especially helpful. Tangible support was rarely reported as especially helpful in the case of bereavement (7.3%), work or school stress (15.4%), or others' injury, illness, or suicide attempt (15.8%).

Unhelpful Responses

Ninety percent of participants reported at least one unhelpful or upsetting action by others (see Table 2). Unlike the helpful actions, there were no differences across event types for any of the major unhelpful categories. A sizable proportion of the total sample reported that others responded with general negative actions (41.0%), provided them with unwanted information (39.9%), or avoided them (30.3%). Minimization (23.9%) was also regarded as unhelpful by recipients, while maximization was mentioned by just 5.3% of respondents.

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Insert Table 2 About Here

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One specific type of negative action, blame, was mentioned differentially across event types, $X^2(5) = 22.74$, $p < .001$. Specifically, approximately one quarter of the respondents who had experienced divorce or relationship problems (28.6%), or work or school stress (23.1%) reported that others' blaming was regarded as especially unhelpful or upsetting. Such a response was essentially non-existent for those who had suffered a personal injury or illness (0%), psychological problems (0%), or bereavement (1.8%).

**Attributions for Unhelpful or Upsetting Actions**

Ninety-one percent of respondents reported at least one attribution for the negative social interactions they had described (see Table 3). A substantial number of these were benign attributions. For instance, 34.0% of participants gave general helpful attributions, such as "the provider was only trying to be helpful," or "the provider was concerned and worried about me," and 31.4% of respondents reported that providers gave unhelpful responses because they lacked information or did not know what to do. An additional 31.4% of respondents attributed unhelpful actions to providers' emotional difficulties, such as feelings of denial, fear, or discomfort. No differences were found across event types for any of these attributions.

Only 21.3% of respondents offered critical attributions for the unhelpful actions, such as reporting that others were blameworthy or inconsiderate. Such attributions varied across event types, $X^2(5) = 15.62$, $p < .01$. Negative attributions were most commonly reported by people experiencing work or school stress (41.0%), followed by bereavement (23.6%) and
psychological problems (23.1%), and least likely for others' illness or injury (10.5%), divorce or relationship problems (10.2%), and own injury or illness (7.7%). Finally, 12.2% of respondents attributed others' unhelpful or upsetting actions to religious or philosophical orientation (such as a minister's unhelpful statement "It's God's will" being attributed to religious orientation). Such attributions did not vary across event type, $X^2(5) = 6.63, \text{ ns.}$

Insert Table 3 About Here

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 Responses to Unhelpful Actions

Fully 47% of respondents (most of whom had reported multiple unhelpful actions) reported that they did not do or say anything in response to the unhelpful actions by others. Thus, participants were roughly as likely as not to let their dissatisfaction be known. There were no differences across event types. Of those who indicated that they responded to others who had said or done unhelpful things (see Table 4), the most frequent response was discussing the issue rationally with the provider (26.1%), followed by verbally abusing the provider (14.4%), downplaying the problem (11.2%) (such as denying what was said or done), blocking further communication (5.9%), and being submissive (4.8%).

Insert Table 4 About Here

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Discussion

Findings from Study 1 extend the relatively recent research on perceptions of support attempts. Respondents who had experienced one of a number of stressful life events viewed various forms of emotional support as especially helpful, whereas informational and tangible support were mentioned as especially helpful in particular circumstances. Informational support was mentioned as especially helpful for stressful life events that are relatively common and modifiable, suggesting that experience with a stressor and malleability of the situation may be important. Such events also tend to be more transitory and less chronic than those for which informational support was rarely mentioned as being especially helpful. Tangible support was appreciated for events in which the recipient was unable to complete tasks because of physical disability (e.g., physical illness or injury), or when provision of practical assistance would alleviate burden in order to facilitate coping (e.g., psychological problems).

General negative actions, avoidance by others, and minimization were consistently regarded as especially unhelpful across the range of life events represented here. A subsample of respondents mentioned that providers' actions implying recipients were to blame for their predicament were especially unhelpful or upsetting (cf. Dakof & Taylor, 1990; Jung, 1989). As expected, these were most often respondents who had experienced events that may be perceived by providers as being caused, at least in part, by recipients' own actions (such as divorce or relationship problems and work or school stress); respondents experiencing situations beyond their control (e.g.,
bereavement or injury to another person) were less likely to report such blaming acts by others. This pattern is consistent with the notion that others are likely to elicit pity if onset of victimization is perceived as uncontrollable, whereas blame may result when the person's situation is regarded as controllable (Schwarzer & Weiner, 1991).

Corroborating past research (Lehman & Hemphill, 1990), respondents in the present study overwhelmingly attributed others' unhelpful actions to benign causes, and were unlikely to characterologically blame providers for the unhelpful things they said or did. Only a minority of participants mentioned that providers were inconsiderate, thoughtless, or insensitive. Instead, such actions were more commonly attributed to factors such as lack of knowledge about the situation, or emotional difficulties inherent in the helping context (see Lehman et al., 1986, for a discussion of this issue). These benign attributions were offered by those experiencing problems that were both relatively common and uncommon, and were not specific to situations in which providers might be unfamiliar with the problem.

The preamble to the unhelpful question was eliminated. Therefore, the alternative explanation, that benign attributions were offered because participants restricted their answers to behaviors that were intended to be helpful, was ruled out. In the present study, respondents were asked about others' unhelpful actions without any mention that such behaviors were meant to be supportive, and most respondents still offered benign attributions.

This study extends work on the negative aspects of social
interactions by taking a preliminary step toward examining its bidirectional nature. Participants were asked whether they said or did anything in response to others' unhelpful actions. Interestingly, almost half of the respondents reported that they did not respond at all. These results are consistent with Dunkel-Schetter (1984) and Meyerowitz, Watkins, and Sparks (1983), who found that cancer patients were sometimes reluctant to share their negative feelings with others. Perhaps recipients were reluctant to say or do something in response to an unhelpful or upsetting interaction for fear of appearing ungrateful. Recipients may feel that giving feedback to providers regarding their unhelpful actions will result in the caregiver's reluctance to be supportive in the future. If so, informing would-be providers about their unhelpful actions would lead not only to fewer negative exchanges, but also to a reduction in helpful actions as well.

Alternatively, recipients' lack of response may be due to their concern that others would not respond to the feedback in a constructive manner, or that statements of dissatisfaction would accomplish nothing or make matters worse. In support of such a suggestion, of those who did say or do something, many of the actions seemed dysfunctional, or at least unlikely to reduce negative exchanges in the future. For instance, respondents mentioned that they became verbally abusive, downplayed the problem, blocked communication, or acquiesced to what the provider said. Only a minority of respondents reported discussing the issue rationally with the provider. This is perhaps the most socially acceptable way of resolving these issues, in that it informs the provider that his or her actions
were unhelpful or upsetting, and the reasons for such perceptions, while minimizing the likelihood of alienating the provider.
Chapter 3
Study 2

One of the main goals of Study 1 was to provide a basic understanding of the types of exchanges that recipients view as especially helpful and unhelpful, and attributions for negative actions. To review, helpful actions included emotional, informational, and tangible forms of support. In contrast, unsupportive behaviors comprised general negative actions, provision of unwanted information, avoidance, and various forms of minimization and maximization. The majority of attributions for unhelpful actions were benign; few recipients made characterologically blaming statements. Nonetheless, the findings from Study 1 were somewhat limited because they were only based on answers from open-ended questions. Although data obtained from such a methodology are undoubtedly important in helping establish a knowledge base, only a limited number of responses of especially helpful and unhelpful actions were offered by each respondent. On the closed-ended items that were employed in Study 2, recipients reported, for example, whether or not someone had provided informational support or minimized their problem. By using such a methodology, it is possible to pursue whether respondents received a number of helpful and unhelpful actions, allowing for a standardized set of response options. The use of Likert scales also enables analyses to be made with respect to the amount that particular actions are received, as respondents indicate how frequently various types of exchanges have occurred.

Lehman and Hemphill (1990) noted that the majority of upsetting exchanges experienced by MS patients were attributed
by them benignly, and this finding was confirmed in Study 1 across a range of stressful life events. Study 2 extends these findings by examining source of support provider (e.g., relatives, close others, or more distant others) as a potentially important variable to account for this effect. Some recent data (e.g., Dakof & Taylor, 1990) suggest that the quality of the relationship between providers and recipients may be an important factor in determining whether a particular action is perceived as helpful or unhelpful. The preponderance of benign attributions that we have found, then, may reflect respondents' tendencies to think primarily about exchanges with people who are generally supportive or emotionally close to them.

Recipients may be less willing to entertain critical thoughts regarding the causes of others' unhelpful acts when the provider is an important member of the support network. This may be due to a heightened dependence on them for assistance, or because of fear of rejection and alienation (Lehman & Hemphill; 1990; Wortman & Lehman, 1985). Questioning, or being critical of, the motives of close friends or family members may threaten the relationships, prompting recipients to be concerned that future support will not be forthcoming, and that other negative actions will occur in the future. There would be much less motivation to block, or offset, these concerns when considering the antecedents of unhelpful actions provided by mere acquaintances. Therefore, recipients may be more likely to attribute unhelpful or upsetting actions of strangers to, for example, their callousness or their negative feelings toward the recipient.
Recipients may also report different helpful and unhelpful actions for subtypes of significant others (e.g., friends vs. family members). There is likely to be greater freedom with respect to the degree and type of interaction that takes place with friends than with family members. Although we have the option of spending varying amounts of time with friends, this is less true for family members. Thus, communications with relatives are more likely to be "forced" (Hanson, Sauer, & Seelbach, 1983; Stein, 1992), and familial ties typically entail greater obligations (Lichtman, Taylor, & Wood, 1988). In addition, we are likely to choose friends who are similar to ourselves on important dimensions (Festinger, 1954), and research has shown that similarity is an important determinant of liking (Byrne, 1971). Because of the selection that takes place regarding friendship development and maintenance that is not possible with familial ties, we are likely to obtain a better "match" in terms of personality compatibility with friends than with relatives. To the extent that this is true, we are more likely to have positive interactions with friends than with relatives, and are also likely to give friends the benefit of the doubt in more instances. Therefore, it is predicted that study participants will (1) indicate more helpful interactions, (2) offer more benign and (3) offer fewer blaming attributions for close friends, followed by relatives and then more distant others.

Because the present study is exploratory, no predictions are offered with respect to the receipt of unhelpful actions by significant others when compared to acquaintances. Nonetheless, several possibilities suggest themselves. On the one hand,
strategies such as conflict avoidance are used to maintain harmonious familial relationships (Stein, 1992), suggesting the receipt of few unhelpful actions from kin. On the other hand, because one is more obligated to interact with family members compared with acquaintances, one might anticipate receipt of more unhelpful actions due to problems associated with forced communications. Consistent with this latter notion, Lehman et al. (1986) found that more than half of their bereaved respondents who spontaneously mentioned the source of unhelpful responses attributed them to relatives.

In Study 1, half of the participants indicated that they did not say or do anything in response to others' unhelpful actions. Study 2 extends this research by examining whether the rate and type of responses reported by recipients vary as a function of the relationship type between provider and recipient. On the one hand, recipients may be more likely to respond to more distant others' unhelpful actions than those by close friends or relatives. To the extent that failure to respond is based, at least in part, on the recognition that dysfunctional responses may occur, it may be less threatening to make such a response in a more distant relationship. Because of the more limited contact and emotional involvement with more distant others, the need for maintenance of good relations is less apparent. Ineffective responses may threaten the stability of a long-term relationship, such as a close friendship or kinship. On the other hand, recipients may experience greater commitment to maintenance of relationships with significant others than with acquaintances (Dakof & Taylor, 1990). If so, then recipients may recognize the value of discussing problems
with close providers. If unhelpful actions by others are not discussed, then their recurrence is likely because providers may be unaware that such responses were problematic in the first place.

Issues to be Explored in Study 2

1. It is predicted that recipients will report more supportive actions, more benign and fewer blaming attributions for unhelpful behaviors by close friends, followed by relatives and then more distant others.
2. Are recipients more or less likely to respond to providers' unhelpful actions as a function of relationship type between providers and recipients?

Method

Participants

Respondents were 153 students enrolled in a third year social psychology class. Of those who completed questionnaires, 104 (68%) were female, and 49 (32%) were male. The average age was 22 years.

Dependent Measures

Stressful life event. Participants were asked to "Please take a moment to think about the most stressful event you have experienced (for example, the death of a loved one, a personal injury or illness, loss of a job, relationship break-up). Please give a brief account of this event." Category codes were developed based on responses from Study 1, and an examination of Study 2 participants' responses. Open-ended responses were coded into one of the following ten categories: 1) relationship problems (56 respondents; 37% of total sample); 2) work or school stress (25; 16%); 3) bereavement (21; 14%); 4) others'
injury, illness, or suicide attempt (11; 7%); 5) own illness or injury (10; 7%); 6) immigrating/moving away (7; 5%); 7) automobile accident (no injury mentioned (4; 3%); 8) legal problems (4; 3%); 9) sexual assault or abuse (3; 2%); or 10) miscellaneous (6; 4%). Reliability was calculated by having a second rater code all of the responses. Discrepancies were resolved through discussion between the raters. Cohen’s kappa was .87.

**Relationship between provider and recipient.** Participants were asked to "think about the one person (such as a relative, close friend, acquaintance) who said or did the most unhelpful or upsetting things when you were coping with the stressful event."

Respondents indicated their relationship to this person by checking one of several closed-ended options (e.g., sister, brother, mother, father, close friend, acquaintance, and stranger). Respondents were also given the opportunity to mention somebody who did not fit into any of the above categories. Because of the small number of mentions in each category, the original 17 categories were collapsed into one of three major categories. Category one (33% of the total sample) comprised "relatives," and included mother (12% of sample), father (11%), sister (3%), aunt (3%), brother (2%), grandmother (1%), and cousin (1%). Category two (36% of the total sample) comprised "close others" and included close friend (26%), girlfriend (5%), and boyfriend (5%). Category three (18% of the total sample) comprised "more distant others" and included acquaintance (14%), stranger (3%), and doctor/nurse (1%). Because they could not reliably be put into any of the above categories, roommate (1%), coworker (1%), employer (1%), and ex-
Respondents were asked to indicate the sex of the person who responded in an unhelpful or upsetting manner toward them. Of the 139 respondents who answered this question, 72 (52%) reported that the provider was female and 67 (48%) said the provider was male.

Helpful and unhelpful actions. The Social Support Behavior Questionnaire (SSBQ), a 14-item scale developed by Johnson, Hobfoll, and Zalcberg-Linetzy (1993) was used to tap helpful and unhelpful actions. The scale, which was based on findings of previous research (e.g., Truax & Carkhuff, 1967; Wortman & Lehman, 1985), evaluates the extent to which a provider engages in certain behaviors when the recipient is in distress and needs aid or support. Questions were presented on four-point scales, ranging from 1 "never" to 4 "often." The scale comprises six helpful (e.g., "How often has your close other provided you the chance to openly express your feelings? Examples: Listened. Asked questions that didn't close the topic or your expression of feelings. Encouraged expression of feelings, even painful feelings.") and nine unhelpful (e.g., "How often has your close other encouraged you to simply overcome what occurred to you? Example: Told you to "pick yourself up by your bootstraps."") items.

Rather than scoring the scale as it is traditionally scored (that is, by subtracting unhelpful items from helpful ones to generate a single social support behavior index), one score was calculated for the unhelpful actions by summing unhelpful and upsetting actions, and a separate score was generated for the helpful actions. This was done because previous research has
shown that helpful and unhelpful aspects of social support are differentially related to psychological well-being (Rook, 1984). Cronbach’s alpha for the "unhelpful" scale was .67, and .92 for the "helpful" scale. Higher scores on the "helpful" scale indicate more helpful actions by others, and higher scores on the "unhelpful" scale indicate more unhelpful actions.

**Attributions.** Respondents were asked the following attribution question for others’ unhelpful actions: "WHY do you think the person you indicated said or did these unhelpful things?" Twenty closed-ended options, developed on the basis of previous research (Lehman & Hemphill, 1990) and the results of Study 1, were presented on 4-point scales, ranging from 1 "Does not apply at all" to 4 "Applies a lot." Fifteen "benign" items comprised forgiving attributions by the recipient suggesting that the provider was not to blame for his or her actions (e.g., "He or she was concerned or worried about me" and "He or she was trying to do what was best for me. He or she had my best interests at heart"). Five "blame" items included attributions suggesting the provider was responsible for his or her unhelpful actions (e.g., "He or she is an inconsiderate person" and "He or she is a thoughtless person").

All 20 items were subjected to a Principal Components Analysis with Varimax rotation. A scree plot indicated that a three factor solution fit the data best. One item ("He or she is a nosy person") was omitted because it did not load strongly (<.30) on one factor, and loaded with roughly equal magnitude on all 3 factors. The first general factor included "Blame/Benign" items. The "blame" and "benign" attribution items were computed individually in subsequent analyses because of the theoretical
significance of separating them. The second factor, labeled Ignorance, comprised items suggesting that the provider was uncertain about what to do to help the recipient. The third factor, labeled Emotional Distress, comprised items suggesting that the provider responded in an unhelpful manner because he or she was somewhat psychologically distressed at the time (see Table 5). Subsequent analyses were conducted after computing means with items that comprise each of the factors.

Insert Table 5 About Here

Responses to other’s unhelpful actions. Respondents were asked "At the time (of the negative interaction), did you say or do something to the person in response to his or her unhelpful or upsetting action?" If participants answered affirmatively, they were asked to describe how they responded. Perusal of the responses led to the development of five discrete categories (discussed the issue rationally, blocked communication, became emotional, verbally abusive, and miscellaneous), into which answers were coded by two raters. Cohen’s kappas were computed for each of the categories, and ranged from .77 to .90.

Results

Analyses by Type of Relationship

One-way ANOVA’s were conducted with the three levels of relationship (relatives, close others, more distant others) as the between subjects factor. As predicted, others’ helpful actions differed across relationship types, $F(2, 133) = 6.17, p < .005$. Specifically, more helpful actions were offered by close others ($M = 2.54$) and relatives ($M = 2.37$) than by distant
others (M = 1.90), t(85) = 3.93, p < .001 and t(77) = 2.37, p < .05, respectively. The former two groups did not differ from one another, t(104) = 1.04, ns. Reports of others' unhelpful actions did not differ by relationship type, F(2, 132) = 1.99, ns.

Analyses were conducted to test whether or not attributions offered by participants would vary as a function of relationship between provider and recipient. As anticipated, the effect for the "Benign" items was significant, F (2, 133) = 9.40, p < .001. Follow-up analyses revealed that recipients were less likely to offer benign attributions to distant others (M = 1.88) than to relatives (M = 2.63), t(78) = 4.32, p < .001, or close others (M = 2.64), t(79) = 5.08, p < .001. The latter two groups did not differ from one another, t(96) = .07, ns. Partially supporting expectations, the effect for "Blame" items was marginal, F (2, 132) = 2.27, p = .11. The analysis for Ignorance (Factor 2) was nonsignificant, F (2, 133) = .04, ns. The ANOVA for Emotional Distress (Factor 3) was significant, F (2, 133) = 3.16, p < .05. Follow-up analyses revealed that close others (M = 2.05) were seen as more emotionally troubled than distant others (M = 1.54), t(81) = 2.78, p < .01. There was no difference between either of these groups and relatives (M = 1.84).

Stressful Life Event Analyses

A series of analyses were conducted with stressful life events as discrete categories. In order to reduce the number of events to an acceptable number, and to ensure greater robustness of findings, only categories with at least ten respondents represented within each group were retained. Thus, five minor categories were dropped. One-way ANOVA's were conducted with
stressful life events (relationship problems; work or school stress; bereavement; others' injury, illness, or suicide attempt; own illness or injury) as the between subjects factor for the closed-ended data.

Helpful, $F(4, 112) = .58$, $p = .68$, and unhelpful, $F(4, 109) = 1.67$, $p = .16$, actions did not vary according to stressful life events. In contrast, one of the attribution analyses was significant. Thus, benign attributions were reported to a different extent depending upon the stressful life event experienced, $F(4, 111) = 3.39$, $p < .01$. Follow-up Scheffe analyses revealed that bereavement ($M = 2.00$) differed from relationship problems ($M = 2.76$), such that more benign attributions were offered by respondents in the latter category. Although none of the other attribution factors were significant (Emotional Distress and Blaming $p$'s > .25), there was a tendency for "Ignorant" attributions to vary across stressful life events, $F(4, 110) = 2.38$, $p = .06$.

Five separate chi-square analyses were conducted to determine whether or not recipients' responses toward providers subsequent to receiving the unhelpful actions varied according to stressful life event experienced. Presence or absence of each response was cross-tabulated with the five stressful life events categories. None of the analyses were significant (all $p$'s > .15).

Relation Between Helpful and Unhelpful Actions

Recipients selected providers to report about on the basis of the most unhelpful things that one person in their social network had said or done. Therefore, in the present study, respondents were biased in favor of reporting negative aspects
of social exchanges. However, it is unclear whether such providers were viewed as primarily offering unhelpful actions, or whether they were also perceived as doing helpful things for recipients. In order to address this issue, a correlational analysis was conducted with the "helpful" and "unhelpful" subscales of the SSBQ. There was a significant association between the "helpful" and "unhelpful" subscales, \( r(138) = .37, p < .001 \), suggesting that recipients tended to report on providers who not only did unhelpful things but also did helpful things.

To examine further the relation between helpful and unhelpful actions, a paired \( t \)-test was conducted with means of the helpful and unhelpful subscales of the SSBQ as the dependent variables. Participants reported that unhelpful actions (\( M = 2.08 \)) were offered to a lesser extent than were helpful actions (\( M = 2.33 \)), \( t(138) = 3.49, p < .001 \). Thus, even though the methodology of the present study emphasized problematic exchanges, and included individuals who did things that were often considered to be extremely negative, recipients believed that providers said or did more helpful than unhelpful things. This finding suggests that even relationships punctuated with undesirable actions are also seen as having beneficial aspects to them.

**Responses to the Unhelpful Actions**

When asked how they responded to providers' unhelpful actions, approximately half of the recipients (78 or 51% of total sample) indicated that they said or did nothing. Forty-one percent (62 respondents) indicated that they responded in some manner, and 9% of the participants (13 respondents) left the question blank. Open-ended responses were coded into one of
the following five categories: 1) discussed the issue rationally (23 respondents or 15% of total sample); 2) blocked communication (16; 10%); 3) became emotional (11; 7%); 4) verbally abusive (11; 7%); and 5) miscellaneous (8; 5%).

A series of chi-square analyses were conducted to determine if recipients responded differentially depending on their relationship with providers. Each of the five categories was analyzed separately, such that the presence and absence of each response (e.g., "discussed the issue rationally") was cross-tabulated with the three levels of relation. None of the analyses achieved significance (all p's > .10).

Discussion

The present study investigated the provision of helpful and unhelpful actions as a function of type of relationship between recipients and providers. Results indicate that, although unhelpful or upsetting exchanges may be offered by virtually anybody, recipients spontaneously said that relatives (33% of providers) and close friends (26% of providers) offered the most unhelpful actions. These findings are consistent with those of past research (Dakof & Taylor; Lehman et al., 1986). In contrast, when the total number of unhelpful actions was obtained by summing closed-ended items from the SSBQ, there were no differences across groups of providers (e.g., relatives, close others, and more distant others). Thus, although close others offered particularly unhelpful or upsetting actions to recipients, the former were overall no more likely to offer unsupportive actions than were more distant others. Such a finding highlights the fact that those who are close to us are perceived as making a similar number of critical comments and
behaving in the same annoying way as do mere acquaintances and
strangers. This assertion may not be too surprising, however,
if one considers the fact that close others spend more time with
us than more distant others and, therefore, have a greater
opportunity to say or do things that are unappreciated.

Despite the fact that respondents had little difficulty
reporting others' unhelpful actions, the preponderance of
behaviors were perceived to be helpful. The total number of
helpful actions varied across relationship type such that close
others were perceived as offering more helpful actions than were
distant others. This difference in provision of helpful (as
opposed to unhelpful) actions may be important in accounting for
the fact that respondents offered more benign attributions for
close others than for distant others. Results suggest that
people involved in relationships that are characterized by fewer
positive behaviors will be less likely to offer benign
attributions, and more likely to offer ones that emphasize
blame. Moreover, in relationships characterized by the absence
of positive aspects, people may interpret ambiguous situations
pejoratively by emphasizing the negative aspects of social
exchanges when positive attributions are also possible. This is
precisely what has been found in the attribution literature with
maritally distressed couples (Schmaling et al., 1989). Benign
attributions may be offered to close others because negative
actions are interpreted against a backdrop of primarily positive
exchanges.

The prediction that close others differ from relatives in
terms of recipients' perceptions of helpful actions and
attributions for unhelpful actions received mixed support.
Although the mean differences were consistent with predictions, the two groups were not statistically distinguishable. Perhaps this finding is due to the fact that the "close others" group comprised a fairly heterogeneous subset of individuals. Thus, it included partners and close friends, two groups that have been found to differ in terms of the overall amount of support provided (Primomo et al., 1990). Alternatively, many of the measures were developed specifically for this project, and may not have been sensitive enough to detect such differences.

Consistent with the results of Study 1, few participants in the present study indicated that they responded to the unhelpful actions. Thus, even when providers said or did things that were not appreciated by recipients, recipients typically did not inform the provider that their action was unhelpful. Recipients might have thought that, by focusing on the negative, providers would feel that they were being overly critical, and did not recognize the positive things that the provider had done. It is possible that, even though unhelpful actions are offered, recipients do not believe that such interactions affect the long-term stability of the relationship. Along this same line of reasoning, recipients may perceive unhelpful actions to be fleeting and isolated, and not likely to occur in the future. If the perceived costs of saying or doing something to the provider outweigh the perceived benefits, then recipients may decide against having a discussion with providers (Hobfoll, 1989). From this point of view, it is neither necessary nor perhaps even desirable for recipients to indicate their discontent.

In other instances, however, it may be important for
recipients to respond directly to providers' unhelpful actions. This is especially likely to be true when similar sorts of negative exchanges occur repeatedly, and are expected to continue if something is not said or done. Recipients may also benefit from indicating their discontent if the upsetting action is sufficiently troublesome to impede relationship quality.

In Study 2, recipients' responses to the unhelpful actions did not vary according to the type of relationship with providers. It is plausible that these findings are due to the fact that few participants (41% of the sample) answered affirmatively to the response question. When the responses were coded into categories, there were too few cells represented by enough observations for reliable effects to be found. Thus, it was not possible in this study to test adequately whether participants said and did different things to providers as a function of type of relationship with them.
Chapter 4
Study 3

The first two studies examined several issues related to helpful and unhelpful actions directed toward a recipient who is coping with one of a number of stressful life events. Although some behaviors in Studies 1 and 2 were perceived as helpful or unhelpful across a broad range of events, others were not. Nonetheless, the sample sizes in many of the event categories were relatively small. It is extremely difficult, in broad-based studies, to eliminate the problem of small sample sizes within event types without sampling a huge number of respondents. Therefore, Study 3 examines positive and negative exchanges among a sample of recipients experiencing the same life event, namely Myalgic Encephalomyelitis (M.E.). The literature on supportive and unsupportive actions provides a useful framework within which to understand social exchanges that occur among people with M.E. and those in their social network.

A decision was made to focus on M.E. because it is a major health and economic threat (Hyde, 1990). Moreover, very little has been written about interpersonal aspects of this illness. For example, the only comprehensive scientific text on the subject includes chapters on immunology, infectious origins (e.g., enteroviral and retroviral theories), neurological features, central and peripheral nervous systems, and neuromuscular and cardiac abnormalities (Hyde, Goldstein, & Levine, 1992). Social science researchers who have written about the illness have tended to focus on psychiatric diagnoses (Abbey & Garfinkel, 1990; Dutton, 1992), psychopathology (Iger,
1992), or neuropsychological abnormalities (Bastien, 1992). To my knowledge, no research has systematically investigated supportive and unsupportive processes in social networks of people with M.E.

Although there is currently no reliable method to determine incidence or prevalence rates of M.E., it is estimated that between 2 and 10 million North Americans are afflicted with the illness (Berne, 1992). Other researchers have estimated that there may be 30 to 40 cases of M.E. per every 100,000 individuals in the general population (Lloyd, Hickie, Broughton, Spencer, & Wakefield, 1990). Many people with the illness are undiagnosed or incorrectly diagnosed, in part because M.E. was only recently given a working definition (Holmes et al., 1988) and because it includes a heterogeneous cluster of symptoms that is poorly understood by the medical community. Nonetheless, there is a wide range of public interest in the disorder, exemplified by the large number of books and articles that have appeared in recent years, and the fact that the Centers for Disease Control receive an estimated 1,000 to 2,000 M.E.-related calls per month (Berne, 1992).

M.E. provides a fertile testing ground for the potential influence of psychological variables associated with the illness. Uncertainty exists at all stages from diagnosis to treatment. Also, people with M.E. tend not to know how they contracted the illness, and may search for causes (Powell, Dolan, & Wessely, 1990). The skepticism about M.E. from professionals and the lay public alike may be conveyed to people with the illness, potentially leading to resentment or to the internalization of public stereotypes (Weinberg, Louw, &
Schomer, 1994). Most importantly perhaps, there is substantial anecdotal evidence that many actions and statements by others toward the person with M.E. are unappreciated (e.g., Bazell, 1987; Conant, 1990; Feiden, 1990).

First, a description of M.E. and background information about the illness will be presented. Next, the first major class of variables (i.e., the types of helpful and unhelpful actions from significant others) will be outlined and justified. Then, the second major class of variables (i.e., potentially important antecedents of supportive and unsupportive actions) will be discussed. For example, personality dimensions of providers and their possible relations with helpful and unhelpful actions will be reviewed. Moreover, perceptions of need for assistance will be outlined. Discrepancies between providers’ and recipients’ perceptions of physical and mental health, and perceived causes (and their potential relations to supportive and unsupportive actions), will also be discussed. Then, factors that may prevent providers from responding in more effective ways will be reviewed. Finally, the third major class of variables (consequences) will be discussed. In particular, the issues of when and how providers became aware that their actions were unappreciated will be outlined.

Description of Myalgic Encephalomyelitis

Myalgic Encephalomyelitis (M.E.) is a term that has emerged in recent years to describe a constellation of symptoms of unknown etiology. The syndrome has been variously referred to as Chronic Fatigue Syndrome, Chronic Epstein-Barr Virus Syndrome, Chronic Mononucleosis, Post-Viral Fatigue Syndrome, and Chronic Mononucleosis-like Syndrome.
The syndrome was not given a working case definition until 1988. The Centers for Disease Control (CDC), recognizing heterogeneity of the syndrome, proposed rather restrictive research criteria for M.E. diagnosis to ensure that false positives were minimized (Holmes et al., 1988). In order to meet the CDC criteria for M.E., two major criteria must be satisfied. First, the disorder must be characterized by "new onset of persistent or relapsing, debilitating fatigue or easy fatigability in a person who has no previous history of similar symptoms, that does not resolve with bedrest, and that is severe enough to reduce or impair average daily activity below 50% of the patient's premorbid activity level for a period of at least 6 months" (p. 388). Second, other conditions that include similar symptoms must be ruled out as possible causes.

In order to receive a diagnosis of M.E., one must also have 8 or more of the following 11 symptoms: 1) mild fever; 2) sore throat; 3) painful lymph nodes; 4) unexplained generalized muscle weakness; 5) muscle discomfort or myalgia; 6) prolonged generalized fatigue after exercise; 7) generalized headaches; 8) migratory arthralgia without joint swelling or redness; 9) neuropsychologic complaints; 10) sleep disturbance, and 11) development of symptoms over a few hours to a few days.

Alternatively, one may be diagnosed with M.E. if both of the major criteria are satisfied, 6 or more of the 11 symptom criteria listed above are evident, and 2 or more of the following 3 physical criteria are met. The physical criteria, which must be confirmed by a physician on at least two occasions at least one month apart, include: 1) low-grade fever; 2) nonexudative pharyngitis; and 3) palpable or tender anterior or
posterior cervical or axillary lymph nodes.

Background Information About Myalgic Encephalomyelitis

The onset of M.E. is typically sudden, and the symptoms may be mistaken for those of the flu or a cold (Cowley, Hagar, & Joseph, 1990). However, unlike less serious illnesses, the symptoms persist across time. M.E. may begin after the patient has contracted an infectious illness such as the flu, hepatitis, bronchitis, mononucleosis, or the Epstein-Barr virus. The modal patient is a well-educated and relatively high socio-economic status woman between the ages of 25 and 55 (Brody, 1988).

Certain aspects of the illness have prompted medical professionals and laypeople alike to consider it to be a psychological disorder, or nothing more than a somatic presentation of psychological problems. For example, although some patients evidence immunological abnormalities (Buchwald & Komaroff, 1991; Klimas, Salvato, Morgan, & Fletcher, 1990; Krupp, Mendelson, & Friedman, 1991), this is not always the case (Abbey & Garfinkel, 1990; Jones, 1991), and such deviations from normality do not typically correlate with symptom severity (Straus, 1988). Similarly, although many patients report muscle weakness, abnormal muscle strength and recovery after activity have not been found (Stokes, Cooper, & Edwards, 1989). Cognitive difficulties in the form of attention, concentration, and memory are typically reported by patients. However, neuropsychological tests have often failed to substantiate cognitive impairments in M.E. patients (Grafman, Johnson, Jr., & Scheffers, 1991), and some even indicate that patients do better than age matched controls on neuropsychological tests (Altay et al., 1990).
Supportive and Unsupportive Actions

To my knowledge, there have been no systematic studies conducted on supportive and unsupportive exchanges among people coping with M.E. Therefore, the findings discussed here are based on research from other samples or anecdotal accounts in the M.E. literature. Moreover, most studies on support attempts that succeed and fail have been conducted from recipients' points of view; few have looked at providers' perspectives. In one of the rare studies that has examined potential providers' perceptions of supportive actions, Lehman et al. (1986) first asked "control" participants how they would comfort and help a friend if the close other had lost a spouse or child in a motor vehicle accident. Then they compared these responses with the bereaved's responses of what they actually found to be helpful. Providers mentioned that they would engage in support tactics that were also frequently mentioned by the bereaved as helpful. Control respondents reported that they would be there for the victim, that they would express concern, and that they would provide opportunities for discussion of feelings. Moreover, potential providers did not indicate that they would engage in actions considered to be unhelpful by the bereaved.

Although Lehman et al.'s (1986) study has provided insight into perceptions of helpful exchanges between providers and recipients, there are some limitations. Their control respondents were not actual providers in the bereaved's social network. Thus, the control respondents did not indicate what they had done; they only mentioned what they believe they would do if actually in the hypothetical scenario. Some research indicates that what people say they will do and what they
actually do may be quite discrepant (Wortman & Lehman, 1985). In order to avoid this problem, providers in the present study will be close others of people experiencing M.E., a naturally occurring stressful life event. Moreover, providers and recipients will be asked to indicate supportive and unsupportive exchanges that have actually occurred between them.

Lehman et al. (1986) only examined hypothetical providers' views regarding helpful aspects of social exchanges. It seems equally important to consider unhelpful aspects, given the relations between these latter exchanges and poor mental functioning (Rook, 1984). Thus, in the present study, providers will be asked what they said or did that they think was perceived to be helpful and unhelpful by the recipient (see Antonucci & Israel, 1986, for an example of this methodology with respect to social support processes).

Persons with M.E. may very well experience particular kinds of unhelpful actions by support providers. Negative exchanges are reviewed, along with specific features of the illness that render such actions understandable. This discussion is followed by more detailed accounts of the possible reasons for such dysfunctional interactions.

A paucity of research has focused on helpful and unhelpful actions offered to people with M.E. Nonetheless, anecdotal accounts and case studies are available to suggest some of the important negative exchanges that might occur. Because the literature includes few empirical studies, it is difficult to ascertain the extent to which experiences of some people with M.E. are shared by others. The present study investigates the unhelpful or upsetting interactions that a significant
percentage of people with M.E. have had with providers.

If support providers possess particular schemata for illness or chronic fatigue, then they may compare the physical appearance of the afflicted individual with their notion of how, if they were really suffering from a serious illness, they should look and behave (Lehman & Hemphill, 1990). If, as is often the case with M.E., the recipient’s physical appearance is relatively unaffected, then minimization or denial of illness severity by the provider may occur (Lehman et al., 1986; Wortman & Lehman, 1985).

In fact, people with M.E. have indicated that others often challenge the existence of their illness (Conant, 1990). This may be especially likely if medical tests are negative, or if previous medical treatment has been ineffective (Cowley et al., 1990). People with M.E. seem to have a particular aversion to psychiatrists (Abbey & Garfinkel, 1990), and more generally appear irritated by those who suggest that there may be a psychological component to the disorder. Patients may be offended by being diagnosed with depression because they often assume that it implies that their complaints are imaginary or "all in the mind" (Kendell, 1991). Trivialization of the illness is implicit in terms such as "affluenza" or "the yuppie plague" that have been used to describe M.E. (Bazell, 1987).

The tendency of providers toward disbelief and minimization may be exacerbated by the fact that symptoms fluctuate across time; one day the person with M.E. may feel quite well, while at other times they may feel particularly ill and unable to do much of anything (Hyde, Bastien, & Jain, 1992). Providers may assume that M.E. sufferers are not really ill because they see the
patient only at certain times. Those with M.E. often feel entirely drained of energy, unable to socialize with others. However, at other times they may feel well enough to go out with their friends. Potential support providers, then, are likely to have a biased sample, only seeing patients when they are feeling their best (Lehman & Hemphill, 1990). If providers assume that this is indicative of how people with M.E. function on a daily basis, they may assume that patients are exaggerating their symptoms or "acting ill" for secondary gain (Fisher, 1989). One of the major themes of most of the self-help literature is the lack of recognition of illness by relatives, friends, and professionals (MacIntyre, 1989).

Even potential support providers who accept the severity of the illness may nevertheless engage in unhelpful actions. Some individuals, for instance, may be fearful that the illness is contagious, and may avoid the M.E. sufferer (Wortman & Lehman, 1985). Such a belief may lead to reduced physical contact (including kissing, hugging, touching) and increased distance (Conant, 1990). The unsolicited giving of advice may also be seen as particularly unhelpful by recipients (Lehman et al., 1986). For example, providers may suggest coping with the illness through the use of various strategies such as ingesting vitamins, development of a positive mental attitude, stress reduction, and religious guidance (Conant, 1990). Some providers may indicate that bedrest is needed, whereas others may consider avoidance of physical activity to be counterproductive (Butler, Chalder, Ron, & Wessely, 1991).

Because M.E. is a chronic illness, coping with it entails an alteration in the way in which sufferers and families
structure their lives and the expectations they hold for the future. Many researchers believe that defining recovery as a return to premorbid levels of functioning is unrealistic (Peel, 1991). Although those suffering from M.E. may note improvement, it is often incomplete, and recovery comes slowly (Feiden, 1990). Even when a more liberal definition of recovery is adopted, some people with M.E. remain ill years after diagnosis (Komaroff & Buchwald, 1991). Unhelpful actions as perceived by the person with M.E. may focus on failure of significant others to accept the reality that accommodations to the illness often entail a permanent change in the way in which daily routines are structured. If M.E. is viewed as merely a temporary hassle, rather than a long-term debilitating illness, providers may expect and encourage recovery (Wortman & Lehman, 1985) when the person with M.E. is still unable to do much of what he or she formerly did.

**Antecedents**

Now that helpful and unhelpful exchanges have been reviewed, antecedents (or pre-behavioral support processes) will be discussed (see Figure 1). These are factors that precede supportive and unsupportive actions, and that are hypothesized to be important in leading to their occurrence.

**Interpersonal traits and their potential relations to supportive and unsupportive actions.** The first antecedent that will be examined is personality, or the relatively enduring aspects of individuals that may influence supportive interactions (see e.g. Sarason, Sarason, & Shearin, 1986, for an exception). Few researchers have attempted to integrate the social support literature with that concerning dimensions of personality as
predictors of social behavior. Although little comprehensive research of this kind has been carried out, isolated personality dimensions have been associated with general measures of social support. For example, investigators have noted that individuals who perceive themselves as affiliative (e.g., high Extraversion) tend to be more satisfied with their support networks than those low in affiliation (Henderson, Byrne, & Duncan-Jones, 1981). Similarly, affiliative tendencies are related to an exchange of supportive actions and large social networks (Connell & D’Augelli, 1990).

To date, the importance of individual differences has been considered primarily with respect to specific recipient characteristics that have been posited to influence others’ responses toward such individuals (e.g., Silver et al., 1990; Trobst, Collins, & Embree, 1994). In the present study, key personality traits of providers and recipients will be associated with views regarding how supportive or unsupportive providers’ actions are considered to be.

Research examining the importance of personality in various contexts has previously been difficult because of the lack of agreement regarding which dimensions to include, and the paucity of psychometrically acceptable measures. As a result, past studies have been rather idiosyncratic.

Recent research in personality psychology has provided strong evidence that five robust personality dimensions explain differences in the ways people behave (e.g., Digman & Inouye, 1986; McCrae & Costa, 1987; Norman, 1963). These dimensions comprise the five-factor model and consist of Extraversion, Agreeableness, Conscientiousness, Neuroticism, and Openness to
Experience (Digman & Takemoto-Chock, 1981). One of the goals of Study 3 is to examine whether these personality dimensions of providers and recipients are associated with specific helpful and unhelpful exchanges.

Individuals with certain dispositions have been shown to provide certain forms of supportive and unsupportive actions. For example, extraverts attempt to relate with others (Thorne, 1987) and share their own experiences. Because of their tendency toward assertion, dominance, and self-confidence (Digman & Inouye, 1986), extraverts may be especially likely to provide active forms of support, such as getting recipients to talk about their problems (Wiggins & Trobst, in press). However, Extraversion is also associated with unfavorable characteristics, and interpersonal problems revolve around their dominance or intrusiveness (Alden et al., 1990).

The second factor of personality, Agreeableness (Norman, 1963), is also known as the Nurturance dimension on the interpersonal circumplex (Trapnell & Wiggins, 1990). Agreeable individuals tend to be considerate, sympathetic, and caring (Digman & Inouye, 1986; Wiggins, 1995). More so than other personality dimensions, Agreeableness is apt to be associated with various forms of emotional support. For example, agreeable providers may hug recipients (Wiggins & Trobst, in press) and give them the opportunity to vent (Lehman et al., 1986). Because of their helpful and supportive nature, agreeable individuals are expected to offer few unhelpful actions.

The first two factors define the arena within which interpersonal transactions occur (Wiggins, 1979), and it is for this reason that social support, clearly interpersonal in
nature, is well captured by the circumplex model of personality. The other three factors of the five-factor model (Conscientiousness, Neuroticism, and Openness to Experience), in contrast, include affective, experiential and motivational traits in addition to interpersonal ones (McCrae & Costa, 1989). As such, there has been less research conducted on the relations between these other factors and interpersonal problems. Therefore, predictions regarding the remaining traits in relation to supportive and unsupportive actions are offered more tentatively.

The third factor of the five-factor model, Conscientiousness, comprises planning, persistence, neatness, and carefulness (Digman & Inouye, 1986; Norman, 1963). To the extent that highly conscientious people are also more reliable and industrious, they may offer a variety of helpful actions, such as those revolving around the use of reason or verbal forms of support (Buss, 1992). In contrast, those low on Conscientiousness tend to be unreliable and disorganized, and may not provide helpful support because they do not follow through with tasks. Thus, it may be that providers low in Conscientiousness are unsupportive not because of the unhelpful things that they do, but because of the helpful things that they fail to do.

The fourth factor of personality, Emotional Stability or Neuroticism (Norman, 1963), involves a strong component of anxiety (Wiggins, 1968). Those low on emotional stability are apt to be concerned about their own needs, and may be unable to provide effective support to others. Accordingly, such individuals may do things in order to maintain their own
emotional equilibrium (Gottlieb & Wagner, 1991), and may be unable to help the recipient cope with his or her distress. It has been found that those high on neuroticism tend to pout, sulk, or whine until their significant other stops doing something they perceive as aversive (Buss, 1992; Buss, Gomes, Higgins, & Lauterbach, 1987). With respect to unhelpful actions, those high on neuroticism may appear self-centered and, because they wish to terminate their own emotional discomfort, may distance themselves from the problems of recipients (Lehman et al., 1986; Lehman & Hemphill, 1990). Moreover, those high on Neuroticism may be critical toward providers in need of their assistance (Wiggins & Trobst, in press). In contrast, emotional stability enables providers to attend to the concerns of recipients. Therefore, providers low on Neuroticism are hypothesized to be nurturant and provide adequate emotional support (Dakof & Taylor, 1990; Lehman et al., 1986).

The fifth factor, Openness to Experience (Digman & Takemoto-Chock, 1981; McCrae & Costa, 1985), is associated with knowledgeability, perceptiveness, and imaginativeness (Digman & Inouye, 1986). Providers high on Openness may help recipients explore thoughts and feelings about their stressful situation (Dakof & Taylor, 1990; Lazarus & Folkman, 1984). Although such an orientation is often appreciated, it is conceivable that those high on Openness to Experience may also offer actions that are unappreciated by recipients, such as disseminating unwanted information or viewpoints (Lehman & Hemphill, 1990; Lehman et al., 1986).
Perceived need for assistance. The vast majority of data on helpful and unhelpful actions has been collected from recipients (e.g., Dakof & Taylor, 1990; Lehman & Hemphill, 1990). Few studies have examined providers' perceptions of the support process (House, 1981). Such research is important, given that providers are likely to respond toward recipients according to perception of need. For example, if providers believe that recipients want tangible assistance, then that is what they are likely to provide. Moreover, exclusive reliance on recipient self-report is inadequate for a comprehensive understanding of support processes, given that social interactions are a dyadic process involving both the provider and recipient (Dunkel-Schetter & Skokan, 1990). The following discussion of providers' perceptions emphasizes the importance of how providers become aware that recipients need assistance.

The first step to engaging in supportive behaviors is for the potential provider to perceive the recipient's need (Latane & Darley, 1970). As discussed earlier, M.E. is an illness with few observable symptoms or obvious signs that the person requires assistance. This ambiguity may be an important determinant of a failure to offer assistance (Clark & Word, 1972). If the potential provider does not believe the recipient requires help, then assistance is unlikely to be forthcoming or may be inadequate.

In this study, respondents will be asked to think back to the most important time that recipients needed providers' help, and indicate what assistance the recipient needed at that time. It is anticipated that many of the categories reported for the "most helpful actions" question will be reported here, such as
various forms of emotional and tangible support. However, given that respondents will be mentioning the most important assistance needed, more intrusive forms of help due to physical limitations imposed by the disorder are also expected. For example, participants may become immobilized to the extent that they need assistance revolving around basic issues of personal care, such as bathing and feeding (Barrows, 1995).

Then, recipients will be asked to report whether or not providers were aware that recipients needed help. Those who answer affirmatively will be asked to indicate how they became aware that the person with M.E. needed assistance. There are several possible ways that people may determine if another needs help. For example, providers may rely on verbal indicators, nonverbal signs of distress (such as crying), alterations in behavior (such as the recipient withdrawing from a particular situation), and so on.

Congruence between providers' and recipients' ratings. In Study 3, both the person with M.E. and a significant other (the provider) will rate the M.E. sufferer's psychological and physical symptoms. People with M.E. will be asked to rate how they are feeling, thinking, and behaving, and providers (typically a spouse or close friend) will be asked to offer similar ratings for how they believe the recipient is doing.

Several studies have examined the relations between self and other ratings of a target individual's behavior (e.g., Achenbach, McConaughy, & Howell, 1987; Marsh, Barnes, & Hocevar, 1985; Piedmont, 1994). However, only a small subset of these studies has investigated such ratings among individuals experiencing physical illness. A notable exception is Gray,
Brogan, and Kutner (1985), who studied individuals with end-stage renal disease (ESRD) and their spouses, and found congruence on 10 out of 13 measures of life areas (e.g., self-care, family relationship, financial situation, work, leisure time). To my knowledge, no research has investigated the congruence of physical and psychological functioning, or ascertained how discrepancies between such perceptions are related to unhelpful actions.

Although some previous research has indicated that significant others tend to believe that persons with cancer (e.g. Baider & Sarell, 1984) and adolescent ESRD (Wright, Brownbridge, Fielding, & Stratton, 1990) are doing worse than the patients themselves report, discussions of maximization or catastrophizing are virtually absent in the M.E. literature. Instead, there are a larger number of reports emphasizing minimization or trivialization of the illness by professionals and laypeople alike (Feiden, 1990; Shepherd, 1990). Therefore, it is anticipated that people with M.E. will report more health problems than will their significant others.

Many M.E. symptoms are largely unobservable by others (e.g., myalgia, visual disturbances, fatigue) and difficult to validate externally (Fisher, 1989; Lehman & Hemphill, 1990). Nonetheless, such symptoms are inner states that are especially salient from the recipient’s own perspective (Funder, 1980; Funder & Colvin, 1988). Therefore, it is predicted that significant others will underestimate the type and number of physical concerns relative to people who have the illness.

The lack of observable signs of disease among people with M.E. may stand in stark contrast to potential providers’ beliefs
about what it is like to be ill (Lehman & Hemphill, 1990). For example, providers may believe that illness is characterized by observable manifestations of pain (such as facial grimacing, impaired gait), the use of canes or other mobility aids, lack of muscle coordination (such as tics, tremors, or choreiform movements), gross impairments in speech, loss of limbs, or disfigurement. Evidence of "real" illness may also be reflected in outcomes of treatment. For example, patients who have received chemotherapy may lose their hair, and following operations people have scars. With M.E., however, most of the symptoms such as fatigue and generalized muscle weakness are unobservable and may hence seem rather benign; we all feel these ways at times. In a study in which the importance of various symptoms was rated, "feeling weak all over for much of the time" was considered to be "very serious" by only 6% of psychiatrists and 9% of physicians (Dohrenwend & Crandell, 1970). Thus, for example, one of the main symptoms of M.E. was not considered to be particularly problematic by many professionals.

Because of the potential importance of the distinction between different types of M.E. symptoms, observable and unobservable physical symptoms will be examined separately. It is predicted that providers who believe that respondents with M.E. are experiencing observable and unobservable physical symptoms will also report that they offer more supportive behaviors and less unsupportive actions than close others who believe recipients are experiencing fewer symptoms. Discrepancies between providers and recipients will be calculated, and symptoms will be related to supportive and unsupportive behaviors. It is expected that greater
discrepancies between providers and recipients (i.e., providers who believe their significant others are doing much better than recipients themselves believe) will be associated with more unsupportive actions and fewer supportive actions by providers from the recipients' points of view. By underestimating the physical symptoms that recipients experience, providers will likely overestimate the things that people with M.E. are able to accomplish, and will therefore be less likely to provide effective assistance.

Study 3 seeks to investigate congruence between providers' and recipients' perceptions regarding emotional as well as physical health. The importance of investigating psychological symptoms is indicated by the fact that depression is commonly experienced by people with M.E. (see Dutton, 1992, for a review). Two possibilities may be offered with respect to perceived psychological symptoms as rated by those with M.E. and significant others. On the one hand, others may overestimate the extent of psychological symptoms if they believe that M.E. is an emotionally-caused disorder (Powell et al., 1990; Wessely & Powell, 1989) that is characterized by psychological complaints. Providers may filter out information inconsistent with their schemata and overemphasize psychological symptoms. On the other hand, providers may underestimate the extent of psychological symptomatology that people with M.E. experience if they are relying on observability of symptoms (Funder, 1980; Funder & Colvin, 1988; Lehman & Hemphill, 1990), because many of these symptoms (e.g., nervousness, feeling lonely, lack of interest in things, feelings of worthlessness) are not readily apparent merely by looking at the respondent.
Two possibilities suggest themselves with respect to relations between psychological symptoms and helpful and unhelpful actions. On the one hand, providers may offer more supportive actions and fewer unsupportive actions if they believe that respondents with M.E. are experiencing psychological symptoms because of the perceived need for assistance due to stresses and limitations imposed by M.E. On the other hand, providers may indicate that they offer fewer supportive actions and more unsupportive actions if the presence of psychological symptoms is thought to be due to lack of perceived effort on behalf of recipients or is considered to be aversive by providers. Because of the different ways in which psychological symptoms may be perceived by providers, no predictions are offered with respect to the relations of discrepancies between providers’ and recipients’ ratings of psychological symptoms and supportive and unsupportive behaviors.

Perceived causes of M.E. Although research has indicated that individuals with M.E. tend to attribute their illness to physical causes (e.g., Powell, Dolan, & Wessely, 1990; Wessely & Powell, 1989), very little is known about the views of support providers, and the relations between such views and reported behaviors. In the present study, providers will be asked about their views regarding causes of M.E., including psychological, physical, environmental, and biological factors. Then, the relations between these views and supportive and unsupportive behaviors will be assessed.

Previous research has indicated that providers’ views of the cause of an illness may alter their behavior toward
individuals in need. When people believe that the cause of an illness is controllable, the result may be anger and reluctance to help (Schmidt & Weiner, 1988; Weiner, 1985; Weiner et al., 1988). M.E. is associated with psychological symptoms, most notably depression (Abbey & Garfinkel, 1990; Blakely et al., 1991; Grafman et al., 1991; Manu, Matthews, & Lane, 1988), which may largely be seen as controllable. To the extent that this is true, providers may believe that the afflicted person is not trying hard enough to get better and may encourage recovery (Lehman et al., 1986). Furthermore, such providers may believe that the person with M.E. is malingering in order to obtain sympathy, or avoid unpleasant tasks (such as working or doing household chores), and may try to force them to do things that the recipients do not feel well enough to do.

A study conducted by Hooley, Richters, Weintraub, and Neale (1987) supports the notion that patients with symptoms believed by significant others to be influenced by an unwillingness of the patient to engage in appropriate behaviors had lower levels of marital satisfaction compared with patients with symptoms thought to be illness-caused. To put it another way, relationship quality seems to be negatively affected when the recipient's symptoms are viewed as intentional and voluntary. According to this view, it is only because sufficient psychological control is not being exercised that amelioration of symptoms has not been achieved. Based on this reasoning, it is anticipated that providers who believe M.E. is primarily due to psychological causes will offer fewer supportive actions, and engage in more unsupportive actions toward the person with M.E., than those who believe M.E. is less significantly due to
psychological causes.

Constraints. Given that unsupportive actions have been offered and received, one may ask: Why did the provider say or do the unhelpful things he or she did? At present, data are only available from the recipient’s point of view. For example, Lehman and Hemphill (1990) asked MS patients why they believe unhelpful actions were performed by their support network members. A substantial number gave responses that absolved the provider of blame for his or her actions. That is, recipients offered benign attributions such as the belief that the provider lacked knowledge or understanding regarding the illness. This finding was replicated in Studies 1 and 2.

Although recipients in past research tended to believe that providers meant them no harm, it is not clear what providers think about this issue. Do providers believe they did or said unhelpful things because they lacked an understanding of what to do? Or do they think that they responded ineffectively because of network stress (Eckenrode & Gore, 1981), interpersonal anxiety (Wortman & Lehman, 1985), expectancy of negative consequences (Fichten & Bourdon, 1986), additional stressors (Holmes & Rahe, 1967), or for other reasons? To address this question, providers will be asked to indicate why they said or did the things that they thought recipients perceived as unhelpful. Their responses will be compared with those of recipients.

In order to obtain a more direct assessment of impediments to effective action, providers will be asked what they think prevented them from responding in more effective ways, a strategy that will guide participants to think about factors
that may have contributed to the unhelpful interaction. Identification of impediments is important because providers may offer optimal support only when they are willing and able to overcome difficulties to help recipients. Potential impediments to effective action include lack of perceived need, anxiety, and ignorance about illness and its consequences (Lehman & Hemphill, 1990; Peters-Golden, 1982). Also, even if providers think they know what is wanted, they may feel unable to offer it because of a skills deficit. For example, providers may know that recipients wish to talk about their illness (Lehman et al., 1986), yet refrain from doing so because they feel poorly equipped to engage in such a discussion. Other impediments to effective action include disagreement with recipients regarding what is actually helpful, lack of motivation to assist the person, lack of resources such as time or money (Darley & Batson, 1973; Hobfoll, 1989), and discrepant coping styles of providers and recipients (Lane & Hobfoll, 1992). For example, an individual’s strategies to cope with a stressor may facilitate, constrict, or interfere with coping efforts of close others which, in turn, may influence the individual’s appraisals and attempts to cope (DeLongis & O’Brien, 1990; O’Brien & DeLongis, in press).

Consequences

The consequences of supportive and unsupportive actions, or those factors that follow helpful and unhelpful behaviors, will be reviewed here.
Awareness that actions were unappreciated. Although much previous research has indicated that people coping with stressful life events report that those in their support network may do or say things that are unhelpful (e.g., Dakof & Taylor, 1990; Davidowitz & Myrick, 1984; Davis, Brickman, & Baker, 1991; Lehman et al., 1986; Wortman & Lehman, 1985), it is unclear to what extent, if at all, providers recognize that their actions are unappreciated. In order to gain a better understanding of the recognition of the unhelpfulness of providers' actions, respondents will be asked when and how they became aware that the things providers said or did were viewed as unhelpful by the recipient. The former issue has not been addressed in previous research, and is important because it may offer some clues regarding ways in which unsupportive actions and their consequences unfold. For instance, do providers recognize immediately that their actions are unappreciated, or do they figure it out only after reflecting on the exchange?

More detailed information will be gathered by asking how providers became aware that their actions were unhelpful. The available data suggest that providers may not be aware that their actions have been unhelpful. For example, Studies 1 and 2 indicated that a preponderance of recipients do not mention to providers that the latter's behaviors were unhelpful, perhaps contributing to a lack of awareness of the problems inherent in the interactions. On the other hand, some recipients do indicate their dissatisfaction through discussion or even verbal abuse directed toward the provider. Moreover, providers may rely on nonverbal cues (Siegman & Feldstein, 1987; Weiner et al., 1972) such as facial gestures or emotional difficulties...
that are inherent in unpleasant exchanges (Wortman & Lehman, 1985) to determine that their actions were not appreciated by the recipient.

Issues to be Explored in Study 3

1.) People with M.E. will report unhelpful actions that involve minimization, avoidance, and giving advice.

2.) Investigate relations between the Big Five personality dimensions and supportive and unsupportive actions.

3.) Investigate how providers became aware that recipients needed assistance.

4.) Greater discrepancies between providers and recipients with respect to assumptions about symptoms experienced by the person with M.E. will be related to more unhelpful actions and fewer helpful actions by providers from the recipients' points of view.

5.) Providers who emphasize psychological causes of M.E. will offer more unsupportive actions and fewer supportive actions than providers who emphasize organic causes.

6.) Investigate constraints (impediments to effective action) such as attributions for unhelpful actions, and factors that prevented providers from responding in more effective ways.

7.) Investigate how and when providers became aware that their actions were unappreciated.

Method

Inclusion in Study/Assessment of M.E.

M.E. is an illness with a heterogeneous group of symptoms. The cause is unknown, and currently there is no test which accurately ascertains whether or not a patient suffers from M.E. As a result, one problem that must be addressed in this research
is how to obtain a group of recipients who suffer from M.E. and not merely chronic fatigue (Dutton, 1992). This problem was addressed in two ways.

First, potential respondents were asked if they were diagnosed with M.E. by a medical professional, and if so, who made the diagnosis. Because of confidentiality, no attempt was made to confirm the diagnosis. Second, in order to obtain more detailed information regarding symptomatology, respondents were given, in lay language, criteria of M.E. developed by the Centers for Disease Control (CDC; Holmes et al., 1988). A more restrictive inclusion of M.E. patients was obtained here than is suggested by the CDC. This is because only people who satisfy the major criterion and at least eight symptom criteria were included in the present study. According to the CDC, inclusion in research may be made as long as the patient satisfies six of the symptom criteria, if at least two out of three of the physical criteria are simultaneously met. However, the physical criteria need to be obtained by a physician on two separate occasions. As most patients are likely unaware of whether these physical criteria were assessed by their family physician or specialist, only patients who met the former criteria (major criterion and at least eight symptom criteria) were included. It is important to identify only those people whose symptoms occur as a result of M.E. Therefore, participants were asked to indicate only those things that they have experienced since the onset of their illness. In sum, respondents were included in the study only if they (1) were formally diagnosed by a health professional and (2) currently met the CDC criteria for M.E.
Procedure

This study was conducted in cooperation with (1) an Infectious Diseases specialist in Vancouver (Dr. Grant Stiver) and (2) the Myalgic Encephalomyelitis Society of British Columbia (MEBC). The specialist (who provides diagnostic and treatment services) invited his patients with M.E. to participate in the study. People with the illness who indicated a willingness to take part in the study were put onto a list for the researchers.

Greater Vancouver area residents with M.E. were chosen randomly from MEBC's pool of active members and were initially contacted by letter describing the study (Appendix 1). The letter included enough information so that potential participants were able to make informed decisions about whether or not to participate. Specifically, the letter indicated how participants' names were obtained, the purpose and goals of the study, and information regarding methodology. In addition, the letter covered issues of confidentiality, anonymity, and time required for participation. The letter informed respondents that if they did not contact MEBC's project office declining an interview within two weeks, an MEBC representative would contact them. One of two MEBC representatives telephoned potential participants to ask if they (1) received the letter, (2) obtained a diagnosis from a medical professional, (3) and were willing to participate in the study (if so, their names and telephone numbers were passed onto the researchers). Potential participants were encouraged to contact the researchers directly if they wanted to talk about the study or its methodology before making a decision regarding participation, or if they wanted to
set up an appointment for an interview directly through the researchers. An MEBC representative gave the researchers a list of names and telephone numbers of members who agreed verbally to participate.

A second telephone call was made, this time by the researchers, to set up an interview date, place, and time (see Appendix 2 for an outline of information that was covered in the telephone call). Participants were asked at what time during the day they tend to feel their best, and interviews were scheduled for that time. Most interviews were scheduled in the respondents' homes, to increase the chance that respondents would be able to complete the interview. Scripted replies to common questions were supplied to interviewers for the phone call (see Appendix 3). If potential participants indicated that they were married, or in a common-law or other long-term intimate relationship, they were asked if they would be willing to ask their partner to complete a brief questionnaire as part of the study. If the participant was not involved in such a relationship, or did not feel comfortable asking their partner to complete a questionnaire, they were requested to think of someone else who knew them quite well that they would be willing to ask.

A follow-up telephone call was made before the interview to remind participants about the appointment, and to check whether or not they were feeling well enough to take part in the study that day. When participants were doing poorly, an interview was scheduled for an alternate day. Prior to commencing the interview, each participant read and signed a consent form (see Appendix 4), and was given a second form to keep for their own
records. Respondents were asked for permission to tape-record the interviews in order to avoid any loss of information, and to ensure that the interviews did not take any longer than was necessary. Because M.E. is sometimes associated with attention and concentration difficulties, participants were encouraged to ask interviewers to repeat questions if necessary. Also, respondents were told that they could ask for elaboration if they were not sure what the question was trying to assess, and that they could skip any questions in the interview for any reason. Interviews were conducted by three graduate students and twelve undergraduate research assistants (see Appendix 5 for M.E. interview).

At the conclusion of the interview, each participant was given a package containing two questionnaires. One questionnaire was to be completed by the person with M.E. (see Appendix 6), and the second questionnaire was to be completed by a close other. Questionnaires included self-addressed stamped envelopes to be mailed to the project office. Participants were given two UBC keychains (one for the person with M.E. and one for the close other) as tokens of appreciation for taking part in the study. Following the interview, a card was sent from the project office thanking respondents for participating in the study.

If either or both of the questionnaires were not received at the project office within one month of the interview date, a reminder letter was sent to the person with M.E. (see Appendix 7), along with replacement questionnaires. Respondents were asked to pass the close other questionnaire onto someone else who knew them quite well if the person that they had initially
asked to take part in the study decided not to participate.

**Participants**

Membership in MEBC is determined by payment of a nominal yearly fee. Because there is limited information available in the MEBC database regarding its members, it was necessary to send all members a letter regarding the study, even though it was recognized that some would not be suitable to participate. One hundred and ninety letters were sent out in four groups of approximately 50 letters in each wave one month apart. Twenty-one potential respondents (11% of people to whom letters were sent) were dropped because they had not been formally diagnosed with M.E., six (3%) indicated that they were either recovered or significantly better, six (3%) failed to meet the CDC criteria (less than eight minor criteria), five (3%) had already participated at some phase in the study, four (2%) were M.E. caregivers who were not themselves ill, three (2%) reported that they had been born with the illness, and one (1%) did not have a significant other whom they would be willing to ask to fill out a questionnaire. The response rate was determined on the basis of the remaining potential participants (144 people) who were eligible to take part in the study. Thirty-three (23%) declined to participate, and 28 (19%) were never contacted by telephone. Eighty-three respondents from MEBC (79% of the total sample) were interviewed, yielding an interview response rate for the MEBC sample of 58%. An additional 13 people (12% of the total sample) were obtained through an Infectious Diseases specialist, and nine (9% of the total sample) were included subsequent to hearing about the study from other study participants. Thus, a total of 105 individuals with M.E. living in the Greater
Vancouver area participated in the study.

**Dependent Measures**

All participants with M.E. were given an interview and a follow-up questionnaire, whereas close others received only an abbreviated questionnaire. The close other questionnaire contained many of the same questions as those in the participant interview/questionnaire, with appropriate wording changes (e.g., changing "My M.E..." to "My close other's M.E...").

Previously developed measures were utilized when available and chosen if, in addition to their content, (1) information regarding the psychometric acceptability of the instrument was available, and (2) the scale was reasonably easy to administer. When these conditions were not met, original questions were constructed or adapted from other researchers.

The interview that was administered to people with M.E. was developed to assess key constructs such as helpful and unhelpful actions, relationship satisfaction, confiding, contact with medical professionals, attributions, meaning, counterfactual thinking, and perceptions of controllability and foreseeability. Weekly focus groups were conducted for two months whereby four researchers met, discussed the interview, and revised it. Subsequently, an advisory panel of seven people with M.E. was formed to talk about the methods and procedures, and review the instrument. Advisory panel members read through the materials (contact letters, telephone scripts, consent forms, interview instruments, and questionnaires), and met with the researchers to discuss the suitability of questions. Ambiguous items were rewritten, inappropriate items were dropped, and additional constructs were added. The measures were pilot tested on eight
people with M.E. to determine their length, the suitability of questions, and the adequacy of the proposed methodology. The measures of particular interest for the present investigation are included below.

**Demographics.** The M.E. sample was predominantly white (96%); the remaining respondents were Asian (2%), Afro-Canadian (1%), and Indo-Canadian (1%). There was a somewhat higher proportion of females (88% of sample) who participated than one would expect given national statistics. Thus, women contract M.E. at a rate of two to five times that of men (Feiden, 1990; Harvey, 1989; Komaroff & Buchwald, 1991). Nonetheless, these numbers do not appear to reflect a bias regarding the greater likelihood of females to participate (Rosenthal & Rosnow, 1975), given that 6 men (22% of men to whom letters were sent) and 27 women (17% of women to whom letters were sent) declined to take part in the study. Rather, the large number of women in the present study is an accurate representation of the gender composition of people who are members of MEBC. Thus, letters were sent randomly to MEBC members, and the pool from which the present sample was drawn comprised 86% women (163 out of 190 letters).

Sixty percent of participants with M.E. were in an intimate relationship (married, common law, or other long-term relationship), and 40% were not. Respondents with M.E. noticed onset of their symptoms an average of 8 years earlier (ranging from 1 to 22 years). The number of years since diagnosis ranged from 0 to 18, with the average being 5 years.

The M.E. and close other samples had an average of 14.67 and 14.19 years of education, respectively. Respondents with M.E. had a mean age of 47, and their close others had a mean age
of 50. Respondents with M.E. had a mean (1994) personal income of $19,000. The corresponding figure for close others was $31,000.

Helpful and unhelpful actions. Supportive and unsupportive behaviors were measured in 3 separate ways. First, recipients were asked, on a scale from 1 "never" to 5 "almost always" "How often has your [close other] said or done things that were especially helpful to you?" Similarly, recipients were asked, on a scale from 1 "never" to 5 "almost always" "How often has your [close other] said or done things that were unhelpful or that upset you?" If respondents indicated at least "rarely" to either or these questions, they were asked "What were these things? Please tell me one or two of the most helpful [unhelpful or upsetting] things that your [close other] has said or done." Providers were asked the same questions with respect to the helpful and unhelpful actions that they offered to recipients.

Second, a revision of the Supportive Actions Scale (SAS; Trobst et al., 1994), the SAS-Circumplex Version (SAS-C; Wiggins & Trobst, in press) was used to measure a variety of stylistic differences in the types of support that providers deliver. The SAS-C used in the present study is 61-items with ratings ranging from 1 "never" to 5 "almost always." The measure includes items that are placed within the interpersonal circumplex space. Specifically, the SAS-C includes Directive (e.g., "Give advice"), Arrogant (e.g., "Persuade them to change their behavior"), Critical (e.g., "Remind them that people sometimes get what they deserve"), Distancing (e.g., "Try to keep them from leaning on me too much"), Avoidant (e.g., "Avoid being
directive"), Deferential (e.g., "Not argue with them"), Nurturant (e.g., "Give them a hug") and Engaging (e.g., "Get them to talk more about their problem") items that map onto combinations of Dominant and Nurturant tendencies of the interpersonal circumplex. The SAS-C provides a conceptual and measurable basis for representing both helpful and unhelpful actions. Prototypically helpful actions are those that fit within the Nurturant (LM) octant, although the adjacent categories of Deferential (JK) and Engaging (NO) may be primarily helpful. Actions that are further away from the Nurturant (LM) octant are more apt to be unhelpful. Thus, prototypically unhelpful actions are located in the Critical (DE) octant, with adjacent octants Arrogant (BC) and Distancing (FG) also being primarily unhelpful. The scale was originally designed to assess support from the provider’s perspective, and was altered appropriately so that recipients were also able to complete the measure.

Third, the Social Support Behavior Questionnaire (SSBQ; Johnson et al., 1993) comprises behaviors that support providers may perform toward recipients. The scale includes nine unhelpful and six helpful items presented on five-point scales, ranging from 1 "never" to 5 "almost always." The scale was scored in the same way as for Study 2, that is, separate scores were generated for the helpful and unhelpful composites.

The Big Five Inventory-44. The Big Five Inventory - 44 item Version (BFI; John, Donahue, & Kentle, 1991) assesses the five main personality dimensions of Extraversion (e.g., "Is talkative," "Is full of energy"), Agreeableness (e.g., "Has a forgiving nature," "Is considerate and kind to almost
everyone"), Conscientiousness (e.g., "Does a thorough job," "Makes plans and follows through with them"), Neuroticism (e.g., "Worries a lot," "Can be moody"), and Openness to Experience (e.g., "Is original, comes up with new ideas," "Values artistic, aesthetic experiences"). Respondents were asked to rate the extent to which they believe that each of 44 statements describes them on 5-point scales, ranging from 1 "strongly disagree" to 5 "strongly agree." The BFI contains scales that are internally consistent, with good convergent and discriminant validity (John et al., 1991).

Perceived need for assistance. Two questions were developed to determine, from both the providers' and recipients' perspectives, how providers became aware, if at all, that assistance was needed. In order to get participants with M.E. and their close others to recall significant exchanges, both groups were asked to "Think back to the most important time that you [your close other] needed your close other's [your] help." This request was followed by a statement encouraging participants to mention what assistance was needed at the time. Then, recipients were asked, "Do you think that your close other was aware that you needed his(her) help?" Affirmative responses were followed with: "How do you think he(she) became aware that you needed his(her) help?" Providers were asked this latter question, with appropriate wording changes ("How did you become aware that he(she) needed your help?").

M.E. symptoms. As has been noted by previous authors (e.g., Mechanic, 1980), the distinction between psychological and physical symptoms may be somewhat arbitrary; there is often overlap between the two. A fine distinction between symptom
types is therefore not possible. Nonetheless, common physical complaints of people with M.E. were generated from two sources. The Goldstein (1992) M.E. Symptom Checklist includes a variety of symptoms, including nervous system problems (e.g., "seizures," "difficulty with balance," "blackouts," "twitching muscles"), and other physical complaints (e.g., "recurrent flu-like illnesses," "nasal and other allergic reactions," "weight change"). Two items ("rash of shingles" and "painful urination") were dropped because fewer than 30% of people with M.E. were reported to experience such symptoms. Items were also included from Komaroff and Buchwald (1991; e.g., "fatigue," "dizziness," "muscle weakness"), who estimated symptom frequencies of patients from experience and reports in the literature. The resulting scale comprised 42 items on five-point scales ranging from 1 "never" to 5 "almost always."

**Psychological symptoms.** A subset of the 53-item Brief Symptom Inventory (BSI; Derogatis, 1975; Derogatis & Melisaratos, 1983) was employed to assess psychological state. The BSI is a brief form of the 90 item Symptom Checklist - Revised (SCL-90-R; Derogatis, 1977), and includes nine primary symptom constructs. For the present study, the Anxiety (e.g., "Feeling tense or keyed up," "Nervousness or shakiness") and Depression ("Feeling lonely," "Feeling blue") subscales were included, yielding a total of 13 items. The items were rated on 5-point scales ranging from 1 "not at all" to 5 "extremely" depending upon how much it bothered or distressed the respondent in the past month.

**Causal explanations.** Initially, recipients were given the following open-ended question: "There is little agreement among the public and even among medical professionals regarding how
M.E. develops. Nevertheless, some people with M.E. have one or more hunches or theories about the cause of their illness. Do you have any hunches or theories about what caused your M.E. to develop?" Respondents who answered affirmatively were asked, "What are they?" Then, all respondents with M.E. were given a series of closed-ended questions to obtain more specific information regarding perceptions of the development of M.E. They indicated on five-point scales, ranging from 1 "not at all" to 5 "extremely," how important they thought the following eleven factors were in causing their M.E.: 1) a viral infection; 2) a genetic predisposition; 3) working in an environment with no fresh air; 4) toxins; 5) working too hard; 6) worrying; 7) God or some other spiritual force; 8) depression; 9) not doing enough exercise; 10) stress; and 11) chance or pure coincidence. Providers were also asked about their views regarding the cause of their close others' M.E., but were only asked the closed-ended questions.

Constraints. In order to obtain a measure of impediments to effective action, recipients were asked "Why do you think your close other said or did these unhelpful things?" A more direct assessment of constraints was obtained by asking recipients "What do you think prevented your close other from acting in a way that you would have preferred?" Close others were also asked these questions, which were reworded to reflect the fact that providers experienced the impediments.

Awareness that actions were unappreciated. Post-behavioral awareness was measured in two ways. First, with respect to when awareness was obtained, recipients were asked to "Think back to the most upsetting time that your close other said or did..."
unhelpful things. Do you think your close other realized that his(her) actions were unhelpful at the time, did he (she) become aware of them later, or is he(she) still unaware that his(her) action was unhelpful?" If recipients indicated that providers became aware at some point, the former were asked "How do you think your close other became aware that his(her) action was unhelpful or upset you?" These questions were also asked of providers. Of course, because limited awareness would preclude a sensible answer, providers were not given the option of still being unaware that their actions were unappreciated.

Coding

Open-ended questions from respondents with M.E. were transcribed from the tape recordings. Then, a series of codes were developed according to the following method. First, a random sample of responses from providers and recipients was examined in order to develop an initial set of codes. Rules for inclusion and exclusion were made. When possible, categories from previous research were utilized (Dakof & Taylor, 1990; Dunkel-Schetter, 1984; Lehman et al., 1986; Lehman & Hemphill, 1990). Answers that were unique to this sample were also added to the list of codes. The majority of open-ended questions had not been asked by previous researchers, and a new coding scheme needed to be developed through consideration of responses and theorizing.

The author developed categories, coded all of the responses, and modified categories when appropriate. Once a complete set of categories was developed, the author discussed them with a second rater, who then coded all of the responses again. All discrepancies were resolved by deciding which
rater's category reflected best the essence of the answer. Categories were either dropped or collapsed with other categories if responses could not be reliably coded within them (kappa less than .60), or if less than 4% of participants endorsed them.

Up to three answers were coded for each of the questions (except for the "causal explanation" question, for which up to seven responses were coded). For example, when requested to indicate the most helpful actions that were offered to them by providers, participants may have given detailed answers that fit into multiple categories (e.g., "listening/talking," "assisting with daily activities," and "suggestions/coping strategies/information"). If a respondent said more than one thing that was coded within a single category (e.g., "helped me clean the house," "did the dishes," and "cooked dinner," all of which were coded into the "assisting with daily activities" category), the code was used only once. However, the different responses were coded into as many as three categories. Because of multiple mentions per question, totals may exceed 100%.

Cohen's kappas (J. Cohen, 1960) were computed for each category. Because it was of interest only whether or not a participant said something that fit into a certain category, and not the order that such a response was offered, answers were collapsed across mentions. Thus, an answer that fit into a category was coded as a "yes" response, and an answer that did not fit into the category was coded as a "no" response. Agreement occurred when both raters placed responses into the same category, or agreed that such a category did not apply. Lack of agreement occurred when one rater placed the response
into a category, but the other rater did not. Cohen’s kappa ranged between .61 to 1.0, and averaged .87 across the dependent measures.

Comparisons Between Providers and Recipients on the Open-Ended Data

In order to test whether or not differences existed between recipients’ and providers’ responses for the open-ended data, a series of chi-squares of differences for proportions (Glass & Hopkins, 1984) were conducted for each category separately. Thus, participants who mentioned a response that was coded into a category were distinguished from those who did not report such an answer, and proportions of the sample who reported the response were calculated. This procedure was done for both the M.E. and provider samples, yielding 2 ("yes" or "no") X 2 ("recipient" or "provider") contingency tables.

Number of Participants Included in Analyses

The total sample of participants with M.E. was 105, and all of these respondents were included in analyses for questions only asked of them. The percentage of respondents with M.E. who answered such questions was calculated by using a denominator of 105; results are reported in the tables in this manner. When questions were asked of both groups, then the matched pairs were compared. That is, even though 105 people with M.E. answered such questions, those who did not have close others who completed questionnaires were dropped from these analyses (leaving a total of 87 pairs of respondents). This decision was made to ensure that discrepancies between groups that emerged were not due to differences between close others who answered the questionnaires and those who did not. It is conceivable,
for example, that close others who did not send questionnaires back to the project office were less helpful or offered particularly unhelpful actions. The percentage of matched pairs who answered the open-ended questions was calculated by using a denominator of 87; results are reported in the tables in this manner. Eighty-five pairs of respondents (close others and participants with M.E.) completed both questionnaires, which comprised primarily closed-ended questions. When comparisons were made between providers and recipients for closed-ended questions, all 85 pairs were used.

Results

Descriptive Statistics for Scales

Table 6 includes scale score means, standard deviations, number of items per scale, and Cronbach alpha reliabilities for participants with M.E. (recipients). Table 7 includes the same information for scales given to close others (providers).

Insert Tables 6 and 7 About Here

Helpful Responses

On average, participants with M.E. (M = 4.00) said that providers offered helpful actions "often," whereas close others (M = 3.74) said that they helped between "sometimes" and "often." The independent t-test for differences between groups was significant, t(184) = 2.08, p < .05, such that recipients indicated that close others provided helpful actions more frequently than providers did.

Of the respondents who indicated that providers offered helpful actions at least "rarely," 99% of participants with M.E.
and 95% of close others reported at least one especially helpful action by providers that was coded into one of 9 categories (see Table 8). A substantial number of respondents reported that

Insert Table 8 About Here

some type of emotional support (63% of recipients and 68% of providers) was helpful, followed by tangible (54% of recipients and 40% of providers), and informational (17% of recipients and 18% of providers) support. As is evident in Table 8, there was substantial agreement between providers and recipients regarding what they believed was helpful. Thus, each group mentioned things that were codable into similar categories, and such answers were offered in roughly equal proportions. Interestingly, both groups mentioned that a particular form of tangible support, assisting with daily activities, was appreciated more often than other forms of support (47% of recipients and 37% of providers). Expressing love, concern, or understanding was seen to be helpful by both providers and recipients, and was the category mentioned second in frequency for both groups (24% of recipients and 29% of providers). Suggestions/coping strategies/information (17% of recipients and 18% of providers), accepting or acknowledging the illness or its severity (17% of recipients and 14% of providers), and listening/talking (17% of recipients and 26% of providers) were considered to be helpful in each group to a similar extent. A substantial minority also indicated that they considered the absence of negative actions to be helpful (14% of recipients and 7% of providers). Thus, recipients appreciated, and providers
recognized, not only helpful things that providers said and did, but also the fact that they did not say or do unhelpful things. Finally, providing accommodations/making decisions/acting on behalf of participants with M.E. (13% of recipients and 6% of providers), providing encouragement or reassurance (12% of recipients and 17% of providers), and physical presence/being there/including in social activities (10% of recipients and 9% of providers) were valued by both providers and recipients.

Unhelpful Responses

On average, participants with M.E. (M = 2.41) and close others (M = 2.38) said that providers offered unhelpful actions between "rarely" and "sometimes," t(186) = .29, p = .77.

Of the respondents who indicated that providers offered unhelpful actions at least "rarely," 91% of participants with M.E. and 81% of close others reported at least one especially unhelpful or upsetting action by providers that was coded into one of eight categories (see Table 9). As with the "helpful" question, there was substantial agreement between providers and recipients regarding what they believed was unhelpful.

As anticipated, a substantial proportion of participants with M.E. (33%) reported negative exchanges that focused around denial or minimization of the illness, or statements or actions on the part of providers which suggested that the person with M.E. had a greater capacity to accomplish various tasks than was actually the case. Three M.E. respondents said:
Denial that I can't do something. Refusal to accept it when I say I can't do it, or expectation for me to carry on as if I was normal.

He'll wonder why things aren't done. He doesn't realize the day-to-day dealing with the two kids and being sick. He asked me if I was phoning the bank once a week to check on the interest rates. He'll ask "Well, how come you didn't do this," and I'll get really offended by it.

At the very beginning, he said "Sometimes you can do this, and sometimes you can't do the other, so I think that you use the illness as an excuse to get out of things."

Close others also mentioned unhelpful or upsetting actions that they offered to recipients that focused on challenging the illness or pushing recipients too much (28%). Providers' statements tended to be less harsh than those of recipients, but nevertheless clearly reflected the essence of this category (sometimes the statement included a sense of guilt):

Expected too much. She said that she was "up" for an activity, but wasn't. I took her beyond her limits. She "crashed and burned" for a week. I felt guilty.

I at one time remarked that she should not feel so tired. This hurt her very much and remains with her to this day. I have since realized that this person was completely overloaded emotionally, physically, and spiritually and I felt very badly about my careless remark made four or five years ago.

My lack of a constant, vigilant, awareness as to the extent of the devastation this condition/disease brings to a person's life.

Twelve percent of recipients and 14% of providers reported that close others experienced negative emotional reactions, and expressed them toward the person with M.E. These reactions ranged from anger, frustration, and impatience. Respondents indicated that close others often failed to offer assistance that was wanted or needed (10% of recipients and 13% of
As predicted, respondents indicated that providers may avoid the M.E. sufferer through failure to communicate with them (8% for recipients and 9% for providers), or decreased contact (e.g., not visiting or including in social activities; 5% of recipients and 9% of providers). To illustrate this point, the responses of four people are provided below.

There have been times when I've felt worse after talking to her, almost like I shouldn't have had that conversation. Sometimes you're just looking for somebody, for a shoulder to lean on or an ear to listen, and sometimes you don't get that. [Participant with M.E.]

If I was complaining, she would say, "Enough of that. I want to tell you about something else." I felt like I couldn't talk about that because she wanted to talk about her illness. [Participant with M.E.]

I left her alone when she was having difficulty functioning--partly due to the distance involved. [Provider]

I did not make myself available to discuss his worries about his feelings of worthlessness and possible loss of job...I tend to ignore what is going on and get on with things as we have a very busy household. [Provider]

As anticipated, some participants said that others' unhelpful actions revolved around giving advice (7% of recipients and 8% of providers). Participants said that it was unappreciated when close others gave advice relating to treatment, and things that respondents with M.E. should be doing differently in their lives. For example:
The most unhelpful thing he's done is accusing me of not wanting to get better because I didn't want to go see another naturopath. He always wants me to try different things to get better. [Participant with M.E.]

Telling me to get rid of my boyfriend because he was making me worse. It was upsetting. [Participant with M.E.]

I have offered explanations for her illness and advice on how to get better. This often offended her as her previous efforts seemed invalid. Quick-fix ideas really upset and frustrated her. [Provider]

Encouraged her to exercise or pushed different vitamin or herb compounds. [Provider]

Not surprisingly, some people focused on rude remarks or criticisms that were made (5% of recipients and 5% of providers). And, finally, participants with M.E. found it unhelpful when close others were being overly protective/patronizing (5%), but providers did not mention this category at all (0%). The difference between groups for this last category was significant, $X^2(1) = 4.09, p < .05$.

Nonetheless, because of few endorsements in all categories, the results need to be interpreted cautiously.

Interpersonal Traits and Their Relations to Supportive and Unsupportive Actions

In addition to the open-ended reports, people with M.E. and their close others were also asked closed-ended questions about the different types of supportive and unsupportive actions that providers offered. Octant scores from the SAS-C were computed, and correlations along the diagonal were calculated in order to determine the level of agreement between respondents with M.E. and their close others (see Table 10). As anticipated,
statistically significant relations were found between providers' and recipients' ratings for 7 of the 8 correlations. Not surprisingly, the strength of associations was generally higher for those octants that contain socially desirable actions and lower for those octants that contain socially undesirable actions. The only nonsignificant correlation was for providers' and recipients' reports of close others' actions that fit in the BC (Arrogant) octant. In contrast, the strongest association was for behaviors that fit into the LM (Nurturant) octant.

To investigate the relations between personality and supportive and unsupportive actions, correlations were computed between SAS-C, SSBQ, and BFI subscales. Providers and recipients gave ratings for their own personality dimensions, and also reported on helpful and unhelpful actions offered to participants with M.E. by close others. It was of interest to investigate the relations between (1) recipients' ratings for dimensions and their ratings for supportive and unsupportive actions, and (2) providers' ratings for dimensions and their ratings for supportive and unsupportive actions.

Table 11 indicates that there were few relations between recipients' personality scores and their reports of providers' actions. One interpretation of these results is that people with M.E. do not tend to "pull" certain actions from providers.
There were two exceptions to this trend. There was an association between recipients' Agreeableness scores and their views of providers' DE (Critical) scores, $r (94) = -.22, p < .05$, such that agreeable individuals tended to report receiving fewer critical actions from providers. Similarly, the negative relation between Agreeableness and FG (Distancing), $r (94) = -.22, p < .05$, is consistent with the idea that people with M.E. who are agreeable tend to receive fewer distancing actions from close others than do those low on agreeableness. An alternative explanation is that people who are agreeable tend to differ from their counterparts who are low on this dimension not in terms of negative behaviors offered to them, but rather their perceptions regarding those behaviors.

Table 12 includes relations between providers' self-reported personality dimensions and their reports of supportive and unsupportive actions that they offered their close other with M.E. There were no significant associations between

PA (Directive) or BC (Arrogant) behaviors and the BFI subscales, that is, supportive and unsupportive actions that map onto dominant and cold octants of the circumplex are unrelated to providers' reports of their personality dimensions. In contrast, the other six octants were all related, to a greater or lesser extent, with personality dimensions. The strongest associations were evident in the LM (Nurturant) octant, such that all personality dimensions were associated with nurturance in the expected directions. Thus, Extraversion, Agreeableness,
Conscientiousness, and Openness were positively related, and Neuroticism was negatively related to the LM (Nurturant) octant. Correlations ranged from -.28 to .52. The NO (Engaging) octant included three out of five significant associations, such that Extraversion, Agreeableness, and Openness were all positively related to NO (Engaging). Correlations ranged from -.06 to .34. JK (Deferential) was correlated with Agreeableness, such that people who indicated that they were high on this dimension also said that they offered deferential behaviors. The remaining octants of the SAS-C (DE, Critical; FG, Distancing; and HI, Avoidant) tended to be related to the dimensions of personality in the opposite direction of those mentioned thus far, and there were fewer significant associations. For example, DE (Critical), FG (Distancing), and HI (Avoidant) were associated with Neuroticism, such that high scores on the dimension was related to more actions considered to be cold and submissive. Finally, DE (Critical) was correlated with Agreeableness, such that those who reported being low on the dimension also reported more critical behaviors.

The SAS-C has a factor structure comprising three factors, such that behaviors fall into clusters of Nurturant/Extraverted, Dominant/Hostile, and Avoidant items (Trobst, 1991; Trobst et al., 1994; Wiggins & Trobst, in press). When the three factors are computed from providers' self-reports, and correlated with their personality dimensions of the BFI, it becomes apparent that the Nurturant/Extraverted factor is more strongly associated with scores on the BFI than the other two factors (see Table 13). In fact, the Nurturance/Extraversion factor
was positively related to Extraversion, Agreeableness, Conscientiousness, and Openness, and negatively related to Neuroticism. In contrast, neither of the other factors were correlated with any of these personality dimensions.

Another way to investigate the relations between supportive and unsupportive actions and personality is to compute helpful and unhelpful subscales for the SSBQ separately, and correlate them with dimensions from the BFI (see Table 14). Using providers' self-reports from both of these measures, there are significant associations between the helpful subscale and all of the dimensions of personality. Thus, the SSBQ helpful composite was positively related to Extraversion, Agreeableness, Conscientiousness, and Openness, and negatively related to Neuroticism. Interestingly, Openness was also positively related to the unhelpful composite of the SSBQ. None of the other dimensions were significantly correlated with the unhelpful composite.

Perceived Need for Assistance

Participants were asked three questions about perceived need for assistance. The first question was designed to orient participants toward interactions that were important. The second question was designed to assess if pre-support awareness was obtained, and the third question focused on how awareness
was obtained.

**Most important assistance needed.** In order to get providers and recipients to think about meaningful exchanges, participants were asked to mention the most important time that recipients needed assistance. Eighty-four percent of participants with M.E. and 83% of providers gave responses to the "most important assistance needed" question that were coded into 1 of 9 categories (see Table 15). Emotional (49% of recipients and 45% of providers) and tangible (33% of recipients and 30% of providers) support categories were reported by a substantial number of respondents. Various forms of emotional support were considered to be particularly important. Thus, recipients mentioned expressions of love, concern, or understanding (21% of recipients and 17% of providers), listening/talking (15% of recipients and 16% of providers), physical presence (10% of recipients and 8% of providers), provisions of encouragement or reassurance (9% of recipients and 12% of providers), and accepting or acknowledging illness or its severity (6% of recipients and 6% of providers). As anticipated, several participants mentioned incidents indicating severe disability and physical limitations. Thus, 16% of recipients and 10% of providers indicated help that emphasized basic personal care. Four participants said:
My back goes in spasms sometimes. One time when it went into spasms, I couldn’t get off the floor. I had to call him home from work to move me. I was in terrible pain. [Participant with M.E.]

When I went off work, I was bedridden for about two months. I didn’t eat, I couldn’t make my bed, I could barely bend my legs. At that time, there was nobody to help me. After being bedridden for two months, I went to my sister’s. She said "come here and I’ll look after you." She helped me into the tub, she made my bed, changed my sheets, cooked. [Participant with M.E.]

She developed a very painful muscle/nerve disorder which kept her bedridden for three weeks. I had to nurse her in every way possible. [Provider]

When she first got sick, she needed to be bathed and have her hair washed. She needed me to make all of the meals, grocery shop, clean house, etc. [Provider]

In the most extreme cases, participants said that immediate medical assistance or an ambulance was needed. There was a trend for providers (10%) to mention assistance revolving around an ambulance, physician, or hospital more often than their counterparts with M.E. (3%; $X^2(1) = 3.22, p = .07$). To highlight the seriousness of their symptoms, reports from four participants are listed below:

I had about three or four trips to emergency, and one time there was something quite wrong. It was first thing in the morning, the ambulance was here, the kids had to be taken to school, and it was very traumatic for me. [My significant other] dealt with the ambulance, stayed with me, and then at lunch time he looked after the kids. [Participant with M.E.]

I was lying in the corner in my bedroom crying, and wanting to kill myself, and she and a girlfriend took me to the hospital. [Participant with M.E.]

She had gone to emergency. They did not want to admit her, but she could not care for herself or her children. I met her at the hospital, took her home, and stayed until a homecare worker could arrive. [Provider]
She had constricted breathing from a food reaction while we were driving in the car on holidays. We turned around to go to the nearest hospital. [Provider]

Although not all participants mentioned as dramatic situations as those reported above, several respondents said that help was needed with other basic tasks. In fact, the single category identified most often was assisting with daily activities (24% of recipients and 26% of providers), such as cooking, cleaning, and driving to scheduled appointments. Twelve percent of respondents with M.E. said that the most important help they received revolved around others making accommodations for them or acting on their behalf. For example, three respondents with M.E. said:

I found it really helpful when [my close other] went to the doctor and told his side of things because at one point I was incapable of expressing how bad my life was, so he was able to put an objective, credible story.

When I was dealing with the law suit, he was the one who read over the reports that I received because I wouldn’t read the negative ones, and he viewed the video tape. He offered to testify and write an affidavit. He was very supportive, and helped me not get into the insurance company way of looking at it.

The assistance I needed the most was somebody to take over completely, to make all the decisions, to do all the housework, to make all the decisions in regards to my youngest child.

Close others rarely reported that providing accommodations/making decisions/or acting on behalf of the respondents with M.E. (3%) was the most important help that was needed, \( \chi^2(1) = 4.07, p < .05 \).
How did providers become aware that M.E. recipients needed help?

After recalling the most important assistance needed by recipients, all participants with M.E. were asked whether or not they believe that their significant other was aware that such assistance was needed. Ninety-one percent of respondents with M.E. answered affirmatively, which is not surprising given that participants restricted their answers to precisely that subset of situations in which providers would most likely be aware that help was needed.

When asked how pre-support awareness was obtained, 92% of recipients and 87% of providers gave open-ended answers that were coded into 1 of 8 categories (see Table 16). For both samples, the most commonly reported way was discussing the issue or talking with the provider (43% of recipients and 48% of providers). For example, four participants said:

I was always in touch with her, so I’ve always reached out to her, and we’re very close. [Participant with M.E.]

I called him and said, "Come home, I can’t move." [Participant with M.E.]

I asked her for her thoughts and she told me. [Provider]

I became aware that she was more bored and frustrated as she seemed to need more time visiting on the phone seeking my opinion on relationships within her family or to talk about frustrations of M.E. [Provider]

For recipients, the next most commonly reported method was observation or looking (14%). Providers reported answers that
were coded into this category 10% of the time. Overall, respondents did not mention specifically what it was about the recipients' appearance that alerted providers to the fact that assistance was needed. Rather, brief statements regarding looking at the person with M.E. were typically reported. Some examples are included below:

To see me from what I once was and to what I had turned into. She said my eyes looked dead and dull. They used to be sparkly and happy. [Participant with M.E.]

Sometimes when he saw me being shut out of everything, he'd notice that I get really depressed. [Participant with M.E.]

Sometimes I can see her not feeling well so I try and do my utmost to make her comfortable. I can see it in her eyes. [Provider]

In person she didn't look well, and needed support when sitting. [Provider]

The third most frequent method that recipients (10%) indicated, and the second most frequent method for providers (20%), was expression of emotional difficulties or distress. This category included methods that may have been determined on the basis of observation, and may therefore be considered a subset of the observation or looking category. Nonetheless, the present category was distinguished from observation or looking in that it contained explicit statements pertaining to emotional distress. Moreover, the emotional difficulties category included statements of distress that were not necessarily observable, but that were conveyed through discussion (e.g., "She spoke openly about her distress at having to do it") or were inferred by the provider (e.g., "I felt that her spirit was suffering due to the intense pressure placed upon her as such a
young person"). Six out of the 9 statements by recipients and
13 out of 17 statements by providers belonging to this category
involved respondents with M.E. crying or becoming upset. There
was a tendency for providers to mention this category more often
than recipients, $\chi^2 (1) = 2.89, p = .09$. Four respondents said:

Lying in a heap on the bed, torrential tears. I was a
mess. [Participant with M.E.]

He saw me crying on the stairs. [Participant with
M.E.]

[She] was bursting into tears every 30-40 minutes
while studying. We were very close then, as now, and
she was hurting too much to bother trying to hide her
feelings and needs. [Provider]

She could barely move without crying out. She rarely
cries, and is generally extremely stoic. I knew she
was in extreme pain and distress. [Provider]

Empathy, understanding, or perceptiveness was reported by 9% of
recipients and 3% of providers. Such responses emphasized the
psychological connection between providers and recipients, or
ability of close others to consider the perspectives of
participants with M.E. Five respondents said:

He could sense it. I met him when I was 18. We had
dates every night until we got married, and we have
been together every day. You get to know a person.
[Participant with M.E.]

Through her sensitivity to me. [Participant with M.E.]

She knows me better than I know myself. [Participant
with M.E.]

I understand her needs. [Provider]

It’s intuitive. [Provider]

Eighteen percent of providers said that they became aware that
their close other with M.E. needed help because of
incapacitation or poor physical health. Fewer people with M.E. (7%) said the same thing, $X^2 (1) = 5.20, p < .05$. For example, four respondents said:

I couldn't get out of bed. It's just total incapacitation on my part. I know, even now, when we're talking about things when my brain just doesn't function. It's like your brain has a complete shut down. [Participant with M.E.]

I couldn't stand up. I couldn't do anything. [Participant with M.E.]

Her legs went blue, her complexion white and pasty, sweaty, and she was moving in and out of consciousness. [Provider]

He left simple chores that used to be no problem, and lay down pale, exhausted, aching, barely able to physically move. He felt overwhelmed. [Provider]

The next most frequently reported categories for recipients were obvious/common sense (7% of recipients and 5% of providers), and voice tone or body language (5% of recipients and 2% of providers). Confusion/being lost was never mentioned by recipients, but 7% of providers did, $X^2(1) = 6.21, p < .01$. For example, two providers said:

She became so confused at times that she couldn't remember what she had just been doing moments earlier or what to do next--if she had the energy to do anything next at all.

She didn't return on time. I spent hours looking for her and found her still walking on the roadside.

Providers' and Recipients' Views of Symptoms, and Their Relations to Supportive and Unsupportive Actions

Two raters divided the M.E. physical symptoms into three categories: 1) symptoms that are clearly observable; 2) symptoms that are clearly unobservable; and 3) symptoms that are
sometimes observable and sometimes unobservable. Because this section emphasizes ratings of symptoms for observable and unobservable symptoms, and their relations to supportive and unsupportive actions, items placed in category three were omitted from subsequent analyses. There was reasonable agreement between raters, as emphasized by kappa coefficients for observable (.69 for recipients and .77 for providers) and unobservable (.76 for recipients and .83 for providers) symptoms, respectively.

A series of t-tests were conducted in order to determine if providers or recipients view physical and psychological symptoms of those with M.E. as occurring more frequently. As anticipated, people with M.E. (M = 2.71) said that they experienced more physical symptoms than their close others reported (M = 2.36), t (180) = 4.82, p < .001. The same pattern was found for unobservable symptoms (M = 3.10 for recipients and M = 2.75 for providers; t (180) = 4.26, p < .001).

As expected, results were less clear for psychological symptoms. Thus, providers (M = 2.14) said that those with M.E. were marginally more depressed than did respondents with M.E. (M = 1.99), t(179) = 1.34, p = .18, but this trend was reversed for anxiety (M = 2.09 for recipients; M = 1.92 for providers), t(179) = 1.57, p = .12. These findings may be due, in part, to the opposing possibilities discussed earlier. It was suggested that emotional symptoms may be emphasized by providers if they believe that M.E. is an emotionally caused disorder. In order to test such a notion directly, providers' causal notions were correlated with their views of recipients' psychological symptoms. As anticipated, there were significant relations
between the Psychological factor and depression, $r(85) = .45, p < .001$, and anxiety, $r(85) = .28, p < .01$. Working against this finding is the possibility that providers may underestimate psychological symptoms if they rely on observability of symptoms as an indication of how the recipient is doing.

As with the personality data, a decision was made to focus on same rater pairs with respect to symptom reporting and helpful and unhelpful actions (that is, providers' reports of both measures). In order to determine if perceptions of symptoms are associated with actions, providers' views of physical and psychological symptoms were correlated with their views of supportive and unsupportive behaviors that they offered (see Table 17). Because of the potentially large number of correlations that could be computed, only composite scores were examined. As anticipated, the Helpful Actions subscale of the SSBQ was significantly related to observable and unobservable physical symptoms. The Helpful Actions subscale was also associated with Anxiety. Providers indicated that they were more likely to offer supportive behaviors to recipients if the former also believed that participants with M.E. were experiencing physical or psychological symptoms. Contrary to expectations, the Unhelpful Actions subscale of the SSBQ was unrelated to physical symptoms. Nonetheless, the Unhelpful Actions subscale was associated with psychological distress, such that anxiety and depression were positively associated with unsupportive behaviors.
The Nurturance factor of the SAS-C was correlated with unobservable symptoms and marginally correlated with observable symptoms ($p = .06$). Thus, providers who believed that their significant others with M.E. had a large number of physical symptoms, regardless of whether or not they could be seen, were also likely to report that they engaged in nurturant behaviors. The Avoidance factor was marginally associated with unobservable symptoms ($p = .06$), such that providers who indicated that their significant others with M.E. were experiencing symptoms that could not be seen also said that they tended to avoid that person. Finally, the Dominance factor was significantly related to anxiety, and marginally related to depression ($p = .10$).

One goal of the present study was to investigate discrepant ratings of symptoms by providers and recipients, and the associations between such discrepancies and supportive and unsupportive behaviors. Researchers have often calculated congruence scores between different raters by taking the simple difference between the two, and using the difference scores in subsequent analyses (John & Robins, 1994). However, such a procedure has been criticized by psychometricians because the reliabilities of difference scores are low, and they tend to be confounded with variables that comprise the index (Cohen & Cohen, 1983). To provide unconfounded measures of congruence for psychological and physical symptoms, residual scores were computed by regressing the close other ratings onto the ratings by the person with M.E. and retaining the standardized residuals. For physical symptoms, observable and unobservable residuals were computed separately. For psychological symptoms, depression and anxiety residuals were computed separately.
These residual scores represent the variance that remains in recipients' ratings of symptoms after the variance predictable from close others has been removed. Positive values on these residualized indexes reflect higher ratings by participants with M.E. relative to their close others.

In order to maintain rater consistency, correlations were then computed between the residualized ratings for (1) observable and unobservable physical symptoms and supportive and unsupportive actions from recipients' points of view, and (2) psychological symptoms and supportive and unsupportive actions from recipients' points of view. Relations between the residualized ratings and SSBQ composite scores and SAS-C factor scores were investigated (see Table 18).

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Insert Table 18 About Here

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Partial support was found for the hypotheses that greater discrepancies between providers' and recipients' ratings of physical symptoms are related to provision of helpful and unhelpful actions. Thus, although standardized residuals of observable symptoms were unrelated to the helpful subscale of the SSBQ, they were significantly correlated with the unhelpful subscale, $r (84) = .22$, $p < .05$. A greater discrepancy between providers' and recipients' ratings was associated with recipient self reports of unhelpful actions by providers. This same pattern of results was found for unobservable symptoms; only the unhelpful composite of the SSBQ was significantly related to the standardized residual, $r (84) = .23$, $p < .05$. Observable and unobservable symptom residuals were unrelated to the three SAS-C
factors.

The standardized residuals from the psychological subscales (depression and anxiety) were then correlated with supportive and unsupportive actions. Although depression scores were uncorrelated with the helpful and unhelpful composites of the SSBQ, anxiety was significantly associated with the unhelpful subscale, \( r (83) = .23, p < .05 \). Standardized depression residuals were unrelated to the Nurturance and Dominance factors of the SAS-C, but positively correlated with Avoidance, \( r (83) = .23, p < .05 \). Similarly, standardized anxiety residuals were unrelated to the Nurturance and Dominance factors, but marginally related to Avoidance, \( r (82) = .20, p = .07 \). Thus, higher ratings of psychological symptoms by recipients relative to providers was associated with reports of avoidance.

**Perceived Causes of M.E.**

Ninety-two percent of participants with M.E. reported that they had thought about causes of their M.E., and their answers were coded into 1 of 8 categories (see Table 19).

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Insert Table 19 About Here

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Participants with M.E. gave more responses to this question than any of the other open-ended questions and, consequently, up to 7 mentions were coded. In fact, fully 75% of the sample gave multiple responses. Participants often indicated that an interlocking set or chain of causal factors were implicated in the development of their illness. Responses varied in terms of the connection between each of the causal factors, but the acknowledgment of several influencing agents was nonetheless
apparent. For example, three answers from participants with M.E. were:

I saw a little picture in a book one time, and it was of a camel and he had all these bales of hay on his back, and they were called allergies, pollutants, and antibiotics. Then he’s flat on the ground like he’s broken his back—it’s like one bale too many was put on his back. It’s just a combination and everybody’s combination is different, and that’s why it’s so hard to cure it. That breaks down your immune system and you can’t cope. Pollutants in the home, chemicals, physically exhausted for a long time.

Either delayed reaction from the polio vaccine (because of headaches, muscle pain, joint pain, and weakness), a viral infection that I caught (like germ warfare), or a genetic thing triggered by a virus, bacteria from drinking water or food poisoning, or working in an air tight building.

Enteroviral origin; genetic predisposition; a dysfunction in the brain—this is an organic brain disease and it affects the limbic system (there’s a dysfunction in the hypothalamus) and it affects all the systems in the body. Maybe a retroviral factor. I think it’s a multicausal illness, that socio-environmental stresses going on at the same time could cause that non-recoverable relapse.

The foregoing highlights that it is unreasonable to pursue the issue of perceived causes as though they are independent. Nonetheless, in the present sample there were variations across individuals, and respondents’ particular views were often quite idiosyncratic. Therefore, participants typically had complex theories regarding the manner in which various causes were combined, but all of the specific causes could be classified into 1 of the 8 factors identified in Table 19.

The majority of participants with M.E. said that their illness was due to a virus, flu, bacteria, or infection (60%). The flu was identified most often, but other causes such as polio, mononucleosis, and hepatitis were also identified. Three
respondents said:

I really believe that it's some kind of a viral infection getting to you when your immune system is low.

It was after a flu-like viral illness that gave me a post-viral peripheral neuropathy that very much affected my central nervous system, and my brain.

When I was 19, I had a strange virus. My parents were very secretive and never told me what it was. My mother told me it was a thyroid infection. I had a lot of symptoms similar to M.E. It took me six months to recover from it. I often wonder if there's a correlation between the two.

Stress, overwork, and overactivity were viewed as the second most common factor influencing development of M.E., and was mentioned by slightly less than half of the sample (44%). Three typical responses were:

Partly stress. I've been under stress all my life, thrived on it. High goals, high expectations...I've come in contact with at least 400 people with M.E.—and in the discussions we've had, the only common thread we have is that we're all "Type A" personalities.

I'd changed jobs, we'd bought a house and had a huge mortgage, my new job wasn't working out, my children were in a daycare center and I was told by the police that there was an alleged sex offender there, and they wanted to investigate it—this was all happening at the same time.

My husband went through two open-heart surgeries for an aneurysm, and I dealt with a double load of patients at the office, plus dealing with the children, plus running back and forth to the hospital.

Rather than giving answers consistent with a mind-body dualism, participants with M.E. reported intimate connections between the two. Thus, monocausal theories were rarely reported and, instead, explanations for development of M.E. often revolved around the relation between physical and psychological factors.
Thus:

I think it was mononucleosis. I got mono when I was about 19, and although I didn't realize it at the time, I went through a personality change, lifestyle change, and then everything went downhill from there.

I became very physically run down, mentally run down and aggravated. I developed what I felt was a flu-type thing which never went away.

I think lifestyle. I think your head controls your body. What you think is what you are.

Interestingly, a substantial minority of participants with M.E. (14%) said that they believe that emotional factors were important in the etiology of their illness. Thus, two respondents said:

I do think it's very psychosomatic. I think it starts with frustration, stress and unhappiness which somehow disturbs the immune system, and I think the rest follows from there: your sleep disorder and the sickness in the brain.

I think there are a number of factors. One of them was chronic emotional stress from a dysfunctional family relationship.

If "psychological" factors are interpreted broadly to include stress and emotional factors, then roughly half of the M.E. sample (48%) acknowledged contribution of psychological factors in development of their illness. Stress and emotional factors were often mentioned together. Thus, 11 out of the 15 times that emotional factors were reported, stress/overwork/overactivity was also mentioned. However, it is important to note that this does not mean that people with M.E. believe that the illness is "all in their head." That is, participants indicated that they had a "legitimate" physical illness, but nonetheless acknowledged the contribution of
psychological factors. For example, one participant said: "I am of the firm belief that it's not psychological, although I believe there is a great influence of the psyche." People who mentioned the psyche or stress were sometimes reluctant to call such agents "causative," but preferred to talk about them as influencing, triggering, or contributing factors. Thus, a respondent said: "I think it [stress] is not the cause but a triggering agent."

Forty-one percent of participants with M.E. indicated that an immune system disturbance was implicated in the development of the illness. Respondents viewed immune system problems as preceding and following other causative factors:

I really believe that it's some kind of viral infection getting to you when your immune system is low.

Studies have shown that severe, repeated stressors can lead to a depressed immune system, so I think in my case, that happened--stressors both physical and emotional.

I probably go along with the theories put out by the Centers for Disease Control, and that it looks like it's probably some sort of infectious process that does something to the immune system, and the symptoms result from that.

Thirty-one percent of respondents with M.E. identified a number of physical problems, such as injuries, operations, illnesses, diseases, allergies, and brain abnormalities that were important in the etiology of their M.E. Moreover, a host of environmental factors, such as toxins in the water, air, or food, were implicated (25%). These categories were followed by genetic or other predisposing factors (15%), and vaccines, antibiotics, or anesthesia (14%).
The open-ended causal question was supplemented by various closed-ended causal factors for both participants with M.E. and their close others. All 11 items for each sample separately were subjected to a Principal Components Analysis with Varimax rotation. Using a scree plot as the basis for inclusion, two factors were extracted for both participants with M.E. and close others. Any items that loaded on one of the factors for one sample, but not the other sample, were dropped (see Table 20). Factor 1 for both samples (Psychological) included the items worrying, stress, working too hard, depression, and not doing enough exercise. The second factor for both samples (Environmental/Genetic) included the items working in an environment with no fresh air, toxins, and genetic predisposition. The item virus did not load on either factor for participants with M.E., but was included in subsequent analyses because of theoretical significance ("physical" cause) and high endorsement as a causal factor by participants. Cronbach's alphas were computed for the two factors, and were .78 and .69 for Psychological and Environmental/Genetic, respectively, for participants with M.E. The corresponding alphas for close others were .81 and .59. Three t-tests were conducted to determine if participants with M.E. and their close others view the causal factors as differentially important in causing M.E. Participants with M.E. (M = 2.72) viewed Psychological factors as marginally more important than did close others (M = 2.50), t(189) = 1.56, p = .12. The former (M
also considered Environmental/Genetic factors to be more important than did the latter (M = 2.41), t(189) = 4.30, p < .001. Similarly, participants with M.E. (M = 4.15) considered a virus to be more important than did close others (M = 3.64) in development of the illness, t(160) = 2.79, p < .01.

Items that comprise the two factors were summed to make composite scores which were then correlated with supportive and unsupportive actions to investigate if different causal views are related to the receipt of different behaviors. Virus was correlated with such actions separately (see Table 21). It was of interest to assess providers’ views regarding the cause of illness (rather than recipients’ perceptions of providers’ views). In addition, it was of interest to relate such views to recipients’ assessments of providers’ actions (rather than providers’ assessments of their actions) because the former are likely to be affected by such actions to a greater extent, and respond according to their perceptions. In other words, there are apt to be more psychologically meaningful relations between recipients’ perceptions of providers’ unhelpful actions and measures of, for instance, recipients’ distress, than there are between providers’ views of their behaviors and recipients’ psychological functioning. Such a suggestion is supported by the data, \( \chi^2(1) = 4.13, p < .05 \).

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Insert Table 21 About Here

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Providers’ views regarding causes of the recipients’ M.E. were differentially related to supportive and unsupportive actions as reported by recipients. As anticipated, there were
significant relations between the Psychological factor and provision of supportive and unsupportive behaviors. In fact, the majority of associations included the Psychological factor. Providers who believed that recipients' illness was due to psychological factors engaged in more DE (Critical), FG (Distancing), and HI (Avoidant) actions, and fewer NO (Engaging) behaviors from the recipients' points of view. Moreover, Psychological factors were positively associated with the Avoidance factor of the SAS-C, and negatively related to the Nurturance factor. The FG (Distancing) octant was the only significant association with the Environmental/Genetic factor. Providers who said that they believed their recipients' illness was due to viral factors had recipients who said that their close others offered more LM (Nurturant) actions. The three factors were all unrelated to the Helpful and Unhelpful subscales of the SSBQ.

Constraints

An indirect assessment of impediments to effective action was obtained by asking providers and recipients why providers said or did the unhelpful things they did. A more direct assessment was made by asking what prevented providers from acting in more preferred ways.

Attributions for unhelpful actions. Ninety-six percent of participants with M.E. and 83% of close others offered at least one attribution for unhelpful actions (see Table 22). Providers and recipients gave very similar answers to this question and there were no significant differences between groups. The most
common answer for respondents with M.E. (26%) and the second most frequent one for close others (21%) was ignorance/lack of understanding or knowledge. Recipients often included statements that muted the impact of the unhelpful actions, such as mentioning the nonintentional aspect of the behaviors. Providers rarely added statements regarding their intentions. Examples given by respondents are included below:

She probably just either wasn’t thinking or didn’t understand what I was getting at. I could have not been getting things across properly. I certainly don’t think she would do anything intentionally. [Participant with M.E.]

She was just operating out of ignorance. She doesn’t recognize the limitations of the illness. She’s never read anything about it. She keeps saying she will but she hasn’t. [Participant with M.E.]

Maybe she was having difficulty understanding what I was saying, so her lack of response was because she was trying to work it out. She certainly didn’t do it deliberately. She never does anything deliberately to hurt me—never. [Participant with M.E.]

I did not realize she was as stressed about it as she actually was. [Provider]

I was doing my best but my scientific understanding of M.E. does not equal hers. [Provider]

Seventeen percent of respondents with M.E. and 13% of providers mentioned power struggle/conflicting views or needs/longstanding pattern. The essence of this category is that providers and recipients want or need things that are incompatible with one another, have conflicting viewpoints, or that one of the parties possesses certain characteristics that are not amenable to
change (e.g., gender, personality), and an interpersonal conflict occurs. For example:

He had a father who drilled it into him that he didn’t have to do anything that women told him to do, to do anything that I said. Even though he’s a smart fellow and knows better, it’s so ingrained in him that he still falls into that pattern. [Participant with M.E.]

We had a long discussion about this at one time. Partly it was his whole frame of thought. I would classify as important things that to him simply were not important. [Participant with M.E.]

In some cases to firmly establish my boundaries. For example, some cases triggered a defensive reaction with regard to management of my time. [Provider]

She needed rest, physically and emotionally. I felt that such rest was overwhelmingly more urgent than the list of things to do. She felt that these things must be done. [Provider]

Sixteen percent of respondents with M.E. and 22% of close others gave attributions for unhelpful actions that focused on emotional difficulties. Respondents mentioned emotions such as frustration, resentment, fear, helplessness, hurt, discouragement, annoyance, impatience, confusion, and anger. For example, four participants said:

From his perspective, I’m giving my time and energy to people and causes that he doesn’t see as being as important as home and family. And so perhaps he feels somewhat resentful of my time being spent. [Participant with M.E.]

The bottom line is that sometimes I can be really abusive emotionally, and unfortunately my family gets it the worst. Most of the time she’s compassionate, and understands, but she can’t help but get angry. So I think there’s a bit of hostility built up. [Participant with M.E.]
Because after three years of frustration with doctors and medical people being so unsupportive, numerous trips to emergency rooms, negative responses from hospital staff, sometimes these things become too much to put up with and one should blow off a little pressure or you become this ball of repressed feelings. [Provider]

Sometimes the stress of all this causes me to just emotionally shut down until I can deal with it again. I have a hard time dealing with conflict or problems I can’t control. [Provider]

Both respondents with M.E. (13%) and their close others (17%) indicated that stress was a significant factor that preceded the unhelpful actions.

Because she’s tired too, having to work, raise four kids, keep the house clean, and having me with a sick body. [Participant with M.E.]

It’s his way of dealing with his stress. He all of a sudden has a partner that isn’t the same for all the years that we were married. Now he has not three dependents but four. And he’s not enthusiastic about his job either, so he feels trapped and stressed out. And all his dreams of what he would like to do have gone down the tubes. [Participant with M.E.]

I was ill in crisis and my mother was ill and I was sole caretaker of my mother and feeling resentful that my older brothers and sisters provided very little assistance. [Provider]

Sometimes I get tired and it seems I have so much to do and he can’t help out. Feeling overburdened at times. Not getting enough sleep and feeling at my wits’ end. [Provider]

Participants with M.E. (8%) and close others (8%) reported trying to be helpful/overprotectiveness with equal frequency. The final three categories were denial of problem/forgetfulness (5% of recipients and 3% of providers), going through a new transition (5% of recipients and 2% of providers), and wanting problems to go away (5% of recipients and 1% of providers).
What prevented close others from acting in ways that recipients would have preferred? Providers and recipients were asked what they thought prevented providers from acting in a way that participants with M.E. would have preferred. Eighty-six percent of recipients and 71% of close others mentioned at least one impediment to effective action (see Table 23). The most common was ignorance or lack of understanding/knowledge

Insert Table 23 About Here

(28% of recipients and 25% of providers). Four typical statements from respondents were:

Ignorance of the illness. Also, she didn’t know me as well either, because we were just getting to know each other, so she didn’t understand that I felt insecure at times about my illness. [Participant with M.E.]

She’s not someone who intentionally hurts, she just doesn’t understand M.E. Lack of awareness, not knowing enough about the illness, not having experience with it. [Participant with M.E.]

Not having a full understanding of what she was/is going through. [Provider]

Not really knowing what to do. I did respond on what she asked me to do, but it still didn’t make any difference. The bottom line is that I need some education on how to cope with her and my own needs. [Provider]

The second most commonly reported category was power struggle/conflicting views or needs/longstanding pattern (21% of recipients and 18% of providers), which was followed by emotional difficulties (18% of recipients and 14% of providers). The varied type of emotional reactions is apparent by the responses of some participants:
I see both in his personalized case and at one support group meeting where we had the caregivers there of people with this illness, that they feel victimized because of our illness, and he figures something bad has happened to him. As a result, there's a resentment there. [Participant with M.E.]

She was afraid--she was losing the strong mom that she had always had, and I think it hit my daughter that some day she could be where I was. She was afraid to lose me, and I was going through a lot of pain. When you're going through a lot of pain, and you're trying to tell someone, I think the other person experiences a little bit of that pain themselves. I wondered sometimes that she might have been afraid that she would have had to look after me all the time, and she had a life to live too. [Participant with M.E.]

An inability to discuss problems when angry or emotionally upset. [Provider]

My impatience with the illness. [Provider]

In some instances, respondents framed the reaction in dynamic, rather than blaming, terms. That is, participants recognized the inherent difficulties in dealing with M.E., and did not view the close other as being solely responsible for the negative exchange that occurred. Instead, respondents realized the influence of one person upon the other and vice versa. For example, one recipient said: "Our joint frustrations with my inabilitys to do normal things. We were on a holiday and I was too tired and exhausted to do the things we wanted to do. We were both angry and frustrated."

Fourteen percent of recipients and 13% of providers said that stress or exhaustion were the main reasons why close others did not respond in ways they would have preferred. When the type of stress was specified, it was generally framed in terms of dealing with the person with M.E. or the burdens it imposes, or additional stressors (such as work or other interpersonal
Two questions were asked in order to gather information regarding post-behavioral awareness. The first question emphasized timing of awareness, and the second question focused on how such awareness was obtained. Respondents with M.E. were asked to think back to the most upsetting thing that their significant other said or did. Within this context, 24% of respondents with M.E. reported that their significant other realized their actions were unhelpful at the time, 65% said that they thought the provider became aware later, and 12% thought that the provider was still unaware. Thirty-five percent of providers said that they realized that their actions were unhelpful at the time, and 65% said that they became aware later. Thus, across both samples, the majority said that close others became aware that their actions were unhelpful after the fact.

In terms of how awareness was obtained, 78% of participants with M.E. and 81% of providers said that the latter became aware that their actions were unhelpful or upsetting through 1 of 5 ways (see Table 24). These categories are identical to ones regarding the determination that help was needed in the first place.

By far the most common route to awareness was discussing the issue or talking about it with the close other. A somewhat higher proportion of recipients (52%) than providers (38%)
mentioned this category, $X^2 (1) = 3.35, p = .07$. The second most common route to awareness was through the expression of emotions such as anger or sadness (13% of recipients and 18% of providers). A third category, empathy/understanding/perceptiveness, captures the fact that the provider figured it on his or her own due to previous experience with the recipient, or through an ability to pick up on cues (7% of recipients and 7% of providers). Eight percent of providers and 2% of recipients ascertained that close others' actions were unhelpful or upsetting by observing or looking at recipients' reactions. Finally, respondents indicated that voice tone or body language were sometimes used as cues (2% of recipients and 5% of providers).
Helpful Actions

Consistent with all other research investigating supportive and unsupportive actions of people coping with stressful life events (e.g., Dakof & Taylor, 1990; Lehman et al., 1986; Lehman & Hemphill, 1990; Martin et al., 1994), emotional support was considered to be especially helpful. Clearly, emotional support is a particularly valued aspect of interactions between people that cuts across types of stressful life events.

Different types of practical assistance, such as helping with daily activities and providing accommodations were valued by people coping with M.E. This finding adds to our sense that M.E. is a disorder that presents many significant physical challenges to those who cope with it. Such results are consistent with research by Barrows (1995), who found severe deficits in a sample of people with M.E. in activities of daily living, such as performing housework, shopping, exercise, and recreational or social activities. Such activities may be even more difficult to accomplish if accompanied by fibromyalgia, which is often a concomitant of M.E. (Buchwald & Komaroff, 1991).

Providers were somewhat less likely than recipients to report that tangible support was particularly helpful for people coping with M.E. It is plausible that providers underestimate the importance of tangible assistance because they assumed that other forms of support, such as emotional assistance, are valued more highly than the seemingly mundane activities associated with day-to-day living. Although this may be true in a number of circumstances, the strong endorsement of tangible support
indicates that such assistance is also considered to be very helpful for people coping with M.E. People with M.E. may be least likely to afford cleaning and repair services when they become ill because they are unable to work and earn an adequate income to pay for them, yet this is precisely when the services are most needed. These findings suggest that alleviation of burden associated with inability of people with M.E. to accomplish daily activities will be significantly appreciated. Thus, help from family, friends, or government or volunteer agencies where available may reduce stressors and possibly enhance recipients' moods.

Unhelpful Actions

As hypothesized, a large proportion of unhelpful or upsetting actions focused upon minimization of the illness, or an overestimation of what recipients are able to accomplish. Perhaps this is due to providers comparing the physical appearance of the person with M.E. with their schemata of what someone who is ill should look like (Lehman & Hemphill, 1990). Because many M.E. symptoms are internal, people with the illness are likely to look relatively well, and close others may overestimate what recipients are able to accomplish, and consequently engage in unhelpful actions.

Also as expected, unhelpful actions included avoidance of the person with M.E. (Conant, 1990), both in behavioral and emotional terms. Thus, respondents indicated that providers avoided contact or did not include recipients in social activities with them (behavioral avoidance) and closed off communication (emotional avoidance). Avoidance may stem from providers' desires to control their anxiety in situations that
are highly stressful (Dunkel-Schetter & Wortman, 1982), or feelings of ineptitude resulting from trying unsuccessfully to improve the recipients' mood (Coyne et al., 1988; Notarius & Herrick, 1988). Unfortunately, behavioral and emotional avoidance will likely lead providers to have a decreased sense of recipients' problems, and exacerbate unhelpful actions in the form of further communication breakdown, minimization of the illness, and failure to provide wanted or needed assistance.

Consistent with predictions, respondents indicated that giving advice was not appreciated. Uncertainty about how to behave in interactions with people experiencing life crises may lead providers to fall back on scripted or automatic support attempts such as giving advice (Lehman et al., 1986). To the extent that providers are experiencing additional stressors due to their close others' illness (Gottlieb & Wagner, 1991), they may want "quick-fix" solutions, and offering advice is one way to try to improve the recipients' situation. Offering advice is advantageous to providers because it typically involves expenditure of very little energy for them, and because it provides a problem-focused strategy (Lazarus & Folkman, 1984). However, recipients may not appreciate such an approach because it implies that their problems are easily solved, and that they are not trying hard enough to get better.

Interpersonal Traits

Dunkel-Schetter and Skokan (1990) identified provider and recipient factors as being potentially important in relation to support attempts. In the present study, recipients' personality dimensions were associated with supportive and unsupportive behaviors to a lesser extent than were corresponding dimensions
for providers. These findings will be discussed in turn.

The paucity of associations between recipients’ traits and their views of providers’ supportive and unsupportive behaviors is in line with the notion that recipients’ personality characteristics do not tend to "pull" particular helpful and unhelpful actions from providers. Nonetheless, an exception was noted for Agreeableness. M.E. respondents high on Agreeableness reported fewer Critical and Distancing actions by close others than those low on this dimension. It is possible that highly Agreeable recipients do a better job of muting providers’ unfavorable behaviors than those low on Agreeableness. That is, people with M.E. who are inclined toward interpersonal trust and consideration of others may be able to accept what has happened to them with less anger (Gottman, 1993) and report fewer complaints (Buss, 1991). Moreover, they may be more likely to use reason and emphasize the positive aspects of a situation than their low Agreeableness counterparts (Buss, 1992). These responses, in turn, may lead to fewer aversive behaviors by providers.

Providers’ personalities were correlated with their self-reported supportive and unsupportive behaviors. Extraversion, Agreeableness, Conscientiousness, and Openness subscales of the BFI were positively related to the Nurturance factor of the SAS-C. This factor was negatively related to Neuroticism. These findings are consistent with previous research which suggests that the provision of Nurturant actions is extremely important (Dakof & Taylor, 1990; Davidowitz & Myrick, 1984; Martin et al., 1994; Wortman & Lehman, 1985). The present study extends past findings by indicating that such behaviors cut across
personality dimensions, that is, are related to many different robust traits.

Extraversion from the BFI was associated with providers’ ratings of their LM (Nurturant) and NO (Engaging) actions on the SAS-C. This is perhaps not surprising, given that the LM (Nurturant) and NO (Engaging) octants are highly correlated (Wiggins & Trobst, in press). Connell and D’Augelli (1990) found that affiliative individuals receive supportive behaviors. Results of the present study extend those of Connell and D’Augelli (1990) by obtaining data from providers (rather than recipients), and by examining the specific types of supportive and unsupportive behaviors that are associated with extraversion. Thus, it is particularly those supportive actions that involve the provision of love and status (Foa, 1965) to recipients with M.E. that are associated with providers’ Extraversion.

Agreeableness was also related to providers’ reports of their supportive and unsupportive behaviors. Thus, agreeable individuals reported fewer DE (Critical) actions, and more JK (Deferential), LM (Nurturant), and NO (Engaging) behaviors. Previous research has found that low agreeableness predicts marital dissatisfaction (Kelly & Conley, 1987). In social support terms, low agreeableness may be related to fewer helpful and more unhelpful actions.

Neuroticism was related to providers’ reports of more DE (Critical), FG (Distancing) and HI (Avoidant) actions, and fewer LM (Nurturant) actions. These results are consistent with previous research that has found that neuroticism or emotional instability is the most consistent personality predictor of
relationship instability (Buss, 1991). Neuroticism is strongly related to reactivity to stressors (Bolger & Schilling, 1991), suggesting that providers may not deal effectively with recipients' M.E. status. In turn, neurotic individuals are likely to engage in fewer supportive behaviors and more unsupportive ones.

Conscientiousness and Openness were associated primarily with supportive actions in the present study. Thus, Conscientiousness and Openness were both positively related to LM (Nurturant) actions of the SAS-C. In addition, Openness was associated with NO (Engaging) actions. Future research should be directed toward an examination of the specific ways in which these dimensions play a role in the support process. For instance, are the actions that Conscientious and Open individuals perform helpful by themselves? Or are they beneficial largely because they elicit actions from their recipients that in turn make providers feel better?

Helpful and Unhelpful subscales of the SSBQ were calculated for close others, and then correlated with providers' personality dimensions of the BFI. The SSBQ Helpful composite was related to all of the BFI scales. This suggests that, even though only two of the factors (Extraversion and Agreeableness) are primarily interpersonal in nature (Wiggins, 1979), there are interpersonal correlates of the other ones. For example, a neurotic person may experience distress internally, but it may also be manifested interpersonally (Kelly & Conley, 1987).

The Unhelpful composite was associated only with Openness. Open individuals are receptive toward varied experiences and ideas (Costa & McCrae, 1985), and their suggestions and actions
may have been unappreciated because they were considered to be too unconventional or unusual.

The findings from the SSBQ are generally consistent with those from the SAS-C. Thus, for both sets of measures, the majority of significant associations were found for socially desirable actions (Helpful subscale of the SSBQ; LM and NO octants of the SAS-C). There were far fewer relations for socially undesirable actions (Unhelpful subscale of the SSBQ; PA and BC of the SAS-C). Nonetheless, there were a greater number of relations between the dimensions of personality and the SAS-C than the SSBQ subscales. Thus, Agreeableness was associated with DE (Critical) actions, but not the SSBQ Unhelpful composite. Similarly, Neuroticism was related to a number of undesirable SAS-C octants (DE, FG, and HI), but not the Unhelpful subscale of the SSBQ. These differences may be due to differences in the scales themselves. The SAS-C is considered to be a better measure of helpful and unhelpful actions than the SSBQ because of the former's established theoretical tradition, rigorous scale construction, and superior psychometric qualities, and because it affords a more fine-grained analysis of the relations between personality and supportive and unsupportive behaviors.

Respondents' Understanding of the Support Process

Most important assistance. Consistent with data from the most helpful assistance question, providers and recipients indicated that the most important assistance primarily revolved around emotional (49% of recipients and 45% of providers; see also Dakof & Taylor, 1990; Davidowitz & Myrick, 1984; Goldsmith, 1992; Lehman et al., 1986) and tangible (33% of recipients and
30% of providers; see also Lehman & Hemphill, 1990; Martin et al., 1994) support.

Data from the present study are in line with the notion that M.E. is a serious illness that sometimes affects those afflicted with it in devastating ways. Thus, participants with M.E. indicated that, at the time when they most needed assistance, help focused on tangible aspects (cooking, cleaning) and personal care (such as showering and dressing; see also Barrows, 1995). Previous research has shown that people coping with stressful life events that pose physical challenges ask for tangible assistance, whereas those that are coping with primarily cognitive or emotional challenges rarely request such assistance (see Lehman & Hemphill, 1990, for a review).

An extreme form of assistance, needing an ambulance or someone to bring the recipient to the hospital, was mentioned somewhat more often by close others than respondents with M.E. Perhaps this is because such situations are more memorable for providers than recipients. People with M.E. typically experience substantial challenges that they may not share with others (Conant, 1990; Silver et al., 1990). Thus, going to the hospital may be considered to be merely an extension of discomfort and fatigue that are experienced every day by persons with M.E. Providers may be unaware of much of the recipients' suffering, and register going to the hospital as an indicator of how poorly the person with M.E. is really doing. In other words, the backdrop of unpleasant experiences is more pronounced for the recipient than it is for the provider, and therefore such negative situations may serve as markers for the need for assistance to a greater extent for close others.
In the present sample, 12% of respondents with M.E. said that the most important support they received revolved around others making decisions for them or acting on their behalf. Although previous research with individuals with MS has found that recipients appreciate it when significant others make helpful accommodations (Lehman & Hemphill, 1990), some researchers have suggested that others taking charge of care is unappreciated (Coyne et al., 1988), in part because it may be viewed as foisting incapacitation on the recipient (Peters-Golden, 1982). It is suggested that a subset of people with M.E. in the present sample did not have problems with others doing things for them because they were quite ill and could not do them for themselves. If anything, close others probably erred in the direction of not providing enough support rather than providing too much.

This interpretation is bolstered by findings from the "most unhelpful" question. Even though a small percentage of participants with M.E. found others' efforts to assist them to be unhelpful because they were viewed as overly protective or patronizing (5%), it was much more common for respondents with M.E. to say that others' unappreciated efforts involved minimizing seriousness of the illness, not providing enough accommodations (33%), or failure to provide assistance (10%).

How awareness of the support process was obtained. Respondents used the same methods to assess that support was needed (pre-behavioral awareness) as they used to gauge that providers' actions were unhelpful or upsetting (post-behavioral awareness). Therefore, both of these questions will be discussed here.

For both questions, providers and recipients said that the
most common way that close others became aware that support was
needed was through discussion or talking. This suggests that,
even though the communication process may be adversely affected
by experiencing stressful life events (Coyne et al., 1988;
Meyerowitz et al., 1983; Silver & Wortman, 1980), in many cases
communication is clearly a significant factor in enhancing
awareness. These results are consistent with those of Study 1,
in which a substantial minority of recipients reported that they
discussed the issue rationally with providers when confronted
with unhelpful actions from them.

For the post-behavioral awareness question, a somewhat
larger proportion of recipients (52%) than providers (38%) men
discussed the issue/talking as an influential method.
This may have been because respondents with M.E. were unaware of
additional methods used by close others due to a lack of
information regarding the latter's internal states. To put it
another way, providers who were asked to recall how awareness
was obtained were able to rely on their thoughts, feelings, and
behaviors about negative exchanges, whereas recipients could not
rely on such factors. If this reasoning is correct, then a
variable that may enhance awareness is
communication/relationship quality (Fincham, Beach, & Baucom,
1987). Thus, as people with M.E. and their close others discuss
different issues, recipients may gain a greater understanding of
providers' internal states. An additional advantage is that
intimacy is related to greater satisfaction with social support

When there was a difference (or a trend) between providers
and recipients, providers used more emotionally charged cues and
illness-related signs than recipients realized to assess that support was needed. For example, providers were more likely to rely on physical incapacitation or poor physical health, and there was a trend for emotional difficulties/distress. Part of this may have to do with the differential focus of attention for providers and recipients. That is, M.E. participants' attention is focused outward and away from themselves, whereas providers look at the target individual (Jones & Nisbett, 1971; Storms, 1973). As a result, providers may be able to recall factors that are associated with the recipients' emotional and physical state to a greater extent. Mere attention may not be enough to account for all of the effects, however, as observing/looking did not differ across groups for the question assessing that support was needed and observation/looking only approached significance for awareness regarding unhelpfulness of actions. Taken together, there was mixed support for the notions that increased salience and perceptually prominent factors may explain provider/recipient differences.

More close others than participants with M.E. mentioned that recipients needed support because of confusion or becoming lost. These results support Barrow's (1995) findings that almost all of her clients reported that they got lost while driving, and many had difficulties with attention, learning new material, word finding, and calculation abilities. Similarly, Sandman, Barron, Nackoul, Goldstein, and Fidler (1993) report that people with M.E. overestimate their ability, and have significant memory deficits. These results suggest that recipients may report confusion or becoming lost less often than providers because the former do not recognize that they have
such problems, or do not fully appreciate their impact.

**Congruence Ratings**

Consistent with anecdotal accounts, self-help literature, and case studies (e.g., Conant, 1990; MacIntyre, 1989), people with M.E. reported that they experienced more physical symptoms (regardless of whether or not they were observable) than their close others mentioned. The findings were less clear for psychological symptoms. There was a trend for providers to indicate that recipients were experiencing more depressive symptoms than recipients actually reported. This may be due to the emphasis on depression in the scientific literature (see Dutton, 1992, for a review). Thus, providers may have assumed that their close others with M.E. were experiencing depression because such symptoms are often mentioned in articles and the media as being an integral part of the illness. In support of such a notion, providers' views of psychological etiology were also related with their reports of psychological symptoms. M.E. recipients, on the other hand, may have relied less on what they have read or heard about the illness, and instead concentrated on their own symptoms. Interestingly, not all psychological symptoms were reported more often by providers than recipients, as the latter said that anxiety was somewhat more common than the former.

As anticipated, providers' supportive actions (as measured by their Helpful actions subscale of the SSBQ) were related to observable and unobservable physical symptoms. Similarly, the Nurturant factor of the SAS-C was significantly associated with unobservable and marginally associated with observable physical symptoms. These findings suggest that providers will offer
assistance when there are physical problems (Dakof & Taylor, 1990; Lehman & Hemphill, 1990). Moreover, it is not necessary for providers to be able to observe physical symptoms for help to be offered. Rather, close others only need to believe that physical problems are being experienced by people coping with M.E. Although the unhelpful actions composite was unrelated to physical symptoms, the Avoidance factor of the SAS-C was marginally associated with unobservable physical symptoms. If Avoidance can be considered to be a form of unhelpful actions, a suggestion supported by previous research (Lehman & Hemphill, 1990), then partial evidence for the association between unhelpful actions and physical symptoms was found.

Discrepancies between recipients' and providers' symptom ratings, and the associations between such ratings and supportive and unsupportive behaviors were calculated. As predicted, higher ratings of observable and unobservable symptoms by recipients relative to providers were significantly associated with the unhelpful subscale. That is, providers tended to offer actions that were unappreciated by recipients when the latter indicated that they were more impaired than did the former.

Contrary to predictions, observable and unobservable physical symptom residuals were unrelated to the helpful subscale. In other words, recipients were not more likely to report that providers offered actions that were appreciated when recipients and providers held similar views regarding impairment of people with M.E. This result may have been due to the large percentage of helpful actions. That is, recipients indicated that providers offered a substantial number of helpful actions.
Unfortunately, the present study relies on the reports of close others who are willing to complete their own questionnaires. As a result, there may have been a bias toward providers who are particularly supportive. In future studies, recipients might be asked to report on a range of close others (e.g., Dakof & Taylor, 1990; Martin et al., 1994) who vary in terms of supportiveness, to determine if discrepancies of ratings are associated with helpful and unhelpful actions.

The same set of analyses were conducted for psychological symptoms. Providers’ views of helpful actions were positively related to anxiety, and unhelpful actions (on the SSBQ) were positively related to anxiety and depression. Only the Dominance factor from the SAS-C was significantly related to anxiety, and marginally related to depression. Thus, it appears that psychological symptoms may be associated with both the presence of supportive and unsupportive behaviors, depending upon the measures used.

The findings regarding relations between unsupportive actions and psychological symptoms are consistent with Coyne’s (1976) interactional theory of the social environment’s role in maintaining depression. Briefly, the theory posits that stress (in this case, development of the M.E.) produces depressed affect in the person experiencing it, signaling the need for support and reassurance. Previous research is in line with the notion that there are elevated rates of depression among people with M.E. (Abbey & Garfinkel, 1991; Dutton, 1992; Katon, Kleinman, & Rosen, 1991; Kruesi, Dale, & Straus, 1989). According to Coyne’s (1976) model, expression of negative affect by the afflicted individual creates depressed mood in close
others across time, which leads to aversive interactions which are perpetuated in a vicious cycle. If the situation does not resolve itself, as in the case of M.E. which is, by definition, chronic, providers may simultaneously experience annoyance and guilt. Unsupportive behaviors, such as nongenuine reassurance and avoidance, may result.

Discrepancies between raters for anxiety were associated with unhelpful actions (on the SSBQ), such that recipients who believed they experienced more distress than providers reported also said that close others offered more unhelpful actions. Similarly, standardized residuals for depression were also related to Avoidance (on the SAS-C), and marginally associated with anxiety. Providers who reported fewer psychological symptoms than recipients tended to avoid the latter. These findings are in line with previous research that highlights relations between distress and avoidance (Coyne, 1976; Wortman & Lehman, 1985), but extends these results by also examining discrepancies between providers' and recipients' reports. Thus, supportive and unsupportive behaviors are related not only to the absolute number of psychological symptoms, but also to the lack of correspondence between raters. Discrepancy scores may be considered to be estimates of accuracy (John & Robins, 1994). If recipients are considered to be more accurate than providers due to the former's greater access to internal states (Funder, 1980) and understanding across a range of situations, then minimization of symptoms (Lehman & Hemphill, 1990) by providers is associated with unhelpful actions.
Perceived Causes of M.E.

Powell and colleagues (Powell et al., 1990; Wessely & Powell, 1989), in one of the few studies to date that has attempted to examine the perceived causes of M.E., found that 80% of people with M.E. attributed their illness to a physical cause; only one patient wrote "depression." Such views were collected by using a 5-point scale ranging from "My illness is a physical one" to "My illness is psychological in nature." In contrast, the present study included finer distinctions between causal factors. Thus, respondents gave answers on multiple 5-point scales (e.g., a viral infection, toxins, worrying, stress, etc.), and were not required to classify such views according to the mind-body distinction.

Moreover, in the present study open-ended answers from people with M.E. were coded according to content. The data captured the greater complexity of views by respondents than that gathered by Powell et al. (1990), highlighting the need to obtain detailed assessments of perceived causation. Consistent with Powell et al. (1990), the majority of participants indicated that the illness was due to physical causes (such as virus/flu/bacteria/infection; immune system disturbance; other physical problem; genetic factors/predisposition; vaccine/antibiotics/anesthesia). Contrary to Powell et al. (1990), however, a substantial proportion of participants (48%) also endorsed "psychological" causes such as stress/overwork/overactivity and emotional factors. Thus, when participants were able to spontaneously report perceived causal factors, and were given multiple scales that emphasized various antecedents, the complexity of their views became apparent.
However, when respondents were asked merely to make a distinction between physical and psychological causes, as was the case in Powell et al.'s (1990) study, participants tended to emphasize physical ones.

Results of the present study are consistent with the seemingly contradictory findings that a substantial number of people with M.E. experience depression (see Dutton, 1992, for a review) yet view their illness as caused by an initial, presumably viral, illness (see Hotopf & Wessely, 1994, for a review). This is because the methodology used in the present study enabled respondents to describe lengthy causal chains with multiple causes. Although people with M.E. recognized the existence of psychological symptoms, and even viewed them as marginally more important than close others did in terms of etiology, they also emphasized the contribution of physical factors. These findings are consistent with Kelley's (1972) assertion that people often generate multiple causes for an event. This tendency may even be exacerbated as seriousness of a situation increases.

It was not a goal of the present study to determine whether psychological or physical causes more accurately reflect the etiology of M.E. In fact, the medical profession is divided on this issue, and there are proponents of both perspectives. Consistent with Wessely and Powell (1989), it is suggested that such distinctions are essentially meaningless because of the influence of biological factors in psychiatric illnesses and vice versa. It is proposed here that, rather than perpetuate this false dichotomy, it is perhaps more fruitful from a pragmatic perspective to expand professionals' and the public's
view to include multidimensional causal factors. Moreover, given the relations between providers’ perceived psychological causes and recipient’s reports of fewer supportive and more unsupportive behaviors in the present study, it may not be particularly therapeutic, and may well be counter-therapeutic, to tell people that the illness is "all in the mind" (Kendall, 1991). Instead, personal responsibility, and factors that are within an individual with M.E.’s personal control, may be taught in an empathic way in order to assist in alleviating M.E. symptoms through problem-focused coping efforts (Lazarus & Folkman, 1984). It is equally important to emphasize physical causes because such an etiology has the advantage of reduced guilt and self-esteem preservation (Powell et al., 1990). The disadvantages of emphasizing only physical causes include helplessness due to the belief that the illness is untreatable, increased fatigue, lack of self-efficacy, and diminished responsibility for one’s health (Powell et al., 1990). In sum, it is perhaps most worthwhile for recipients’ well-being to emphasize positive aspects of psychological and physical causative factors that are consistent with prevailing medical opinions regarding etiology. Emphasizing one at expense of the other may be detrimental by undermining self-esteem or diminishing views of personal responsibility.

The present study extended previous research by investigating the relations between perceived causes and helpful and unhelpful actions. There were a larger number of significant relations between the Psychological factor and supportive and unsupportive behaviors than between the Environmental/Genetic factor or Virus and such behaviors. A
stringent test of the relations between causal factors and behaviors was used in the present study. This is because causal factors were reported by providers and social support measures were collected from recipients. Problems of response styles, such as acquiescence, social desirability, or extremity (Wiggins, 1973) by single raters were avoided in the present study because of the use of multiple raters (Johnson et al., 1993). Nonetheless, it must be acknowledged that the Psychological factor, with which most of the significant associations were found, contained five items, and had the highest Cronbach's alpha (.78). In contrast, the Environmental/Genetic factor comprised only three items, and had a lower alpha (.69). Virus comprised a single item. Therefore, an alternative explanation is that there were a larger number of significant relations between Factor 1 than Factor 2 or Virus with supportive and unsupportive behaviors because the former set of items tapped into the construct more reliably than the latter two. In order to test these possibilities in greater detail, future researchers will benefit from gathering information regarding causal factors that are comparable in terms of psychometric qualities. Thus, more rigorous scale construction needs to be attempted now that important causal factors have been identified.

Constraints

Two classes of constraints, attributions for unhelpful actions and factors that prevented providers from acting in more preferred ways, will be discussed below.
Attributions. Results from Lehman and Hemphill (1990) and Studies 1 and 2 converge on the notion that recipients overwhelmingly attribute others' unhelpful actions to benign causes. The present study extends this work by investigating perceived causes of unhelpful actions by close others. Providers and recipients gave similar attributions across all categories. Thus, providers reported that they engaged in unsupportive behaviors for similar reasons as those mentioned by recipients.

Previous researchers have asked whether or not supportive and unsupportive behaviors are due to lack of understanding or knowledge on behalf of providers. Evidence that is both consistent (Johnson et al., 1993; Lehman & Hemphill, 1990; Peters-Golden, 1982) and inconsistent (Lehman et al., 1986) with such a claim has been gathered. Data from the present study support the ignorance/lack of understanding perspective. Nonetheless, such an interpretation cannot account fully for the presence of unhelpful actions. Thus, participants indicated other factors such as power struggles or conflicting views of providers and recipients (Goldsmith, 1992), emotional difficulties (Gottlieb, 1991; Wortman & Lehman, 1985), and additional stressors (Holmes & Rahe, 1967) that may involve accurate understanding from providers' perspectives. Perhaps a more comprehensive way to address this issue is to suggest that the presence of understanding/knowledge is important to prevent unsupportive behaviors from being offered, but that unhelpful actions may still occur if other unfavorable conditions exist.
Impediments to effective actions. Providers and recipients gave similar answers when asked what prevented providers from acting in a more preferred way. Moreover, the categories mentioned by respondents were the same ones that were reported for the previous ("attribution") question. Thus, the primary reason given was ignorance/lack of understanding or knowledge (Lehman & Hemphill, 1990; Peters-Golden, 1982). Assuming that such views are an accurate reflection of reality, then enhanced provider education about the illness is suggested. Thus, informational resources such as books, articles, and consultation with specialists may be beneficial. Furthermore, enhanced communication between providers and recipients may reduce problems that are due to providers' ignorance about what to do.

However, it is clear that enhanced knowledge about the illness is only one important factor, and that there are other impediments to effective action for providers and recipients that may be more difficult to combat. For instance, stressors (Conant, 1990; Feiden, 1990) and emotional difficulties (Dutton, 1992) may be natural concomitants of the disorder. Stressors, such as strain of household duties, financial burden, time pressures and demands of providers at work, may be particularly difficult to deal with. Although psychotherapeutic techniques such as implementation of coping strategies designed to facilitate constructive responses to stressors, and cognitive therapy for depression, may improve the situation, such problems may be chronic, especially given the chronic nature of M.E.

Moreover, providers' coping efforts may constrict or interfere with the coping efforts of recipients (Lane & Hobfoll, 1992). This problem was evident in the present study, in which
respondents mentioned power struggles and conflicting views between participants with M.E. and close others. Previous research has supported the notion that coping strategies that improve an individual's well-being may be detrimental to close others (Coyne & Smith, 1991), and that successful management of chronic stress may depend heavily upon how effectively providers and recipients coordinate their coping efforts (O'Brien & DeLongis, in press).

Method of Data Collection

Because of practical considerations, unlike with participants with M.E., it was not possible to interview providers. Therefore, their data are based on questionnaire, rather than interview, responses. It is possible that differences between groups, or lack thereof, may be due to the different methodologies used for each group. However, there are several points that argue against such a suggestion. First, providers gave responses that were codable into the same categories mentioned by recipients, even though there was less detail provided from the questionnaire data. Second, previous researchers in the area of stress and coping have found useful open-ended data from questionnaires (Pennebaker, 1989). For instance, Lehman and Hemphill's (1990) findings with participants with MS were based upon questionnaires, and responses from participants followed consistent patterns, and were clearly codable. Third, many comparisons between providers and recipients were made on questionnaire data, that is, the two groups were equated at times in terms of methodology. Thus, the SAS-C measure for supportive and unsupportive behaviors and the subscales of the BFI were administered in questionnaire format,
and there were significant relations between measures for providers and recipients. Fourth, presentation of questions via questionnaire may have resulted in even more accurate data than presentation via interview because providers may have been more willing to disclose sensitive information about themselves under conditions of anonymity. For example, when asked about impediments to effective action, one provider answered: "If she thinks vacuuming is more important than resting, even when she really is very sick, then to hell with her stupidity." It is quite possible that such candid responses would not have been as forthcoming from providers if they were required to talk about their experiences with interviewers, particularly those that pertained to unsupportive behaviors.
Chapter 5

Summary of Results and General Discussion

The three studies that comprise this dissertation have examined supportive and unsupportive behaviors within an interpersonal context. The studies were an initial attempt to investigate antecedents and consequences as contextual factors of helpful and unhelpful actions. The primary aims have been to document positive and negative exchanges between providers and recipients, map out the terrain in which helpful and unhelpful behaviors occur, and develop a framework within which to better understand these findings in the future.

The research reported in this dissertation will be integrated according to the organizational framework presented earlier (see Figure 1). In the following sections, an emphasis will be placed upon the supportive and unsupportive exchanges between providers and recipients, pre- and post-behavioral processes, and moderating variables.

Behaviors: Helpful and Unhelpful Exchanges

All three studies investigated supportive and unsupportive behaviors through the use of open- and closed-ended data. Interestingly, there was a substantial amount of consistency of responses from people coping with different types of stressful life events. Such findings are in line with traditional approaches, which emphasize that interpersonal relationships are universally helpful (Cohen & Wills, 1985). Thus, different forms of emotional support figured prominently in the answers provided by respondents for the helpful question. For example, people coping with one of a number of stressful life events mentioned that it was helpful when providers listened to or
talked with them; expressed love, concern, or understanding; were present physically; included them in social activities, praised the recipient; provided encouragement; or removed blame. Such responses are consistent with the growing literature that emphasizes the importance of emotional support (e.g., Dakof & Taylor, 1990; Lehman et al., 1986; Lehman & Hemphill, 1990; Martin et al., 1994).

Unhelpful actions reported across event types include avoidance, closing off communication, giving advice, and various forms of minimization and maximization. Respondents generally had little difficulty generating answers to the unhelpful question, emphasizing the frequent occurrence of negative interactions (Davidowitz & Myrick, 1984; Rook, 1984).

However, there was also support for specificity models, that is, the notion that the effectiveness of supportive actions will depend upon characteristics of the stressor (e.g., Cohen & McKay, 1983). For instance, tangible support, such as provision of practical assistance, was mentioned as especially helpful primarily by participants who were physically ill. Thus, people coping with M.E. or other illnesses or injuries reported that provision of practical assistance was particularly valued, while few responses of this type were mentioned by people coping with the loss of a loved one. Similarly, informational support was reported primarily by respondents coping with events associated with greater control or a favorable course (Buunk et al., 1990; Hemphill & Lehman, 1991). Blaming actions were reported to be unhelpful primarily by respondents coping with events that were considered to be mutable or influenced by recipients' actions (Schwarzer & Weiner, 1991).
Unhelpful actions that were unique to participants with M.E. included providers challenging, denying, or not recognizing the seriousness of the illness. Such responses were rarely mentioned by people coping with a host of other stressful life events, and may be offered primarily to recipients with M.E. because of skepticism about the illness by professionals and laypeople alike. Moreover, many symptoms such as weakness are unobservable (Fisher, 1989) and may be considered to be trivial to many providers (Dohrenwend & Crandell, 1970).

**Antecedents**

Although there is a clear need to examine antecedents such as providers' beliefs and intentions prior to interactions with recipients (Lehman et al., 1986), little research has been conducted on these issues to date. One goal of the present set of studies was to fill this void by examining five distinct antecedents to helpful and unhelpful actions.

First, dispositional characteristics were significantly associated with social support. Personality of providers was more consistently related to supportive and unsupportive behaviors than enduring characteristics of recipients. Thus, all five personality dimensions of providers were related to supportive actions, and providers' agreeableness, neuroticism, and openness scores were related to certain types of unhelpful actions. However, agreeableness of recipients was only associated with unsupportive behaviors (in an inverse way).

Second, need for assistance (Latane & Darley, 1970) was examined from the providers' and recipients' points of view, and similar answers were given from these two groups for most of the dependent variables. Despite the fact that communication issues
are often mentioned as being problematic for people coping with stressful life events (Silver et al., 1990), both recipients and providers said that awareness of the need for assistance was obtained most often through discussion/talking. As anticipated, other less direct indicators of need, such as observation/looking, emotional distress, and voice tone/body language, were also reported. As a whole, respondents tended to report fairly simple methods of perceiving need, and did not mention complex strategies such as movement of facial muscles, identification of subtle body postures, or disclosure by a mutual friend. In addition, there were few reports involving introspection, such as beliefs about the coping process (Wortman & Silver, 1989).

Third, relations between reports of physical and psychological symptoms and supportive and unsupportive behaviors were examined. Although recipients said that they experienced more physical symptoms than providers reported (Conant, 1990; MacIntyre, 1989), the findings were less clear for psychological symptoms. As expected, providers tended to offer unhelpful actions to recipients when the latter indicated that they were more physically impaired. However, congruence ratings for physical symptoms were unrelated to helpful actions. Discrepancies between providers and recipients for psychological symptoms were associated with unhelpful actions, particularly avoidance (Coyne, 1976). Thus, congruence between providers and recipients with respect to reports of physical and psychological symptoms were predictive of social support.

Fourth, views regarding the cause of M.E. were examined from providers' and recipients' points of view. Guided by the
work of Weiner and his colleagues (Schmidt & Weiner, 1988; Weiner, 1985), it was hypothesized that the perceived cause of a stressful life event may affect subsequent behavior. Consistent with this view, there were several significant relations between perceived psychological causation and supportive and unsupportive behaviors. It is quite possible that providers believe that psychological factors are more mutable than physical ones (Hemphill & Lehman, 1991), and that the former views of causation elicit little pity, much anger, and lack of assistance (Weiner et al., 1988). In contrast, providers' views of environmental/genetic and viral causes were largely unrelated to recipients' reports of helpful and unhelpful behaviors.

Fifth, constraints on helpful actions were examined. Interestingly, both providers and recipients indicated the same factors. Across the three studies, respondents mentioned constraints that emphasized benign factors. In line with previous work (Johnson et al., 1993; Lehman & Hemphill, 1990; Peters-Golden, 1982), respondents said that unsupportive behaviors were primarily due to ignorance/lack of understanding or knowledge. Other categories that were mentioned include conflicting needs or views (Goldsmith, 1992; Lane & Hobfoll, 1992), emotional difficulties (Wortman & Lehman, 1985), additional stressors (Holmes & Rahe, 1967), and overprotectiveness (Lehman et al., 1986).

Consequences

Post-support processes of interpersonal, perceptual, and behavioral natures need to be investigated in order to obtain a more comprehensive understanding of human interactions and the cyclical pattern of communication (Gottman et al., 1976).
Approximately half of the participants in Studies 1 and 2 reported that they did not say or do anything in response to unwanted actions by providers. Such findings are consistent with the idea that many people coping with stressful life events are reluctant to share their negative feelings with others (Dunkel-Schetter, 1984; Lehman & Hemphill, 1990; Silver et al., 1990). The lack of response may be an attempt to withdraw and avoid confrontation (Burchill & Stiles, 1988).

Nonetheless, not all participants were reticent. In fact, the main category reported by respondents in Studies 1 and 2 included discussing the issue rationally with the provider, a strategy that is often effective at ameliorating problems in the future (Coyne et al., 1988; Schmaling et al., 1989). Other responses included verbal abusiveness, downplaying the problem, blocking communication, acquiescing, and becoming emotional, all of which may serve to exacerbate difficulties, or at least not contribute to their resolution.

Next, three theoretical perspectives (equity, reactance, and threat to self-esteem) that can be employed to think about these results will be reviewed.

Equity theories are based on the assumption that recipients attempt to maintain a similar ratio of outcomes to inputs as those of providers (e.g., Walster et al., 1978). Furthermore, skewed distributions are posited to lead to psychological discomfort and efforts to achieve equity. Equity theories tend to emphasize assistance that is appreciated, and have focused less attention on assistance that is unappreciated. Perhaps this is because recipients who view the actions of others as particularly unhelpful may terminate such relationships, or
reduce the opportunity to experience such exchanges in the future. Nonetheless, it is possible to interpret negative actions within the model. Thus, if the provider alters inputs so that unsupportive actions are offered, then the recipient may respond in turn to achieve parity (termed "negative reciprocity" by Jacobson et al., 1994). That is, matching providers' unhelpful actions by recipients will prevent the latter from being underbenefited and the former from being overbenefited. Using such a criterion, then there is some support for equity theory in this dissertation. For instance, recipients coping with one of a number of stressful life events admitted to becoming verbally abusive (Coyne et al., 1988). Nonetheless, only a small minority of recipients (14% from Study 1 and 7% from Study 2) said that they responded in such a manner.

It is quite possible that assumptions which apply in general provision of aid situations where providers and recipients are both able-bodied individuals will no longer apply, or will apply to a lesser extent, when recipients who are in need of assistance are compromised physically. That is, in the case of chronic illness such as M.E., unidirectional assistance flowing from providers to recipients may be considered acceptable and may not give rise to as many feelings of guilt and need to restore equity by recipients or feelings or resentment by providers. In fact, successful coping with chronic situations involving disability may largely depend upon such a shared conception. Alternatively, helpful assistance that is considered appropriate to restore equity may be different for those suffering from a debilitating illness or disability, and restoration of equity in such cases may involve
different forms of assistance, such as emotional or informational support, given the amount of time and effort that some forms of aid (e.g., tangible assistance) would involve. In any case, future research needs to be conducted in order to clarify these issues, and determine recipients' reactions to wanted assistance.

There was limited support for reactance theory, which posits that perceived reduction in freedom of choice leads to an unpleasant psychological reaction, and accompanying efforts to restore such freedom (Brehm, 1966). Perhaps the most extreme methods for recipients to achieve freedom and autonomy are for them to scream or act in a hostile manner toward providers; however, only a minority of participants said that they acted this way. In contrast, most of the other classes of responses were more consistent with maintenance of harmony or friction reduction (Stein, 1992). These categories include blocking further communication, being submissive, and downplaying the problem. The need to avoid conflict in interactions may be quite strong, given the ideal of positiveness in communication (Montgomery, 1988). A substantial number of participants indicated that they did not say or do anything in response to the unhelpful actions, which may reflect their desire to avoid conflict, further unpleasant interactions, and severing of important relationships (Allan, 1979). The categories discussing the issue rationally with the provider and becoming emotional could reflect either attempts to restore lost freedoms or conflict reduction, depending upon the reason that recipients acted in such a manner, and the manner in which the sequence of events unfolded. Future research may benefit from gathering
more detailed information in order to test these notions in a more fine-grained way.

Threat to self-esteem models (e.g., Fisher et al., 1982) assume that support provision may comprise negative and positive features, and that reactions to support are determined by their threatening or supportive aspects. This theory, more so than equity or reactance, is based on perceptions, and internal thoughts and feelings. In terms of the framework being considered in this dissertation, antecedents are intimately connected with consequences. Threat to self-esteem approaches assume that help that is seen as threatening will lead to negative reactions, whereas help that is seen as supportive will lead to positive reactions. Although Fisher et al. (1982) have formulated a well-articulated self-esteem model, the model does not include statements regarding helpful and unhelpful actions, and it is therefore difficult to test such predictions. Moreover, reactions to supportive interactions were not investigated in the present study, so it is only possible to test part of the model (responses to unhelpful actions). Nonetheless, there are findings in the present set of studies that are consistent with such a tradition. In terms of antecedents, the two main categories that map onto threat to self-esteem models include benign and blaming causes, issues that have been discussed in detail previously. In terms of consequences, recipients could similarly reply benignly (e.g., downplaying problem, discussing the issue rationally) or harshly (e.g., becoming verbally abusive). Thus, even when unsupportive actions are offered, recipients need not necessarily view them in a threatening way, and positive ways of looking at the
behaviors may mute bad feelings and influence subsequent responses in a positive way. Despite the heuristic value of threat to self-esteem models, conditions under which interactions may be perceived as threatening or supportive need to be elucidated. Future studies would benefit from examining directly how self-esteem is affected by the support process, and how perceptions of threatening/supportive components are associated with reactions.

Other consequences examined in the studies that comprise this dissertation include whether or not providers developed awareness of unhelpfulness of their actions, the point at which it was obtained, and how awareness was obtained. With respect to the first issue, it is possible that providers may be unaware that their actions were unhelpful in the first place (Melamed & Brenner, 1990; Peters-Golden, 1982). Despite this possibility, few respondents endorsed such an option. Thus, only 12% of recipients said that providers were still unaware that their actions were unappreciated. In contrast, 24% of recipients and 35% of providers said that providers became aware at the time. Finally, 65% of recipients and the same percentage of providers believe that providers became aware of the unhelpfulness of their actions subsequent to performing them.

If there is an intervening period of time between engaging in negative interactions and development of an understanding that such actions were unappreciated, how is awareness obtained? The most prevalent strategy reported by providers and recipients was through discussions with one another. This suggests that, despite the deleterious effects that may occur when recipients talk about their problems (Costanza et al., 1988), recipients
may find that it is necessary and even beneficial to talk about providers' unhelpful actions with them. That is, in the absence of an informed discussion about the matter, respondents may believe that awareness will not be forthcoming.

Not all participants, however, thought that discussions were necessary for providers to become aware that their actions were unappreciated, as emphasized by the fact that respondents mentioned that awareness was obtained through perceptiveness on behalf of providers. Nonverbal strategies such as observation, voice tone, or body language (Siegman & Feldstein, 1987) were also reported. Interestingly, complex strategies such as learning about ones' actions through a third party, or focusing on subtle forms of nonverbal communication, such as eye contact, were not mentioned. Taken as a whole, these findings suggest that there are a variety of methods that providers used to become aware that their actions were unhelpful, and that most strategies involved communication between the affected parties, self-reflection, or the use of nonverbal strategies.

**Moderating Variables**

Two variables, source of support, and stressor characteristics, were investigated in the present set of studies as variables that may potentially moderate relations between antecedents, behaviors, and post-behavioral consequences.

**Relationship factors.** Previous researchers have noted that source of support is an important variable affecting emotional reactions (Fitz & Gerstenzang, 1978), satisfaction and conflict (Argyle & Furnham, 1982, 1983), and type of support offered to people coping with negative life events (Dakof & Taylor, 1990; Martin et al., 1994; Primomo et al., 1990). In the present set
of studies, relationship factors were associated with proffering of helpful actions, attributions for unhelpful actions, and reports of emotional distress. Specifically, supportive behaviors were reported by recipients as being offered more often by close others, followed by relatives and distant others. The first two groups did not differ from one another, but both differed from the third. Source of support was not associated with unhelpful actions. These findings highlight the importance of helpful, as opposed to unhelpful, actions in close relationships compared to more distant ones. In terms of benign attributions, close others and relatives were more likely to be given benefit of the doubt than more distant others. Results were consistent with the notion that benign attributions are offered primarily to those who are emotionally close to recipients (Bradbury & Fincham, 1992; Lehman & Hemphill, 1990). The pattern was reversed for emotional distress, such that close others were more troubled than distant others. These findings support the idea that close others are stressed by virtue of their intimate connection with recipients (Eckenrode & Gore, 1981). Using open-ended data, there were no differences across relationships for consequences. However, it is premature to conclude that source of support is irrelevant in terms of its contribution to consequences. Future studies need to examine such relations in more detail using standardized scales instead of open-ended questions.

The above results suggest that associations between antecedents and supportive and unsupportive behaviors may vary according to relationship between provider and recipient. Taken as a whole, findings from this dissertation are consistent with
the idea that research needs to be generalized across samples with caution, and that particular attention must be paid to source of support provision.

**Stressor characteristics.** The present set of studies examined consistencies and inconsistencies in reports of helpful and unhelpful actions across a range of stressful life events. In particular, it was of interest to determine which different types of stressors are associated with different types of support receipt (specificity models; Cohen & McKay, 1983), and which behaviors are considered to be helpful or unhelpful regardless of the negative life experience (traditional models; Cohen & Wills, 1985). Consistent with previous research (Goldsmith, 1992), emotional support was considered to be universally helpful. More generally, helpful behaviors did not vary across event type. In terms of supportive actions, informational and tangible support were more consistent with specificity than traditional models (also see Dakof & Taylor, 1990; Dunkel-Schetter et al., 1992; Lehman & Hemphill, 1990; Martin et al., 1994). Moreover, in Study 1, blaming unhelpful actions and critical attributions varied according to event type, and were mentioned for stressors that might be considered to be within recipients' control (Schwarzer & Weiner, 1991). In Study 2, benign attributions were offered more often for those experiencing bereavement than relationship problems, and there was a tendency for ignorant attributions to vary according to type of stressor. There were no significant relations between response to unhelpful actions by recipients and type of negative life event. However, response categories comprised few mentions. Future research would benefit from developing scales
based upon the information gathered from the present set of studies, and having all participants answer questions regarding the extent to which they responded in each of the pertinent ways. Taken as a whole, the present research suggests that stressful life events moderate antecedents, but that their relations with consequences remains to be tested adequately.

Limitations and Areas for Future Research

Information about supportive and unsupportive behaviors culled from the present studies came from participants' retrospective accounts of interactions that took place. It is worthwhile to consider if such accounts were an accurate reflection of reality, or if they were biased in any systematic ways.

On the one hand, it is possible that respondents' assessments were incorrect. Thus, in some circumstances, people coping with stressful life events may be motivated to alter their experiences to others (Silver et al., 1990). For example, because of the desire to appear normal (Lehman & Hemphill, 1990), people coping with stressful life events may present a facade of composure and downplay their symptoms. Individuals who are distressed may also hide their needs and negative feelings so as not to burden, upset, or scare off members of their social network (Lehman & Hemphill, 1990; Silver et al., 1990; Wortman & Lehman, 1985). Previous research has indicated that recipients may fail to convey to others how they are doing. For example, the majority of cancer patients admitted that they sometimes kept their thoughts and feelings to themselves, primarily due to fears with respect to providers' negative reactions (Dunkel-Schetter, 1984). The drawbacks of utilizing
such a strategy may be serious. For example, if successful at deceiving providers, patients may convey the message that they do not really need much help, and providers may act (or not act as the case may be) accordingly (Conant, 1990).

Recipients may alter their presentation of symptoms for providers in yet another way. If recipients believe that providers are skeptical about existence of the former's illness or disease (Shepherd, 1990), or if recipients haven't been getting the assistance they would like, they may exaggerate the symptoms they are experiencing. Expressions of distress by recipients may cause providers to feel helpless and vulnerable, and lead to rejection (Silver et al., 1990). Providers who believe that their significant others are overstating things may consider them to be hypersensitive or hypochondriacal, and fail to offer the needed assistance.

There are other reasons why recipients may be inaccurate about beliefs regarding their stressors and related experiences. Previous research has noted that not only are subjects often unaware of higher order cognitive processes, but they may also even be unaware of their responses to certain situations (Nisbett & Wilson, 1977). This tendency may be exacerbated by the fact that a substantial amount of time may have elapsed since the interactions took place.

On the other hand, the intervening period of time may have provided participants with the opportunity of identifying responses that were helpful and unhelpful in the long run (Lehman et al., 1986). For example, recipients may have blamed support providers for their unhelpful actions initially but, over time, the remarks or behaviors may have "lost their sting"
or been reframed (Lehman & Hemphill, 1990). Moreover, previous research has shown that there are typically stronger associations between perceptions of reality and, for example, mental health, than between actual behaviors and psychological functioning (Sarason, Shearin, Pierce, & Sarason, 1987). This suggests that, in the present context, views regarding supportive and unsupportive exchanges may be better determinants of important psychological variables than those based on observation of behavior. Nonetheless, it would be worthwhile to obtain more objective data via observation to determine if there are any consistent ways in which providers and recipients are biased in their interpretation of events, and how such biases are related to subsequent perceptions and behaviors and reports of them.

Data from the present studies are correlational and, therefore, causal determinations are not possible. Although some of the relations are suggestive of causal processes, more sophisticated designs, such as longitudinal ones, are needed to test predictions more rigorously. Thus, Coyne's (1976) interactional theory of depression, which suggests that exchanges between providers and recipients change across time, cannot be tested adequately with the current design.

This dissertation was not intended to be exhaustive, and could therefore only focus on a subset of antecedents, consequences, and moderating variables of helpful and unhelpful exchanges. Therefore, future research would profit by examining other variables that may influence relations with supportive and unsupportive exchanges. Two particularly fruitful research possibilities include sex and age, both of which have been
associated with social support. For instance, research has found that women have higher perceived support from roommates and friends, and less conflict with roommates than men (Lepore, 1992). In addition, females are perceived as more considerate and friendly than males (Sarason et al., 1986), and may provide more emotional support (Antonucci, 1985). There is evidence that women may be more affected by interpersonal interactions than men. For instance, perceptions of social support in married couples are more strongly related to marital satisfaction and general well-being of wives than husbands (Acitelli & Antonucci, 1994). Moreover, women have been found to have higher levels of need for affiliation and sensitivity to rejection than husbands (Moffitt, Spence, & Goldney, 1986). In terms of physiological consequences, social support was found to be an independent predictor of daily systolic pressure for women but not men (Linden, Chambers, Maurice, & Lenz, 1993). These findings suggest that there may be some interesting relations between gender and various aspects of the support process which warrant further investigation. Despite previous efforts, there have been few attempts to integrate such findings into a comprehensive framework such as that outlined in this dissertation. Therefore, future work would benefit from greater theoretical integration and comprehensive understanding of relations between gender and social support.

Age has also been under-researched, and is intimately connected with disruptions in the social environment. For instance, stressors such as widowhood, retirement, relocation, or the death of relatives and friends typically include the loss of significant social contacts, and may enhance feelings of
isolation and loneliness. Investigators have suggested some intriguing possibilities of the impact of age upon social support. For instance, Olsen, Iversen, and Sabroe (1991) note that social support from family and friends was most prevalent among the youngest participants, but it had a positive impact on health both among the young and the old. Similarly, longitudinal research has found declines in beyond-family contacts for individuals aged 85 and older but not people between 75 and 84; despite these changes in the amount of support received, there was an increase in feelings of closeness of the elderly with their children (Field & Minkler, 1988). These findings suggests that it is important to measure not only social support receipt, but also degree of satisfaction with one's social network. It is possible that age may be associated with changes in the types of support that are offered such as, for instance, tangible support, as mobility decreases and health-related problems increase. Future research would further our understanding of the support process by examining changes in the quality and quantity of support across time, and the manner in which such support is embedded in a larger social context.

This dissertation has been useful primarily in mapping out the terrain of the support process with respect to helpful and unhelpful aspects of interaction. Because the present set of studies was, by necessity, exploratory, only a basic understanding of how the support process unfolds could be developed here. Nonetheless, the present set of studies has documented, in greater detail than has been attempted before, supportive and unsupportive processes that occur between providers and recipients. It will be useful to determine, in a
more precise way, how antecedents, behaviors, and consequences are linked.
References


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<td>REASON</td>
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<td>OR ILLNESS</td>
<td>WORK OR</td>
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<td>OR ILLNESS</td>
<td>RELATION</td>
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<td>providing useful or advice</td>
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<td>understanding</td>
<td>expressing love, concern</td>
<td>listening, asking, giving</td>
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Table I
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**General Negative Actions**

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**Frequencies of Others' Unhelpful Actions from Recipients' Points of View**

Table 2
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<th>Impact of dissonance</th>
<th>Negative for themselves</th>
<th>Emotional Dissonance</th>
<th>What To Do</th>
<th>Importance/Not Knowing</th>
<th>Want problems to go away</th>
<th>Helpful/Harmful</th>
<th>Being told to do</th>
<th>Want to hurt respondent</th>
<th>Concerned, worked, didn't attribute</th>
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<th>Blocked Communication</th>
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**Table 4**

Responses to Others' Unhelpful Actions From Recipients' Points of View
Table 5

Principal Components Analysis Factor Loadings for Attribution Items

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<th>Statement</th>
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<th>Factor 2</th>
<th>Factor 3</th>
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<td>He or she is an inconsiderate person.</td>
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<td>.1686</td>
<td>-.0437</td>
</tr>
<tr>
<td>He or she was trying to do what was best for me. He or she had my best interests at heart.</td>
<td>-.7795</td>
<td>.0789</td>
<td>-.1083</td>
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<tr>
<td>He or she is a thoughtless person.</td>
<td>.7740</td>
<td>.1206</td>
<td>-.0650</td>
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<td>He or she was concerned or worried about me.</td>
<td>-.7050</td>
<td>.1809</td>
<td>-.1050</td>
</tr>
<tr>
<td>He or she is an idiot.</td>
<td>.6672</td>
<td>.1620</td>
<td>-.0934</td>
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<tr>
<td>He or she was trying to be mean to me.</td>
<td>.5362</td>
<td>.1417</td>
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<tr>
<td>He or she wanted my problems to go away.</td>
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<td>.3409</td>
<td>.0608</td>
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<td>He or she didn't want to hurt me.</td>
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<td>.3206</td>
<td>.1512</td>
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<td>He or she was not comfortable interacting with me.</td>
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<td>.2468</td>
<td>.2748</td>
</tr>
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<td>He or she didn't want to get involved with me or my problems.</td>
<td>.3805</td>
<td>.2431</td>
<td>.0075</td>
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<td>He or she didn't know what to do to help me.</td>
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<td>.6252</td>
<td>.1488</td>
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<td>He or she was unaware of what I needed at the time.</td>
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<td>.6199</td>
<td>.2451</td>
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<td>He or she views the world in a different way than I view it.</td>
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<td>.5675</td>
<td>.0365</td>
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<td>He or she lacked knowledge and/or understanding of what I was going through.</td>
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<td>.5500</td>
<td>-.0107</td>
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<tr>
<td>He or she was only trying to be helpful, but his or her actions were unhelpful nonetheless.</td>
<td>-.2926</td>
<td>.4794</td>
<td>-.0891</td>
</tr>
<tr>
<td>He or she was trying to deny the problem existed, or downplayed its importance.</td>
<td>.2052</td>
<td>.4030</td>
<td>.2907</td>
</tr>
<tr>
<td>He or she was afraid for him or herself.</td>
<td>.0668</td>
<td>.0665</td>
<td>.7389</td>
</tr>
<tr>
<td>He or she was anxious, depressed, or otherwise emotionally troubled.</td>
<td>.0399</td>
<td>.0436</td>
<td>.6891</td>
</tr>
<tr>
<td>He or she was caught up in my distress and, as a result, was unable to be effective in helping me deal with mine.</td>
<td>-.1586</td>
<td>.2592</td>
<td>.4993</td>
</tr>
</tbody>
</table>
Table 6

Means, Standard Deviations, and Cronbach's Alpha Reliabilities for Scales and Subscales for Participants with Myalgic Encephalomyelitis

<table>
<thead>
<tr>
<th>Scales (Participants with M.E.)</th>
<th>X</th>
<th>SD</th>
<th>Number of Items</th>
<th>Alphas</th>
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<tbody>
<tr>
<td>Big Five Inventory</td>
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<td>Extraversion</td>
<td>3.08</td>
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<td>8</td>
<td>.79</td>
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<td>Agreeableness</td>
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<td>Conscientiousness</td>
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<td>.70</td>
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<td>8</td>
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<td>Openness</td>
<td>4.06</td>
<td>.68</td>
<td>9</td>
<td>.84</td>
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<td>Brief Symptom Inventory</td>
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<td>Depression</td>
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<td>7</td>
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<tr>
<td>Anxiety</td>
<td>2.09</td>
<td>.78</td>
<td>6</td>
<td>.84</td>
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<td>Social Support Behavior Questionnaire</td>
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<td>3.83</td>
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<td>.72</td>
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<td>Unhelpful</td>
<td>2.07</td>
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<td>9</td>
<td>.69</td>
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<td>Supportive Actions Scale - Circumplex Version</td>
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<td>Directive (PA)</td>
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<td>.55</td>
<td>8</td>
<td>.74</td>
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<td>Critical (DE)</td>
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<td>.50</td>
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<td>.79</td>
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<td>Distancing (FG)</td>
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<td>8</td>
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<td>Avoidant (HI)</td>
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<td>.76</td>
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<td>Deferential (JK)</td>
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<td>.66</td>
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<td>Nurturant (LM)</td>
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<td>.86</td>
<td>8</td>
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<td>Engaging (NO)</td>
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Table 7

Means, Standard Deviations, and Cronbach's Alpha Reliabilities for Scales and Subscales for Close Others

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<thead>
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<th>Scales (Close Others)</th>
<th>X</th>
<th>SD</th>
<th>Number of Items</th>
<th>Alphas</th>
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<tbody>
<tr>
<td>Big Five Inventory</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Extraversion</td>
<td>3.11</td>
<td>.80</td>
<td>8</td>
<td>.82</td>
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<td>Agreeableness</td>
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<td>.76</td>
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<td>Conscientiousness</td>
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<td>.82</td>
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<td>Neuroticism</td>
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<td>8</td>
<td>.74</td>
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<td>Openness</td>
<td>3.84</td>
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<td>9</td>
<td>.83</td>
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<td>Depression</td>
<td>2.14</td>
<td>.77</td>
<td>7</td>
<td>.87</td>
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<tr>
<td>Anxiety</td>
<td>1.92</td>
<td>.64</td>
<td>6</td>
<td>.78</td>
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<tr>
<td>Social Support Behavior Questionnaire</td>
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<td>Helpful</td>
<td>3.85</td>
<td>.65</td>
<td>5</td>
<td>.72</td>
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<tr>
<td>Unhelpful</td>
<td>2.07</td>
<td>.52</td>
<td>9</td>
<td>.69</td>
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<tr>
<td>Supportive Actions Scale - Circumplex Version</td>
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<td>8</td>
<td>.82</td>
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<td>Arrogant (BC)</td>
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<td>8</td>
<td>.68</td>
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<tr>
<td>Critical (DE)</td>
<td>1.30</td>
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<td>8</td>
<td>.52</td>
</tr>
<tr>
<td>Distancing (FG)</td>
<td>1.91</td>
<td>.54</td>
<td>8</td>
<td>.74</td>
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<tr>
<td>Avoidant (HI)</td>
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<td>.72</td>
<td>8</td>
<td>.75</td>
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<tr>
<td>Deferential (JK)</td>
<td>3.55</td>
<td>.62</td>
<td>5</td>
<td>.60</td>
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<td>Nurturant (LM)</td>
<td>3.88</td>
<td>.65</td>
<td>8</td>
<td>.79</td>
</tr>
<tr>
<td>Engaging (NO)</td>
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<td>.67</td>
<td>8</td>
<td>.78</td>
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Table 8

Participants' Views Regarding the Most Helpful Actions Received

<table>
<thead>
<tr>
<th></th>
<th>Respondents with M.E. n (%)</th>
<th>Close Others n (%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional Support</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Expressing love, concern, or understanding</td>
<td>21(24.1)</td>
<td>25 (28.7)</td>
<td>.49</td>
</tr>
<tr>
<td>Accepting or acknowledging illness or its severity</td>
<td>15(17.2)</td>
<td>12(13.8)</td>
<td>.53</td>
</tr>
<tr>
<td>Listening/talking</td>
<td>15(17.2)</td>
<td>23(26.4)</td>
<td>.14</td>
</tr>
<tr>
<td>Providing encouragement or reassurance</td>
<td>10(11.5)</td>
<td>15(17.2)</td>
<td>.28</td>
</tr>
<tr>
<td>Physical presence/being there/including in social activities</td>
<td>9(10.3)</td>
<td>8(9.2)</td>
<td>.80</td>
</tr>
<tr>
<td><strong>Tangible Support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assisting with daily activities</td>
<td>41(47.1)</td>
<td>32 (36.8)</td>
<td>.17</td>
</tr>
<tr>
<td>Providing accommodations/making decisions/acting on my behalf</td>
<td>11(12.6)</td>
<td>5(5.7)</td>
<td>.12</td>
</tr>
<tr>
<td><strong>Informational Support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suggestions/coping strategies/information</td>
<td>15(17.2)</td>
<td>16(18.4)</td>
<td>.84</td>
</tr>
<tr>
<td><strong>Absence of negative</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>12(13.8)</td>
<td>6(6.9)</td>
<td>.14</td>
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</tbody>
</table>
Table 9

Respondents' Views Regarding the Most Unhelpful or Upsetting Actions Received

<table>
<thead>
<tr>
<th>Action</th>
<th>Respondents with M.E. n(%)</th>
<th>Close Others n(%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenging, denying, or not recognizing seriousness of illness/pushing to do more than able/encouraging recovery/not making accommodations</td>
<td>29(33.3)</td>
<td>24(27.6)</td>
<td>.41</td>
</tr>
<tr>
<td>Negative emotional reactions</td>
<td>10(11.5)</td>
<td>12(13.8)</td>
<td>.65</td>
</tr>
<tr>
<td>Not providing wanted or needed assistance</td>
<td>9(10.3)</td>
<td>11(12.6)</td>
<td>.64</td>
</tr>
<tr>
<td>Closing off communication</td>
<td>7(8.0)</td>
<td>8(9.2)</td>
<td>.79</td>
</tr>
<tr>
<td>Giving advice</td>
<td>6(6.9)</td>
<td>7(8.0)</td>
<td>.77</td>
</tr>
<tr>
<td>Rude remark/criticism</td>
<td>4(4.6)</td>
<td>4(4.6)</td>
<td>1.00</td>
</tr>
<tr>
<td>Avoiding contact/not including in social activities</td>
<td>4(4.6)</td>
<td>8(9.2)</td>
<td>.23</td>
</tr>
<tr>
<td>Being overly protective/patronizing</td>
<td>4(4.6)</td>
<td>0(0)</td>
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</table>
### Table 10

**Intercorrelations Between Subscales for Providers and Recipients**

<table>
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<tr>
<th>Subscale</th>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
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</thead>
<tbody>
<tr>
<td><strong>SAS-C Octants</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Directive (PA)</td>
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<td></td>
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<td>.38**</td>
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<td></td>
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<tr>
<td>2. Arrogant (BC)</td>
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<td></td>
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<tr>
<td>3. Critical (DE)</td>
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<td>.30**</td>
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<tr>
<td>4. Distancing (FG)</td>
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<td>.43***</td>
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<td></td>
</tr>
<tr>
<td>5. Avoidant (HI)</td>
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<td></td>
<td>.47***</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>6. Deferential (JK)</td>
<td></td>
<td></td>
<td></td>
<td>.24*</td>
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</tr>
<tr>
<td>7. Nurturant (LM)</td>
<td></td>
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<td></td>
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<td>.49***</td>
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</tr>
<tr>
<td>8. Engaging (NO)</td>
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<td></td>
<td>.39***</td>
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*P < .05  **p < .01  ***p < .001
Table 11

Correlations Between Recipients' Personality Dimensions and Their Reports of Supportive and Unsupportive Behaviors

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Extraversion</th>
<th>Agreeableness</th>
<th>Conscientiousness</th>
<th>Neuroticism</th>
<th>Openness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SAS-C Octants</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Directive (PA)</td>
<td>.08</td>
<td>.00</td>
<td>-.12</td>
<td>.10</td>
<td>.11</td>
</tr>
<tr>
<td>Arrogant (BC)</td>
<td>.01</td>
<td>-.09</td>
<td>-.13</td>
<td>.15</td>
<td>-.03</td>
</tr>
<tr>
<td>Critical (DE)</td>
<td>-.01</td>
<td>-.22*</td>
<td>-.05</td>
<td>.17</td>
<td>-.09</td>
</tr>
<tr>
<td>Distancing (FG)</td>
<td>.00</td>
<td>-.22*</td>
<td>-.04</td>
<td>-.03</td>
<td>-.05</td>
</tr>
<tr>
<td>Avoidant (HI)</td>
<td>-.06</td>
<td>-.10</td>
<td>.02</td>
<td>.11</td>
<td>-.08</td>
</tr>
<tr>
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<td>-.04</td>
<td>-.03</td>
<td>.08</td>
<td>.04</td>
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<tr>
<td>Nurturant (LM)</td>
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<td>-.05</td>
<td>.10</td>
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<td>-.10</td>
<td>.08</td>
<td>.09</td>
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<tr>
<td>Unhelpful</td>
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<td>-.08</td>
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*p < .05  **p < .01  ***p < .001"
Table 12

**Correlations Between Providers' Personality Dimensions and Their Reports of Supportive and Unsupportive Behaviors Offered**

<table>
<thead>
<tr>
<th>Subscale</th>
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<th>Agreeableness</th>
<th>Conscientiousness</th>
<th>Neuroticism</th>
<th>Openness</th>
</tr>
</thead>
<tbody>
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<td>.02</td>
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<td>.03</td>
<td>-.05</td>
<td>.10</td>
</tr>
<tr>
<td>Arrogant (BC)</td>
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<td>-.11</td>
<td>-.04</td>
<td>.08</td>
<td>.02</td>
</tr>
<tr>
<td>Critical (DE)</td>
<td>-.12</td>
<td>-.28**</td>
<td>-.18</td>
<td>.33**</td>
<td>-.12</td>
</tr>
<tr>
<td>Distancing (FG)</td>
<td>-.17</td>
<td>-.19</td>
<td>-.09</td>
<td>.21*</td>
<td>-.02</td>
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<td>Avoidant (HI)</td>
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<td>.01</td>
<td>.06</td>
<td>.25*</td>
<td>.01</td>
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<tr>
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<td>.35***</td>
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<td>-.17</td>
<td>-.07</td>
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<td>.37***</td>
<td>-.28**</td>
<td>.31**</td>
</tr>
<tr>
<td>Engaging (NO)</td>
<td>.32**</td>
<td>.23*</td>
<td>.14</td>
<td>-.06</td>
<td>.34***</td>
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*P < .05  **p < .01  ***p < .001
Table 13

**Correlations Between Providers' Personality Dimensions and Their Factors of SAS-C**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Nurturance</th>
<th>Dominance</th>
<th>Avoidance</th>
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<td>Extraversion</td>
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<td>-.15</td>
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<tr>
<td>Agreeableness</td>
<td>.42***</td>
<td>-.01</td>
<td>.09</td>
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<tr>
<td>Conscientiousness</td>
<td>.26**</td>
<td>-.01</td>
<td>.10</td>
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<tr>
<td>Neuroticism</td>
<td>-.22*</td>
<td>.05</td>
<td>.17</td>
</tr>
<tr>
<td>Openness</td>
<td>.33**</td>
<td>.08</td>
<td>-.02</td>
</tr>
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</table>

*P < .05  **P < .01  ***P < .001
Table 14

Correlations Between Providers' Self-Reported Supportive and Unsupportive Actions and Their Personality Dimensions

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Helpful Actions</th>
<th>Unhelpful Actions</th>
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<tbody>
<tr>
<td>Extraversion</td>
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<tr>
<td>Agreeableness</td>
<td>.53***</td>
<td>.10</td>
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<tr>
<td>Conscientiousness</td>
<td>.31**</td>
<td>-.05</td>
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<tr>
<td>Neuroticism</td>
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<td>.01</td>
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<tr>
<td>Openness</td>
<td>.36***</td>
<td>.22*</td>
</tr>
</tbody>
</table>

*p < .05   **p < .01   ***p < .001
Table 15

Participants’ Views Regarding the Most Important Help Needed

<table>
<thead>
<tr>
<th></th>
<th>Respondents with M.E. n(%)</th>
<th>Close Others n(%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional Support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expressing love, concern, or understanding</td>
<td>18(20.7)</td>
<td>15(17.2)</td>
<td>.56</td>
</tr>
<tr>
<td>Listening/talking</td>
<td>13(14.9)</td>
<td>14(16.1)</td>
<td>.83</td>
</tr>
<tr>
<td>Physical presence/being there/including in social activities</td>
<td>9(10.3)</td>
<td>7(8.0)</td>
<td>.60</td>
</tr>
<tr>
<td>Providing encouragement or reassurance</td>
<td>8(9.2)</td>
<td>10(11.5)</td>
<td>.62</td>
</tr>
<tr>
<td>Accepting or acknowledging illness or its severity</td>
<td>5(5.7)</td>
<td>5(5.7)</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Tangible Support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assisting with daily activities</td>
<td>21(24.1)</td>
<td>23(26.4)</td>
<td>.73</td>
</tr>
<tr>
<td>Physical assistance/personal care</td>
<td>14(16.1)</td>
<td>9(10.3)</td>
<td>.26</td>
</tr>
<tr>
<td>Providing accommodations/making decisions/acting on my behalf</td>
<td>10(11.5)</td>
<td>3(3.4)</td>
<td>.04</td>
</tr>
<tr>
<td><strong>Called ambulance or doctor/took to hospital</strong></td>
<td>3(3.4)</td>
<td>9(10.3)</td>
<td>.07</td>
</tr>
</tbody>
</table>
Table 16

**How Respondents Believe that Providers Became Aware that Support was Needed**

<table>
<thead>
<tr>
<th></th>
<th>Respondents with M.E.</th>
<th>Close Others</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n(%)</td>
<td>n(%)</td>
<td></td>
</tr>
<tr>
<td>Discussing the issue/talking</td>
<td>37(42.5)</td>
<td>42(48.3)</td>
<td>.45</td>
</tr>
<tr>
<td>Observing/looking</td>
<td>12(13.8)</td>
<td>9(10.3)</td>
<td>.49</td>
</tr>
<tr>
<td>Emotional difficulties/distress</td>
<td>9(10.3)</td>
<td>17(19.5)</td>
<td>.09</td>
</tr>
<tr>
<td>Empathy/understanding/perceptiveness</td>
<td>8(9.2)</td>
<td>3(3.4)</td>
<td>.12</td>
</tr>
<tr>
<td>Incapacitation/poor physical health</td>
<td>6(6.9)</td>
<td>16(18.4)</td>
<td>.02</td>
</tr>
<tr>
<td>It was obvious/common sense</td>
<td>6(6.9)</td>
<td>4(4.6)</td>
<td>.51</td>
</tr>
<tr>
<td>Voice tone/body language</td>
<td>4(4.6)</td>
<td>2(2.3)</td>
<td>.41</td>
</tr>
<tr>
<td>Confused/lost</td>
<td>0(0)</td>
<td>6(6.9)</td>
<td>.01</td>
</tr>
</tbody>
</table>
Table 17

Correlations Between Providers' Views of Symptoms and Their Reports of Supportive and Unsupportive Behaviors

<table>
<thead>
<tr>
<th>Supportive and Unsupportive Behaviors</th>
<th>Observable</th>
<th>Unobservable</th>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Symptoms</td>
<td>Psychological Symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSBQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helpful</td>
<td>.26**</td>
<td>.31**</td>
<td>.14</td>
<td>.23*</td>
</tr>
<tr>
<td>Unhelpful</td>
<td>.08</td>
<td>.10</td>
<td>.33**</td>
<td>.44***</td>
</tr>
<tr>
<td>SAS-C</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurturance</td>
<td>.20</td>
<td>.27**</td>
<td>.07</td>
<td>.16</td>
</tr>
<tr>
<td>Dominance</td>
<td>.08</td>
<td>.14</td>
<td>.18</td>
<td>.33**</td>
</tr>
<tr>
<td>Avoidance</td>
<td>.17</td>
<td>.21</td>
<td>.10</td>
<td>-.04</td>
</tr>
</tbody>
</table>

*p < .05  **p < .01  ***p < .001
Table 18

Correlations Between Symptom Residuals and Recipients' Reports of Supportive and Unsupportive Behaviors

<table>
<thead>
<tr>
<th>Supportive and Unsupportive Behaviors</th>
<th>Observable</th>
<th>Unobservable</th>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological Symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>SSBQ</th>
<th>SAS-C</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Helpful</td>
<td>-0.07</td>
<td>0.22*</td>
<td>-0.10</td>
<td>-0.09</td>
</tr>
<tr>
<td>Unhelpful</td>
<td>0.22*</td>
<td>0.23*</td>
<td>0.15</td>
<td>0.23*</td>
</tr>
<tr>
<td>Nurturance</td>
<td>-0.15</td>
<td>-0.03</td>
<td>-0.14</td>
<td>-0.06</td>
</tr>
<tr>
<td>Dominance</td>
<td>0.08</td>
<td>0.06</td>
<td>-0.01</td>
<td>0.14</td>
</tr>
<tr>
<td>Avoidance</td>
<td>0.01</td>
<td>-0.01</td>
<td>0.23*</td>
<td>0.20</td>
</tr>
</tbody>
</table>

*p < .05  **p < .01  ***p < .001
Table 19

Views Regarding the Cause of Their Illness by Respondents with M.E.

<table>
<thead>
<tr>
<th>Cause of Illness</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Virus/flu/bacteria/infection</td>
<td>63</td>
<td>(60.0)</td>
</tr>
<tr>
<td>Stress/overwork/overactivity</td>
<td>46</td>
<td>(43.8)</td>
</tr>
<tr>
<td>Immune system disturbance</td>
<td>43</td>
<td>(41.0)</td>
</tr>
<tr>
<td>Physical problem</td>
<td>33</td>
<td>(31.4)</td>
</tr>
<tr>
<td>Toxins/environmental factors/no fresh air</td>
<td>26</td>
<td>(24.8)</td>
</tr>
<tr>
<td>Genetic factors/predisposition</td>
<td>16</td>
<td>(15.2)</td>
</tr>
<tr>
<td>Vaccine/antibiotic/anesthetic</td>
<td>15</td>
<td>(14.3)</td>
</tr>
<tr>
<td>Emotional factors</td>
<td>15</td>
<td>(14.3)</td>
</tr>
</tbody>
</table>
Table 20

Factor Loadings of Causal Items for Respondents

<table>
<thead>
<tr>
<th>Item</th>
<th>Respondents with M.E.</th>
<th>Close Others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Factor 1 Psychological</td>
<td>Factor 2 Environmental/Genetic</td>
</tr>
<tr>
<td>Worrying</td>
<td>.87</td>
<td>.10</td>
</tr>
<tr>
<td>Stress</td>
<td>.85</td>
<td>.01</td>
</tr>
<tr>
<td>Working too hard</td>
<td>.81</td>
<td>.13</td>
</tr>
<tr>
<td>Depression</td>
<td>.60</td>
<td>.05</td>
</tr>
<tr>
<td>Not doing enough exercise</td>
<td>.49</td>
<td>.15</td>
</tr>
<tr>
<td>Working in an environment with no fresh air</td>
<td>.18</td>
<td>.79</td>
</tr>
<tr>
<td>Toxins</td>
<td>.22</td>
<td>.78</td>
</tr>
<tr>
<td>A genetic predisposition</td>
<td>-.05</td>
<td>.60</td>
</tr>
</tbody>
</table>
## Table 21

**Correlations Between Providers' Views of Causal Factors and Recipients' Reports of Supportive and Unsupportive Behaviors**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Factor 1 Psychological</th>
<th>Factor 2 Environmental/Genetic</th>
<th>Viral</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SAS-C Octants</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Directive (PA)</td>
<td>-.11</td>
<td>.09</td>
<td>.14</td>
</tr>
<tr>
<td>2. Arrogant (BC)</td>
<td>.06</td>
<td>.08</td>
<td>.11</td>
</tr>
<tr>
<td>3. Critical (DE)</td>
<td>.28**</td>
<td>.11</td>
<td>-.09</td>
</tr>
<tr>
<td>4. Distancing (FG)</td>
<td>.31**</td>
<td>.31**</td>
<td>-.05</td>
</tr>
<tr>
<td>5. Avoidant (HI)</td>
<td>.32**</td>
<td>.10</td>
<td>-.05</td>
</tr>
<tr>
<td>6. Deferential (JK)</td>
<td>.18</td>
<td>-.01</td>
<td>.05</td>
</tr>
<tr>
<td>7. Nurturant (LM)</td>
<td>-.18</td>
<td>-.15</td>
<td>.22*</td>
</tr>
<tr>
<td>8. Engaging (NO)</td>
<td>-.24*</td>
<td>-.07</td>
<td>.08</td>
</tr>
<tr>
<td><strong>SAS-C Factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Nurturance</td>
<td>-.26*</td>
<td>-.15</td>
<td>.16</td>
</tr>
<tr>
<td>10. Dominance</td>
<td>.05</td>
<td>.08</td>
<td>.09</td>
</tr>
<tr>
<td>11. Avoidance</td>
<td>.38***</td>
<td>.14</td>
<td>-.05</td>
</tr>
<tr>
<td><strong>SSBQ</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Helpful</td>
<td>-.06</td>
<td>-.04</td>
<td>.09</td>
</tr>
<tr>
<td>13. Unhelpful</td>
<td>.07</td>
<td>-.05</td>
<td>-.15</td>
</tr>
</tbody>
</table>

*p < .05  **p < .01  ***p < .001
<table>
<thead>
<tr>
<th>Reasons for Unhelpful Things</th>
<th>Respondents with M.E. n(%)</th>
<th>Close Others n(%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ignorance/lack of understanding or knowledge</td>
<td>23(26.4)</td>
<td>18(20.7)</td>
<td>.37</td>
</tr>
<tr>
<td>Power struggle/conflicting views or needs/longstanding pattern</td>
<td>15(17.2)</td>
<td>11(12.6)</td>
<td>.40</td>
</tr>
<tr>
<td>Emotional difficulties</td>
<td>14(16.1)</td>
<td>19(21.8)</td>
<td>.33</td>
</tr>
<tr>
<td>Stress/own problems to deal with</td>
<td>11(12.6)</td>
<td>15(17.2)</td>
<td>.40</td>
</tr>
<tr>
<td>Trying to be helpful/overprotective</td>
<td>7(8.0)</td>
<td>7(8.0)</td>
<td>1.00</td>
</tr>
<tr>
<td>Denial of problem/forgetfulness</td>
<td>4(4.6)</td>
<td>3(3.4)</td>
<td>.70</td>
</tr>
<tr>
<td>Going through a new transition</td>
<td>4(4.6)</td>
<td>2(2.3)</td>
<td>.41</td>
</tr>
<tr>
<td>Want problems to go away</td>
<td>4(4.6)</td>
<td>1(1.1)</td>
<td>.17</td>
</tr>
</tbody>
</table>
Table 23

Respondents' Perceptions: What Prevented Providers From Acting in More Preferred Ways

<table>
<thead>
<tr>
<th></th>
<th>Respondents with M.E. n(%)</th>
<th>Close Others n(%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ignorance/lack of understanding or knowledge</td>
<td>24(27.6)</td>
<td>22(25.3)</td>
<td>.73</td>
</tr>
<tr>
<td>Power struggle/conflicting views or needs/longstanding pattern</td>
<td>18(20.7)</td>
<td>16(18.4)</td>
<td>.70</td>
</tr>
<tr>
<td>Emotional difficulties</td>
<td>16(18.4)</td>
<td>12(13.8)</td>
<td>.41</td>
</tr>
<tr>
<td>Stress/own problems to deal with</td>
<td>12(13.8)</td>
<td>11(12.6)</td>
<td>.82</td>
</tr>
</tbody>
</table>
Table 24

**How Respondents Believe that Providers Became Aware that Their Actions Were Unhelpful or Upsetting**

<table>
<thead>
<tr>
<th></th>
<th>Respondents with M.E.</th>
<th>Close Others</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n(%)</td>
<td>n(%)</td>
<td></td>
</tr>
<tr>
<td>Discussing the issue/talking</td>
<td>45(51.7)</td>
<td>33(37.9)</td>
<td>.07</td>
</tr>
<tr>
<td>Emotional difficulties/distress</td>
<td>11(12.6)</td>
<td>16(18.4)</td>
<td>.30</td>
</tr>
<tr>
<td>Empathy/understanding/perceptiveness</td>
<td>6(6.9)</td>
<td>6(6.9)</td>
<td>1.00</td>
</tr>
<tr>
<td>Observing/looking</td>
<td>2(2.3)</td>
<td>7(8.0)</td>
<td>.09</td>
</tr>
<tr>
<td>Voice tone/body language</td>
<td>2(2.3)</td>
<td>4(4.6)</td>
<td>.41</td>
</tr>
</tbody>
</table>
Figure 1

Framework within which to investigate supportive and unsupportive behaviors.
Appendix 1

Initial Contact Letter

June 15, 1995

Dear MEBC Member:

With the support of the Myalgic Encephalomyelitis Society of British Columbia (MEBC), a University of British Columbia (UBC) research team will be conducting a study of people in the Lower Mainland who have Myalgic Encephalomyelitis (M.E.). This study, under the direction of Dr. Darrin Lehman, is aimed at increasing our understanding of how people cope with M.E., something that can only be achieved by obtaining information from those who have had experience with the illness. The researchers will cover topics that people with M.E. have mentioned are important to them, such as life changes as a result of the illness, symptoms, social support, thoughts about the illness, and so on. The investigators are not interested in labeling you, but rather in learning as much as they can about the impact of M.E. on people’s lives. You are in a unique position to inform them about your personal experiences.

The UBC researchers are a completely independent group and have no formal connection with MEBC and absolutely no association with any other private or government organization.

We are assisting Dr. Lehman and his colleagues by sending this letter directly to you, and inviting you to take part in this important study. The researchers have not been given your name, telephone number, or address, but will be given this information only if you agree to participate. An MEBC Representative will telephone you to discuss the possibility of participating in this study if you do not contact MEBC before June 28, 1995. If you would prefer not to participate in the study, please do not hesitate to call MEBC at (604)526-3993. You may also telephone the researchers at their UBC Project Office (822-2613) if you would like
more information about the study, or would like to be recruited directly through them.

Participation in this project is completely voluntary, and would involve about 1 - 2 hours of your time to complete an interview with one of the trained project staff. The research interview was developed in consultation with members of MEBC, and has been approved by Board members.

The researchers realize that you are likely to have good days and bad days. As a result, interviews may be conducted in more than one sitting. The UBC staff will work out whatever situation is best for you.

Although the researchers have found that most people prefer to have interviews conducted in their own homes, if you would prefer to be interviewed elsewhere, they can easily arrange the interview at UBC or at a place of your choosing. In addition to your interview and a brief questionnaire that they ask all participants to complete in the days following the interview, there is a short questionnaire that they hope a close other will be willing to complete. All of the information that both you and your close other provide will be held in the strictest confidence, and anonymity will be assured.

Once again, it is only by talking with people such as yourself that researchers can better understand this extremely significant illness. Thank you very much for your consideration of this request.

Sincerely,

Cassandra Neilson
MEBC Officer of the Board
Appendix 2

Script for Telephone Contact

"Hi, my name is [name] and I'm calling from the University of British Columbia M.E. Project. I'm phoning to check whether or not you received the letter that was sent to you a week ago by MEBC outlining our project on coping with M.E."

[If it was received, say] "If you have a few minutes and are willing, I would like to tell you a bit more about the study."

[If not willing to participate in the study, say] "I appreciate the time you have given me to talk with you." If you decide at a later date that you would like to be in the study, please don't hesitate to contact a member of our research team at (604)822-2613. Thank you very much. Bye."

[If potentially willing to participate in the study, but they don't have the time to talk right now, say] "When is a better time for me to get ahold of you?" [confirm time and date]

[If willing to talk now, say] "We are interviewing people in British Columbia who have been diagnosed with M.E. The purpose of this study is to increase our understanding of how people cope with this serious illness. As you know, MEBC is assisting us with the study by initially contacting its members, and this is how we got your name and phone number."

"To ensure that the findings of our study accurately reflect the experiences of people with M.E., we are focusing only on those individuals who have been formally diagnosed with illness. [Make sure to ask this] Have you been diagnosed with M.E.?"

☐ YES
☐ NO

[If NO, say] "I want to thank you for taking a moment to talk with me, even though we are unable to include you in the study." [ANSWER ANY QUESTIONS ABOUT THE STUDY THAT THEY HAVE].

[If YES, say] "In that case, we would like to invite you to take part in our study. As the letter indicated, participation would involve approximately 1 - 2 hours of your time to complete an interview with our project staff and 20 minutes to complete a questionnaire in the days following the interview. We will cover topics that people with M.E. have told us are important to them, such as views regarding causes of the illness, symptoms, various thoughts about the illness, and so on. We recognize that M.E. can be a difficult illness to cope with, and that it poses unique challenges. We would like to learn as much as possible about this illness, and our aim is to make this as valuable an experience as we can for each respondent."
"Do you have any questions about the study or what your participation would involve?" [Answer any questions that are posed]

"Would you be willing to be part of this study?"

[If NO, say] "I appreciate the time you have given me to talk about the study. If you decide at a later date that you would like to be in the study, please don't hesitate to contact a member of our research team at (604)822-2613. Thank you very much. Bye."

[If YES, say] "That's great. We will do the interview wherever you are most comfortable. The only thing that we need is a quiet location where we will not be disturbed by others. Most people say that they prefer to talk at their home because it saves them the time of traveling to another location, such as UBC. What would be best for you?"

"What day would you be free to talk?" [confirm a date; Saturday and Sunday are OK if it's better for them and OK for you]

"What time of day would you like to meet? We can set up an interview whenever you tend to feel your best." [confirm a time]

"We have slightly different interviews for different people taking part in the study. To make sure that we bring the right interview, we need to get just a few answers to some quick questions. Are you married or in a common law or other long-term relationship?" [check the appropriate space]

☐ YES
☐ NO

[If YES, ask] "We are also hoping to get some information via questionnaire from a close other. Would you be willing to ask your partner if s/he would be willing to complete a questionnaire?"

☐ YES
☐ NO

[If NO to either of the preceding two questions, ask] "Would you be willing to ask someone who knows you quite well to complete a questionnaire?"

☐ YES
☐ NO
[If YES to preceding question, ask] "Is this person male or female?"

☐ MALE
☐ FEMALE

[If the interview is being conducted in the respondent's home, ask] "What is your address?"
[Get closest major intersecting streets] "What is the best way to get to your place? I am coming from UBC." [or other location]

"Thank you very much. I look forward to meeting you in person on [date] at [location] at [time]."
Appendix 3

Replies to Common Questions

How we got their name
"With the assistance of MEBC, your name was chosen from their membership list. We randomly selected people in the Greater Vancouver area who have M.E. Your name was among those individuals."

Estimated time for participation
"We expect that it will take you approximately 1 - 2 hours to complete the interview and 30 minutes to complete a questionnaire. These estimates are based on pilot testing that we have done with other people who have M.E. The interview will vary in length depending on how interested you are in talking about these things and the overall pace of the interview."

The means by which anonymity and confidentiality will be achieved
"We will ensure your anonymity by identifying you by code number only on all documents that include information that you give to us. You will never be identified by name in any reports that are prepared from the study. Only researchers directly involved with the project will have access to the data, which will be located in a locked room. The tapes from the interview will be transcribed, and then erased."

Taping the interviews
"We would like to tape each interview because we want to avoid any loss of information. It is difficult to write down everything that you say as you speak, and we don't want to miss anything. We also don't want the interviews to take any longer than is necessary."

Name and telephone number of person who can verify authenticity of research project.
"Dr. Anthony Phillips, Head of Psychology at the University of British Columbia, can verify that we are conducting this project of “Coping with M.E.” He may be contacted through the UBC Psychology Department at 822-3244."
Appendix 4

CONSENT FORM

I understand that members of the Department of Psychology at the University of British Columbia (UBC) are conducting a study of Coping with Myalgic Encephalomyelitis (M.E.) under the direction of Dr. Darrin Lehman, principal investigator. The purpose of this research is to better understand how this illness affects people's lives.

I have been asked to participate in this study by being interviewed by a member of the UBC M.E. study team and by completing a brief questionnaire at my leisure. I also understand that, with my permission, the interviews will be tape-recorded, transcribed without any identifying information, and then erased. To preserve my anonymity, no identifying information will be recorded on the interview or any transcribed version of it. Confidentiality will be maintained through use of a code number that will be used to identify me at all times. My responses will be placed in a locked room, to which only researchers directly involved with the project will have access.

I understand that I have been randomly selected from the Myalgic Encephalomyelitis Society of British Columbia’s (MEBC) membership list. I understand that my participation is completely voluntary and that I may decide not to participate in the study without jeopardizing my relationship with MEBC.

I understand that all information will be kept confidential. My name will never be used or disclosed in any of the reports that are prepared from the study. Absolutely no information that I provide will be shared with my partner or other family members by the researchers.

I understand that some of the questions may be difficult to discuss, and that whether I choose to discuss such questions is completely up to me. If we come to any questions that I do not want to answer, I understand that I can simply inform the interviewer, and we will go on to the next question. I can also decide to break off the interview or questionnaire at any time. Participation will take about 1 - 2 hours of my time to complete the interview and 20 minutes to complete a questionnaire. I understand that there is also a brief questionnaire for me to ask a close other to complete.
I have signed this consent form, and received a copy of it, before beginning the interview.

If I have any questions about the study, I may telephone Dr. Darrin Lehman (Project Director) or Mr. Kenneth Hemphill (Project Coordinator) at the project office (822-2613).

I have read the above information and consent to participate in this study.

Signed

Date

Interviewer
Appendix 5

Code # _______________________
Interviewer _______________________
Date _______________________
Interview Start Time _______________________

M.E. PARTICIPANT INTERVIEW

We greatly appreciate the time that you have set aside to be a part of our study on Myalgic Encephalomyelitis, or M.E. As mentioned in the letter, our research team at U.B.C. is interested in how people cope with this significant illness. It's the first project of its kind that we are aware of, and your participation will help us learn a great deal.

The questions that I am going to ask you do not have right or wrong answers; we are simply interested in your honest opinions. Please stop me if you're not sure what any particular question is asking, and I will clarify it for you. If you need any breaks during the interview, please let me know and we can wait until you are ready to begin again. Tell me, if at any point, you are feeling particularly poorly and unable to continue. If this happens, we can stop the interview and reschedule the remainder of it for another day if you would like.

Only by asking people direct questions can we understand better the ways in which people with M.E. are affected by the illness. Consequently, if you would rather not answer a particular question, it is perfectly reasonable to say so. You may also break off the interview at any point if you no longer wish to participate.

The interview should take anywhere from one to two hours, depending on the length of your responses.

Before we get started, I would like to ask you to please read over this consent form [HAND IT TO RESPONDENT], sign it, and return it to me. I have a copy that you may keep for your records. With your permission, I’d like to tape record the interview just to be sure that I don't miss anything. This will also speed up the interview considerably. But, let me assure you that no one other than the project's transcribers will ever hear the tape, none of your answers will ever be attached to your name, and the tapes will be erased after they have been transcribed. Is it OK for me to tape the interview? [START TAPE NOW]
SECTION A
DIAGNOSIS

A1) When was the onset of your M.E.? What month and year was it?
   [IF THEY CAN'T REMEMBER, ASK FOR THEIR BEST GUESS]
   _______ (month) _________ (year)

A2) Have you been diagnosed with M.E.?

   1 NO
   [SKIP TO A3]

   2 YES

   (a) When were you first diagnosed? What month and year was it?
       [IF THEY CAN'T REMEMBER, ASK FOR THEIR BEST GUESS]
       _______ (month) _________ (year)

   (b) Who diagnosed you?

   1 GENERAL PRACTITIONER
   [SAY "FAMILY DOCTOR" IF THEY DON'T KNOW WHAT A G.P. IS]

   2 OTHER
   SPECIFY TYPE OF SPECIALIST:

   (c) How many traditional medical professionals did you see for your M.E. before you were given the diagnosis? ______

   (d) Have you been to any alternative medical specialists, such as herbalists, naturopaths, homeopaths, etc.?

   1 NO
   [SPECIFY HOW MANY AND WHICH ONES]

   2 YES
(e) Approximately how many different types of medical tests were you given before you were actually diagnosed with M.E.? Was it 1-5, 6-10, 11-15, 16-20, or more than 20?

(1) 1 - 5  
(2) 6 - 10  
(3) 11 - 15  
(4) 16 - 20  
(5) 21+

(f) Approximately how many different types of medications were you given for your M.E. symptoms before being diagnosed with the illness? ______

A3) Do you have any other major illnesses, injuries, or diseases?

1 NO  
[SKIP TO A4]  

2 YES  
[SPECIFY]

(a) When was its onset?

_______ (month) _______ (year)

(b) Are you still being treated for it (any of them)?

1 YES  
2 NO

(c) [IF PARTICIPANT MENTIONS MORE THAN ONE, ASK]
Which one(s)?

________________________________________

________________________________________
M.E. CRITERIA

A4) Now, I am going to read you a list of things that you may have experienced since you first noticed your M.E. symptoms. Please tell me which of these symptoms you've experienced.

___ a) Extreme fatigue that doesn't go away completely, even after adequate sleep or rest.

___ b) Fatigue that is severe enough to reduce your average daily activity level to less than 50% of what it was before the illness.

___ c) Fatigue that has lasted for a period of at least 6 months.

___ d) Fever or mild fever.

___ e) Sore throat.

___ f) Painful lymph nodes, especially on sides of your neck and under your arms.

___ g) Muscle weakness.

___ h) Muscle discomfort or pain.

___ i) Fatigue after exercise that lasts a day or longer that you would have easily tolerated before getting M.E.

___ j) Headaches of a type, severity, or pattern that is different from headaches that you may have had before getting M.E.

___ k) Joint pain.

___ l) Sleep disturbance.

___ m) [READ ONE AT A TIME: ONCE RESPONDENT SAYS "YES" TO ANY ONE OF THE FOLLOWING SYMPTOMS, SKIP THE REMAINING SYMPTOMS AND GO ON TO A5]

Intolerance of light / blind spots in your visual field / forgetfulness / excessive irritability / confusion / difficulty thinking / inability to concentrate / depression.

A5) OK, now I am going to ask you a few more questions about your illness. Did your illness begin abruptly or gradually? By abruptly, I mean over a few hours to a few days.

1 ABRUPTLY 2 GRADUALLY

A6) Compared to other people with M.E., do you think that, in general, your symptoms are "much better than most others," "somewhat better," "about average," "somewhat worse," or "much worse than most others?"

1 MUCH BETTER 2 SOMEWHAT BETTER 3 ABOUT AVERAGE 4 SOMEWHAT WORSE 5 MUCH WORSE
A7) Compared to how you've generally felt since you were diagnosed with M.E., has your energy level in the past month or so been "much higher than average," "somewhat higher than average," "about average," "somewhat lower than average," or "much lower than average?"

A8) In general, would you say that you are coping with your M.E. "extremely well," "quite well," "OK," "poorly," or "very poorly?"

SECTION B

RUMINATIVE THOUGHTS

Now I am going to read you five statements regarding tendencies some people have [SHOW RED SCALE "A" "STRONGLY DISAGREE" TO "STRONGLY AGREE"]. Using this scale, for each of the statements, please tell me the extent to which you disagree or agree that the statement describes you.

B1) I always seem to be "re-hashing" in my mind recent things I've said or done.

B2) I don't waste time re-thinking things that are over and done with.

B3) Long after an argument or disagreement is over, my thoughts keep going back to what happened.
B4) I tend to "ruminate" or dwell on things that happen to me for a really long time afterward.

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B5) Often I'm playing back in my mind how I acted in a past situation.

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SECTION C
LIFE CHANGES

Now I'm going to ask you some questions about how M.E. has affected your life. Some people with M.E. report that the illness has changed many aspects of their life; sometimes for the better, sometimes for the worse, and sometimes for both the better and the worse.

C1) Has M.E. changed the way you think about yourself as a person?

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(a) Has the way you think about yourself changed for the better, for the worse, or for both the better and the worse?

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(b) How has the way you think about yourself changed?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
C2) Has M.E. changed the way you see the world, or life in general?

1. NO  
2. YES

(a) Has the way you see the world, or life in general, changed for the better, for the worse, or for both the better and the worse?

1. BETTER  
2. WORSE  
3. BETTER AND WORSE

(b) How has your view of the world changed?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

C3) Has M.E. changed your priorities in life?

1. NO  
2. YES

(a) Have your priorities in life changed for the better, for the worse, or for both the better and the worse?

1. BETTER  
2. WORSE  
3. BETTER AND WORSE

(b) How have your priorities in life changed?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
C4) Has M.E. changed your plans for the future?

1 NO [SKIP TO C5]  2 YES

(a) Have your plans for the future changed for the better, for the worse, or for both the better and the worse?

1 BETTER  2 WORSE  3 BETTER AND WORSE

(b) How have your plans for the future changed?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

C5) Were you in an intimate relationship when you first developed M.E.?

1 NO [SKIP TO C6]  2 YES

(a) Are you still in this relationship?

1 NO  2 YES
(b) How has your relationship with this person changed as a result of M.E.?

---

C6) Has M.E. changed your relationships with friends?

1. NO
   [SKIP TO C7]

2. YES

(a) Have your relationships with friends changed for the better, for the worse, or for both the better and the worse?

1. BETTER

2. WORSE

3. BETTER AND WORSE

(b) How have your relationships with friends changed?

---

C7) Has M.E. changed your relationships with family members?

1. NO
   [SKIP TO D1]

2. YES

(a) Have your relationships with family members changed for the better, for the worse, or for both the better and the worse?

1. BETTER

2. WORSE

3. BETTER AND WORSE
(b) How have your relationships with family members changed?


SECTION D
MEANING

D1) OK, now I'm going to ask you some questions about thoughts you may or may not have had with respect to your M.E. Have you ever found yourself going over in your mind the events that led up to your illness?

1 NO [SKIP TO D2]

2 YES

(a) What kinds of thoughts have you had?


D2) How difficult has it been for you to accept, or come to terms with, your illness? Has it been "not at all difficult," "a little difficult," "somewhat difficult," "quite difficult," or "very difficult"?

1 NOT AT ALL [SKIP TO SECTION E]

2 A LITTLE

3 SOMEWHAT

4 QUITE

5 VERY
(a) What would you say has been the most difficult part for you to come to terms with?


SECTION E
COUNTERFACTUALS

E1) People with M.E. sometimes think about how things might have turned out differently. In some instances, they may think of how things might have turned out better. For example, they might think, "If only something had been different, I might not have become ill, or things might not have been so bad." Over the past month or so, have you ever had thoughts of how things might have turned out better?

1 NO
[SKIP TO E2]  

X YES

How often have you had such thoughts? Would you say, "rarely," "sometimes," "often," or "almost always"?

2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

[SKIP TO E3]
E2) Since getting M.E., have you ever had thoughts about how things might have turned out better?

1 NO [SKIP TO E7, PAGE #14] 2 YES

E3) Please tell me what thoughts you’ve had about how things might have turned out better.

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

E4) Are there specific times or instances that trigger thoughts of how things might have turned out better?

1 NO [SKIP TO E5] 2 YES

(a) What are these things? ______________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
E5) [DON'T ASK THESE QUESTIONS IF RESPONDENT IS NOT IN AN INTIMATE RELATIONSHIP]
Now, back to your thoughts of how things might have been better -- have you ever discussed them with your partner?

1 NO [SKIP TO E6]  

2 YES

(a) What was your partner's reaction? ________________

(b) How did your partner's reaction make you feel? ____

E6) [DON'T ASK THESE QUESTIONS IF RESPONDENT IS NOT IN AN INTIMATE RELATIONSHIP]
With respect to your M.E., has your partner ever said anything to you that suggested that things might have turned out better?

1 NO [SKIP TO E7]  

2 YES

(a) What did your partner say? ________________________

(b) How did your partner's statements make you feel? _____

______________________________
E7) People with M.E. may also have thoughts about how things might have turned out worse. For example, some people might think, "At least such and such didn't happen to me" or "Even though I have M.E., it would have been worse if such and such had been different." Over the past month or so, have you ever had thoughts of how things might have turned out worse?

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How often have you had such thoughts? Would you say, "rarely," "sometimes," "often," or "almost always"?

| 2 | RARELY |
| 3 | SOMETIMES |
| 4 | OFTEN |
| 5 | ALMOST ALWAYS |

E8) Since getting M.E., have you ever had thoughts about how things might have turned out worse?

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[SKIP TO E9]

E9) Please tell me what thoughts you've had about how things might have turned out worse.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
E10) Are there specific times or instances that trigger thoughts of how things might have turned out worse?

1 NO [SKIP TO E11] 2 YES

(a) What are these things?

(b) What was your partner's reaction?

E11) [DON'T ASK THESE QUESTIONS IF RESPONDENT IS NOT IN AN INTIMATE RELATIONSHIP]
Now, back to your thoughts of how things might have been worse -- have you ever discussed them with your partner?

1 NO [SKIP TO E12] 2 YES

(a) What was your partner's reaction?

(b) How did your partner's reaction make you feel?
E12) [DON'T ASK THESE QUESTIONS IF RESPONDENT IS NOT IN AN INTIMATE RELATIONSHIP]

With respect to your M.E., has your partner ever said anything to you that suggested that things might have turned out worse?

1 NO
[SKIP TO F1] 2 YES

(a) What did your partner say?

(b) How did your partner's statements make you feel?

SECTION F
PERSONAL THEORIES

F1) There is little agreement among the public and even medical professionals regarding how M.E. develops. Nevertheless, some people with M.E. have one or more hunches or theories about the cause of their illness. Do you have any hunches or theories about what caused your M.E. to develop?

1 NO
[SKIP TO F2] 2 YES

(a) What are they?

(b) On a scale from 0 to 100 with 0 being "not at all confident" and 100 being "completely confident," how confident are you that your hunches are correct?

%
F2) [SHOW YELLOW SCALE “B” "NOT AT ALL IMPORTANT" TO "EXTREMELY IMPORTANT"]

Now I'm going to read to you some possible causes of M.E. Please look at this scale that ranges from "not at all important" to "extremely important," and tell me how important you think each of these things was in causing your M.E.?

(a) A viral infection.

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(b) A genetic predisposition.

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(c) Working in an environment with no fresh air.

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(d) Toxins.

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(e) Working too hard.

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(f) Worrying.

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(g) God or some other spiritual force.

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(g) Depression.

1 NOT AT ALL  2 SLIGHTLY  3 MODERATELY  4 QUITE  5 EXTREMELY

(i) Not doing enough exercise.

1 NOT AT ALL  2 SLIGHTLY  3 MODERATELY  4 QUITE  5 EXTREMELY

(j) Stress.

1 NOT AT ALL  2 SLIGHTLY  3 MODERATELY  4 QUITE  5 EXTREMELY

(k) Chance or pure coincidence.

1 NOT AT ALL  2 SLIGHTLY  3 MODERATELY  4 QUITE  5 EXTREMELY

F3) Some people with M.E. have one or more hunches or theories about how their M.E. might have been prevented. Do you have any hunches or theories about how your M.E. might have been prevented?

1 NO [SKIP TO F3b]  2 YES

(a) What are they? ..................................................................

..................................................................

..................................................................

..................................................................

..................................................................

..................................................................

..................................................................

..................................................................
(b) How often do you think about how your M.E. might have been prevented? Would you say that you "never think about it," "rarely think about it," "sometimes think about it," "often think about it," or "very often think about how it could have been prevented?"

| 1 | NEVER | 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | VERY OFTEN |

(c) How often do you think about how your M.E. might have been caused? Would you say that you "never think about it," "rarely think about it," "sometimes think about it," "often think about it," or "very often think about how it might have been caused?"

| 1 | NEVER | 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | VERY OFTEN |

F4) Some people with M.E. have said that, on a philosophical or spiritual level, they find themselves searching to make sense of, or find meaning in, their M.E. Have you done this in the past month or so?

| 1 | NO | [SKIP TO F5] | X | YES |

Have you done this "rarely," "sometimes," "often," or "almost always?"

| 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | ALMOST ALWAYS |

F5) Since getting M.E., have you ever done this?

| 1 | NO | [SKIP TO F7] | 2 | YES |

[SKIP TO F6]
F6) Have you been able to make any sense of, or find some meaning in, your M.E.?

1. NO
   [SKIP TO F7]

2. YES

(a) How have you done so?

(b) How comforted are you by the meaning you’ve found? Are you "not at all comforted," "somewhat comforted," "quite comforted," or "very comforted?"

F7) How difficult has this been for you? Has it been "not at all difficult," "somewhat difficult," "quite difficult," or "very difficult?"

1. NOT AT ALL
2. SOMEWHAT
3. QUITE
4. VERY

[SKIP TO F8]
IMPROVEMENT OR RECOVERY

F8) There is little agreement among medical professionals regarding how people recover from M.E. or whether or not they show improvement. Nevertheless, some people with M.E. have one or more hunches or theories. Do you have any hunches or theories about how your own improvement or recovery can be facilitated?

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(a) What are they?

SECTION G

CONTROLLABILITY

[SHOW RED SCALE "A" "STRONGLY DISAGREE" TO "STRONGLY AGREE"]

Now please look at this scale that ranges from "strongly disagree" to "strongly agree," and tell me how much you disagree or agree with each of these statements.

G1) When your symptoms worsen, it is your own behavior which determines how soon you will get better.

| 1 | STRONGLY DISAGREE | 2 | SLIGHTLY DISAGREE | 3 | NEUTRAL | 4 | SLIGHTLY AGREE | 5 | STRONGLY AGREE |

G2) If your symptoms are going to worsen, they will worsen, no matter what you do.

| 1 | STRONGLY DISAGREE | 2 | SLIGHTLY DISAGREE | 3 | NEUTRAL | 4 | SLIGHTLY AGREE | 5 | STRONGLY AGREE |
G3) Whenever your symptoms worsen, you consult a medically trained professional.

STRONGLY DISAGREE  Slighty DISAGREE  NEUTRAL  SLIGHTLY AGREE  STRONGLY AGREE

G4) You are in control of your symptoms.

STRONGLY DISAGREE  Slighty DISAGREE  NEUTRAL  SLIGHTLY AGREE  STRONGLY AGREE

G5) Your family has a lot to do with the number of symptoms that you experience.

STRONGLY DISAGREE  Slighty DISAGREE  NEUTRAL  SLIGHTLY AGREE  STRONGLY AGREE

G6) Luck plays a big part in determining when your symptoms improve.

STRONGLY DISAGREE  Slighty DISAGREE  NEUTRAL  SLIGHTLY AGREE  STRONGLY AGREE

G7) The main thing which affects your symptoms is what you yourself do.

STRONGLY DISAGREE  Slighty DISAGREE  NEUTRAL  SLIGHTLY AGREE  STRONGLY AGREE

G8) When your symptoms improve, it's usually because other people, such as doctors, nurses, family, or friends, have been taking good care of you.

STRONGLY DISAGREE  Slighty DISAGREE  NEUTRAL  SLIGHTLY AGREE  STRONGLY AGREE
G9) **You** have control over your daily symptoms, such as the amount of pain, fatigue, discomfort, and immobility you experience from day to day.

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G10) **You** have control over how well you cope psychologically with your illness.

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G11) **You** had control over whether or not you contracted M.E.

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G12) When your symptoms worsen, it is **your own** attitude which determines how soon you will get better.

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SECTION H
FORESEEABILITY

H1) Looking back now, do you think that you could have anticipated or predicted that you would contract M.E.? That is, do you think getting M.E. was "not at all predictable," "slightly predictable," "moderately predictable," "quite predictable," or "extremely predictable"?

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<td>NOT AT ALL</td>
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<td>MODERATELY</td>
<td>QUITE</td>
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(a) Why do you believe that you could have anticipated getting M.E.?

__________________________________________

__________________________________________

__________________________________________

__________________________________________

__________________________________________

H1b) Why do you believe that you could not have anticipated getting M.E.?

[SKIP TO H2]

H2) Was contracting M.E. inevitable in your particular case? That is, do you think it had to happen?

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<tr>
<td>NO</td>
<td>YES</td>
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SECTION J
MEDICAL PROFESSION

Now I'm going to ask you a few questions about traditional medical professionals, that is, general practitioners or specialists.

J1) What is the most helpful thing that a medical professional has said or done to you?


J2) What is the most unhelpful or upsetting thing that a medical professional has said or done to you?


J3) Is there anything that medical professionals could do to help you that they haven't done?

1 NO
[SKIP TO J4]

2 YES

(a) What sorts of things could they do?


J4) In general, how much do you think the medical professionals whom you have seen know about M.E.? "Very little," "a moderate amount," "quite a bit," or "a large amount?"

1 VERY LITTLE

2 A MODERATE AMOUNT

3 QUITE A BIT

4 A LARGE AMOUNT
J5) Thinking about all of the medical professionals that you’ve seen since you’ve been sick, to what extent do you think they behave as though you are responsible for your illness? “Not at all,” “slightly,” “moderately,” “quite,” or “extremely?”

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<th>NOT AT ALL</th>
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<th>SLIGHTLY</th>
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<th>4</th>
<th>QUITE</th>
<th>5</th>
<th>EXTREMELY</th>
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SECTION K
SUPPORT PROCESSES

For the rest of the questions in this interview, I would like you to please think about one person who knows you quite well. If you are married or in a relationship, please answer the questions with your partner in mind. Otherwise, please answer the questions with a "close other" in mind.

K1) Have you got a specific person in mind yet? [PAUSE FOR AFFIRMATIVE RESPONSE] Is this person male or female?

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<th>1</th>
<th>MALE</th>
<th>2</th>
<th>FEMALE</th>
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K1a) What relationship is this person to you? That person is your...

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<tr>
<th>1</th>
<th>SPOUSE</th>
<th>2</th>
<th>PARTNER</th>
<th>3</th>
<th>RELATIVE [SPECIFY RELATIONSHIP]</th>
<th>4</th>
<th>FRIEND</th>
<th>5</th>
<th>OTHER [SPECIFY]</th>
</tr>
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</table>

K1b) Does this person have M.E.?

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<th>1</th>
<th>NO</th>
<th>2</th>
<th>YES</th>
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K1c) [DON'T ASK IF THE PERSON IS A SPOUSE] How often do you see this person or talk with them?

_________ times per month

Now please answer the rest of the questions in the interview with your _________ in mind.
HELPFUL AND UNHELPFUL ACTIONS AND THEIR PRECIPITANTS

K2) [SHOW BLACK SCALE "C" "NEVER" TO "ALMOST ALWAYS" ] On this scale, with respect to your M.E., how often has your ______ said or done things that were especially helpful to you?

1
NEVER
[SKIP TO K3]

2
RARELY

3
SOMETIMES

4
OFTEN

5
ALMOST
ALWAYS

(a) What were these things? Please tell me one or two of the most helpful things that your ______ has said or done.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

(b) Think back to the most important time that you needed help from your ______. Please tell me what assistance you needed at that time. [PLEASE NOTE THAT IN ANSWERING THIS QUESTION, RESPONDENTS MAY ANSWER ONE OR BOTH OF THE NEXT TWO QUESTIONS. IF THEY DO, DON'T GET THEM TO ANSWER THE QUESTION(S) AGAIN.]

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

(c) Do you think that your ______ was aware that you needed his (her) help?

1
NO
[SKIP TO K3]

2
YES

(d) How do you think he(she) became aware that you needed his(her) help?

________________________________________________________________________
(e) Did your______ give you the help or support you needed?


K3) [SHOW BLACK SCALE “C” "NEVER" TO "ALMOST ALWAYS"] On this scale, with respect to your M.E., how often has your_______ said or done things that were unhelpful or that upset you?

| 1. NEVER [SKIP TO K4] | 2. RARELY | 3. SOMETIMES | 4. OFTEN | 5. ALMOST ALWAYS |

(a) What were these things? Please tell me one or two of the most unhelpful or upsetting things that your_______ has said or done.

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

(b) Why do you think your_______ said or did these unhelpful things?

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

(c) Think back to the most upsetting time that your_______ said or did unhelpful things. Do you think your_______ realized that his/her actions were unhelpful at the time, did he/she become aware of them later, or is he/she still unaware that his/her action was unhelpful?

| 1. AWARE AT THE TIME | 2. AWARE LATER | 3. STILL UNAWARE |

(d) How do you think your [blank] became aware that [his/her] action was unhelpful or upset you?

______________________________

______________________________

______________________________

(e) What do you think prevented your [blank] from acting in a way that you would have preferred?

______________________________

______________________________

______________________________

SOCIAL SUPPORT

K4) Now I am going to read you a list of things that your [blank] may have done or said to you. [SHOW BLACK SCALE “C” “NEVER” TO “ALMOST ALWAYS”]

Using this rating scale, please tell me how often, in the past six months or so, he/she has done or said each of the following things.

(a) How often has your [blank] given you advice; for example, told you what you should do?

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<td>SOMETIMES</td>
<td>OFTEN</td>
<td>ALMOST ALWAYS</td>
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(b) How often has your [blank] showed concern; for example, expressed interest or warmth?

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(c) How often has your [blank] told you that he/she knew exactly how you felt or that he/she knew exactly what you were going through?

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(d) How often has your _______ encouraged you to simply overcome the symptoms you were experiencing; for example, told you to "pick yourself up by your bootstraps" or "try harder?"

| 1 | NEVER | 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | ALMOST ALWAYS |

(e) How often has your _______ given you the chance to openly express your feelings; for example, listened or encouraged you to show your feelings?

| 1 | NEVER | 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | ALMOST ALWAYS |

(f) How often has your _______ supported you by his/her physical closeness or displays of affection and caring?

| 1 | NEVER | 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | ALMOST ALWAYS |

(g) How often has your _______ tried to minimize problems for you; for example said things like "It's not so bad" or "It could be a lot worse"?

| 1 | NEVER | 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | ALMOST ALWAYS |

(h) How often has your _______ tried to be cheerful about the situation; for example, smiled or acted in a cheerful manner?

| 1 | NEVER | 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | ALMOST ALWAYS |

(i) How often has your _______ stayed with you when you needed it; for example, spent extra time and paid more attention to you or made it clear that he/she was willing to do so?

| 1 | NEVER | 2 | RARELY | 3 | SOMETIMES | 4 | OFTEN | 5 | ALMOST ALWAYS |
(j) How often has your ________ offered you a philosophical reason for your M.E.; for example, said things like "There is a reason for everything that happens" or "It was just fate that this should happen"?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

(k) How often has your ________ offered you a religious reason for your M.E.; for example, said things like "It’s God’s will" or "God has a reason for everything"?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

(l) How often has your ________ talked about himself(herself) in an effort to steer attention away from your difficulties?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

(m) How often has your ________ helped you with day-to-day tasks; for example, helped you with housework or errands?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

(n) How often has your ________ acted as if your illness was much worse than you believed it was; for example, said things like "This is absolutely terrible?"

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

**FAILURE TO PROVIDE EFFECTIVE ACTIONS**

K5) In general, how often do you indicate to your ________ that you need his(her) help? Do you do this "never," "rarely," "sometimes," "often," or "very often?"

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 VERY OFTEN
K6) Are there things that your _____ could do to help you that he/she hasn't done?

1. NO
   [SKIP TO SECTION L]

2. YES

(a) What are these things?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(b) Why do you think your _____ hasn't done these things?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

SECTION L
EFFECTIVENESS

L1) How effective do you think your _____ has been in helping to reduce your level of distress? Do you think he/she has been "not at all effective," "slightly effective," "moderately effective," "very effective," or "extremely effective"?

1. NOT AT ALL
2. SLIGHTLY
3. MODERATELY
4. VERY
5. EXTREMELY

L2) [SHOW BLACK SCALE "C" "NEVER" TO "ALMOST ALWAYS"] Now I am going to ask you several questions that I would like you to answer on this scale, ranging from "never" to "almost always." How often do you think that your _____ believes he/she is helpless to reduce your distress?

1. NEVER
2. RARELY
3. SOMETIMES
4. OFTEN
5. ALMOST ALWAYS
L3) How often do you think your ________ has been so worried about responding inappropriately that he/she has been ineffective in providing help?

| 1 | NEVER |
| 2 | RARELY |
| 3 | SOMETIMES |
| 4 | OFTEN |
| 5 | ALMOST ALWAYS |

SECTION M
CONFIDING

M1) How often have you felt that you could not share negative feelings such as sadness or anger with your ________?

| 1 | NEVER |
| 2 | RARELY |
| 3 | SOMETIMES |
| 4 | OFTEN |
| 5 | ALMOST ALWAYS |

M2) After developing M.E., different people react in different ways. For example, some people want to talk about what has happened to them, whereas others do not. [SHOW BLACK SCALE “C” “NEVER” TO “ALMOST ALWAYS”]. Please use this rating scale, and answer according to how you have felt or thought in the past month or so.

(a) How often have you wanted to talk with your ________ about your illness or about your coping with it?

| 1 | NEVER |
| 2 | RARELY |
| 3 | SOMETIMES |
| 4 | OFTEN |
| 5 | ALMOST ALWAYS |

(b) How often have you felt that you could discuss your feelings about your M.E. with your ________ if you wanted to?

| 1 | NEVER |
| 2 | RARELY |
| 3 | SOMETIMES |
| 4 | OFTEN |
| 5 | ALMOST ALWAYS |

(c) How often have you felt as though you had to keep your feelings about your M.E. to yourself because they made your ________ uncomfortable?

| 1 | NEVER |
| 2 | RARELY |
| 3 | SOMETIMES |
| 4 | OFTEN |
| 5 | ALMOST ALWAYS |
(d) How often have you actually talked to your ________ about your M.E.?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

(e) How often has your ________ discouraged you from discussing issues related to M.E.?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

(f) When you talked about your M.E., how often did your ________ give you the idea that he(she) didn't want to hear about it?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

(g) When you talked about your M.E., how often did your ________ respond with support and understanding?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

SECTION N

RELATIONSHIP SATISFACTION

N1) How often do you think that things between you and your ________ are going well?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

N2) How often do you and your ________ quarrel?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS
N3) [DON'T ASK THIS QUESTION IF RESPONDENT IS NOT IN AN INTIMATE RELATIONSHIP]
How often do you discuss or consider divorce, separation, or break-up?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

SECTION P
ALTERING PRESENTATION OF SYMPTOMS

[SHOW BLACK SCALE “C” "NEVER" TO "ALMOST ALWAYS" FOR P1 TO P3]

P1) Some people with M.E. have told us that at times they say or do things that indicate to others that they are doing better or worse than they actually are. For example, they may minimize symptoms they have been experiencing so as not to overwhelm others or scare them away. Using this scale, how often have you tried to hide your symptoms, or "put on a happy face" for your ?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

P2) Some people with M.E. have told us that others often underestimate what they are going through or don't seem to accept the fact that they are having difficulties due to the illness. Then, the person with M.E. finds that they need to overstate things in order to be taken seriously by others. Using this scale, how often have you made your symptoms appear worse than they really were for your ?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS

P3) And finally, some people with M.E. have told us that, regardless of the response from others, they tell people what is on their mind. This may include mentioning every symptom they are experiencing or saying that they are feeling well when that is the case. Using this scale, how often have you tried simply to present your symptoms accurately to your ?

1 NEVER  2 RARELY  3 SOMETIMES  4 OFTEN  5 ALMOST ALWAYS
SECTION Q

ADVICE

Q1) And my final question is, if you were to give some advice to someone coping with M.E., what would it be?

__________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

OK, that's the last interview question that I have. Is there anything else related to your M.E. that you would like to discuss?

__________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

Is there anything about the study that I could answer for you now? [IF YES, ANSWER THEM--ANSWER IN AS MUCH DETAIL AS POSSIBLE WITHOUT GIVING THEM ANY INFORMATION THAT MAY CONTAMINATE THEIR RESPONSES TO FUTURE QUESTIONS. TELL THEM THAT WE WOULD BE HAPPY TO DISCUSS ANYTHING IN DETAIL WITH THEM ONCE THEIR PARTICIPATION IS COMPLETED. IF THERE ARE ANY QUESTIONS THAT YOU ARE UNABLE TO ANSWER, REMIND THEM THAT THEY MAY CONTACT THE PROJECT OFFICE FOR FURTHER INFORMATION]

FURTHER INSTRUCTIONS FOLLOWING INTERVIEW:

Here is the brief questionnaire that we would like you to complete at your leisure in the next couple of days. It is extremely important for us to get your responses to these questions as well. Without them, we will be missing much important information that is necessary for us to make sense of what you have told us in the interview. After you have completed the
questionnaire, which should take about 20 minutes or so, please mail it in this self-addressed stamped envelope.

Here is a second questionnaire ["CLOSE OTHER QUESTIONNAIRE"] for you to give to your [CLOSE OTHER]. This is the same person that you had in mind when you answered the questions at the end of the interview. Please ask this person to read the information that is included in the package and to feel free to call us if there are any questions before completing the questionnaire. Their package also includes a self-addressed stamped envelope. If this person would prefer not to participate in the study, we would be grateful if you would give the package to someone else who knows you quite well who would be willing to complete the questionnaire instead.

We can't tell you how much we appreciate the time that you have taken to be a part of this study. If, at any point in the future, you have any questions, please feel free to call us. Thank you very much for participating.

INTERVIEWER: ________________________________

INTERVIEW END TIME: _______________________

R1) RESPONDENT’S GENDER:

1 MALE

2 FEMALE

R2) INTERVIEWEE APPEARED VERY TIRED:

1 NEVER

2 RARELY

3 SOMETIMES

4 OFTEN

5 ALMOST ALWAYS
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<th>R3) INTERVIEW HAD TO BE INTERRUPTED AT RESPONDENT'S REQUEST:</th>
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<th>R4) INTERVIEWEE CRIED DURING THE INTERVIEW:</th>
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<td>1 NEVER</td>
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<th>R5) INTERVIEWEE LAUGHED DURING THE INTERVIEW:</th>
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<th>R6) RESPONDENT'S RACIAL OR ETHNIC GROUP IS:</th>
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<td>1 CAUCASIAN</td>
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<th>R7) OTHER PERSONS PRESENT AT INTERVIEW:</th>
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<td>1 NONE</td>
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PARTICIPANT WITH M.E. QUESTIONNAIRE

We greatly appreciate your time and the important information that you have provided concerning your experiences with Myalgic Encephalomyelitis (M.E.). We have a few more questions regarding symptoms that you may experience and the ways in which you view yourself. Because these questions will go much faster by you answering them on your own, rather than in the interview, we have put them together in this brief booklet.

These questions are crucial because they allow us to get a more complete sense of your experience with M.E. Without your responses to these questions, we will be missing much important information that is necessary for us to make sense of what you have told us in the interview. Please note that the questionnaire is printed on both sides of the pages. When you are finished, please put the completed questionnaire in the self-addressed stamped envelope that is provided, and place the package to be sent to our project office in a mailbox.

It is our hope that this study will benefit people with M.E., their close others, and health care providers. We thank you in advance for your continued cooperation and time. Your contribution to our understanding of this significant illness cannot be overestimated.
M.E. SYMPTOM CHECKLIST

Below is a list of symptoms that you may experience. Using the following scale, please answer each question according to how frequently you have experienced the symptom in the past month. Put the number (for example, "1" for never, "2" for rarely, and so on) that best fits your situation in the space to the left of the statement.

For example, consider the symptom Headaches. If you have not experienced any headaches in the past month, you would write the number "1" beside the item. If, on the other hand, you have often experienced headaches, you would write "4" next to the symptom, and so on. Please fill in each space with only one number.

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<thead>
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<th>1</th>
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<th>RARELY</th>
<th>3</th>
<th>SOMETIMES</th>
<th>4</th>
<th>OFTEN</th>
<th>5</th>
<th>ALMOST ALWAYS</th>
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1) Fatigue
2) Reduced clarity or clearness of vision
3) Seizures
4) Numb or tingling fingers
5) Difficulty with balance
6) Lightheadedness - feeling "spaced out"
7) Unusual nightmares
8) Difficulty moving tongue to speak
9) Ringing in ears
10) Paralysis
11) Blackouts
12) Intolerance of light
13) Intolerance of alcohol
14) Alteration of taste, smell, or hearing
15) Not feeling rested even after sleep that would have been adequate before you got M.E.
16) Decreased sex drive
17) Twitching muscles
18) Recurrent flu-like illnesses
19) Nasal and other allergic reactions
20) Weight change
21) Abdominal pain, diarrhea, or intestinal gas
22) Night sweats
23) Rapid or irregular heart beat
24) Stiffness
25) Excessive urination at night
26) Exaggerated sensations (such as burning, pricking, etc.)
27) Loss of appetite
28) Finger swelling
29) Dizziness
30) Nausea
31) Dry eyes
Never RARELY Sometimes OFTEN ALMOST ALWAYS

1 2 3 4 5

32) Dry mouth
33) Cough
34) Word finding problems
35) Sore, aching muscles
36) Muscle weakness
37) Sore joints
38) Eye pain
39) Weak bladder
40) Food allergies
41) Digestive problems
42) Worsening of premenstrual symptoms

BSI

Please put a number to the left of each item that best describes how much that problem has bothered or distressed you in the past month. Please mark only one number for each problem.

1 NOT AT ALL  2 SLIGHTLY  3 MODERATELY  4 QUITE A BIT  5 EXTREMELY

1) Nervousness or shakiness.
2) Faintness or dizziness.
3) Pains in heart or chest.
4) Thoughts of ending your life.
5) Suddenly scared for no reason.
6) Feeling lonely.
7) Feeling blue.
8) Feeling no interest in things.
9) Feeling fearful.
10) Your feelings being easily hurt.
11) Nausea or upset in stomach.
12) Trouble getting your breath.
13) Hot or cold spells.
14) Numbness or tingling in parts of your body.
15) Feeling hopeless about the future.
16) Feeling weak in parts of your body.
17) Feeling tense or keyed up.
18) Spells of terror or panic.
19) Feeling so restless you could not sit still.
20) Feelings of worthlessness.
BFI-44

Use the spaces to the left to describe yourself as accurately and honestly as possible using the following descriptions. Answer according to how you view yourself right now. Consider the first example: I see myself as someone who... “is talkative.” If you strongly agree, you would put a “5” next to Item #1. If you strongly disagree, you would put a “1” next to Item #1. If you disagree a little, you would put a “2,” etc.

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I see myself as someone who...

1) is talkative
2) tends to find fault with others
3) does a thorough job
4) has a wide range of interests
5) is depressed, blue
6) is original, comes up with new ideas
7) is reserved
8) is helpful and unselfish with others
9) can be somewhat careless
10) is relaxed, handles stress well
11) is curious about many different things
12) is full of energy
13) starts quarrels with others
14) is a reliable worker
15) can be tense
16) tends to be quiet
17) values artistic, aesthetic experiences
18) tends to be disorganized
19) is emotionally stable, not easily upset
20) has an active imagination
21) perseveres until the task is finished
22) is sometimes rude to others
23) is inventive
24) is generally trusting
25) tends to be lazy
26) worries a lot
27) is sometimes shy, inhibited
28) has a forgiving nature
29) does things efficiently
30) can be moody
31) is ingenious, a deep thinker
32) generates a lot of enthusiasm
33) can be cold and aloof
34) makes plans and follows through with them
35) remains calm in tense situations
36) likes to reflect, play with ideas
37) is considerate and kind to almost everyone
38) gets nervous easily
39) is sophisticated in art, music, or literature
40) has an assertive personality
41) likes to cooperate with others
42) is easily distracted
43) is outgoing, sociable
44) has few artistic interests
SAS-C

People respond in various ways when a close other is in need of help or support. In answering the questions that follow please try to be as accurate as possible in assessing how your close other has responded to you. Please think about the types of things your close other has said or done since the onset of your illness.

For each of the items listed please indicate how often your close other has performed these particular behaviors and write the number that best corresponds to your answer in the space next to that item.

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<tr>
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<td>OFTEN</td>
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My close other...

_____ 1) told me how much he felt for my situation.
_____ 2) told me to let him deal with things.
_____ 3) helped in a way that didn’t get him personally involved.
_____ 4) made decisions for me.
_____ 5) encouraged me to consider his insights.
_____ 6) told me how much he has admired my ability to cope in the past.
_____ 7) told me that nobody likes a “cry-baby”.
_____ 8) silently listened to me for as long as I wanted him to.
_____ 9) persuaded me to change my behavior.
_____10) told me I came to the right person.
_____11) didn’t make himself too available.
_____12) didn’t argue with me.
_____13) enthusiastically helped out.
_____14) suggested that others had more serious problems than I did.
_____15) tried to keep me from leaning on him too much.
_____16) refrained from any criticism.
_____17) if necessary, argued for a better course of action.
_____18) reminded me that he has successfully overcome worse problems.
_____19) just listened quietly.
_____20) gave me a hug.
_____21) asked questions to help me find answers.
_____22) remained detached while listening to my problem.
_____23) did his best to protect me.
_____24) told me to let him help with my problem.
_____25) questioned how serious my problem really was.
_____26) felt that any help he could offer would probably make things worse.
_____27) told me that he was in a good position to help me.
My close other...

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28) told me explicitly what to do, step-by-step.
29) got me to talk more about my problem.
30) told me that his advice is usually not that good.
31) just tried to be there.
32) took control of the situation.
33) didn't intrude on my problem.
34) reminded me that people sometimes get what they deserve.
35) avoided influencing my course of action.
36) avoided challenging my point of view.
37) told me that I had to learn to live with it.
38) was afraid to express his point of view on the problem.
39) told me that he didn’t want to get involved.
40) told me that he wasn’t surprised that I had these problems.
41) tried to stop me from talking about my problem.
42) checked up on me frequently.
43) avoided suggesting a course of action for fear of giving the wrong advice.
44) was an attentive listener.
45) took over any matters he felt I couldn’t deal with.
46) told me that I needed to discuss my problem openly.
47) let me know that he believed I would make the right decisions.
48) reassured me that he would stick with me through all of this.
49) helped in ways that did not take up too much of his time.
50) avoided giving any advice.
51) avoided being directive.
52) kept me company.
53) was careful not to pressure me.
54) avoided intruding on my problem.
55) told me that he was worried about me.
56) told me that he had his own problems to deal with.
57) told me the best way to deal with things.
58) told me I had to cope on my own.
59) advised me to take advantage of the resources he could provide.
60) emphasized how well qualified he was to help.
61) avoided trying to change my view of the situation.
Fill in the blank before each statement with the number that best describes how you thought most of the time **before you got M.E.**

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1) If I didn't set the highest standards for myself, I felt I was likely to end up a second-rate person.

2) People would probably think less of me if I made a mistake.

3) If I could not do something really well, there was little point in doing it at all.

4) I would be upset if I made a mistake.

5) If I tried hard enough, I felt I should be able to excel at anything I attempted.

6) It was shameful for me to display weaknesses or foolish behaviour.

7) I felt I shouldn't have to repeat the same mistake many times.

8) An average performance was bound to be unsatisfying to me.

9) Failing at something important meant I was less of a person.

10) If I scolded myself for failing to live up to my expectations, I thought it would help me to do better in the future.

**DEMOGRAPHICS**

These last four questions are being asked for statistical purposes only.

1) When were you born? ________________ (day/month/year)

2) Please circle the highest grade of school or year of post-secondary education that you have completed?

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3) Taking into consideration all sources of money, approximately what was your personal income in 1994?

(1) LESS THAN $10,000

(2) $10,000 - $19,999

(3) $20,000 - $29,999

(4) $30,000 - $39,999

(5) $40,000 - $49,999

(6) $50,000 - $59,999

(7) MORE THAN $60,000

4) Taking into consideration all sources of money, approximately what was your personal income just before onset of your M.E.?

(1) LESS THAN $10,000

(2) $10,000 - $19,999

(3) $20,000 - $29,999

(4) $30,000 - $39,999

(5) $40,000 - $49,999

(6) $50,000 - $59,999

(7) MORE THAN $60,000

We can’t tell you how much we appreciate the time that you have taken to be a part of this study. If you have any questions about the project, please feel free to call us. Thank you very much for participating.
Appendix 7

Reminder Letter

September 11, 1995

NAME
ADDRESS
Vancouver, BC
POSTAL CODE

Dear Participant:

Thank you, once again, for taking part in our study on coping with Myalgic Encephalomyelitis (M.E.). We recently completed all of our interviews; over 100 individuals with this important illness took part. Your participation has been invaluable, and will enable people to learn more about M.E.

Full participation in the study involves completion of an interview and two short questionnaires (one by yourself, and one by a close other). The information collected from these questionnaires is as important as that collected from the interview. Without it, we will have difficulty making sense of your interview responses.

According to our records, we do not have a complete package from you. This means that either the M.E. questionnaire, the close other questionnaire, or both, have not been received at our project office. In case the materials were misplaced, we have enclosed additional copies of the questionnaire(s), which may be sent back to the project office in the self-addressed envelope that is enclosed. If you and your close other have already completed these materials, they have probably been delayed in the mail, and should come to our project office shortly.

It is important for us to get information from someone who knows you quite well so that we may compare responses of people who have M.E. with those provided by their close others. If, for whatever reason, the close other you chose to fill in the questionnaire has decided not to participate in the study, please pass their questionnaire on to someone else who knows you quite well, and who would be willing to complete the questionnaire.

We expect to complete our coding and statistical analyses within a short time, and compile our findings into summary form within six months to one year, at which
time we will send you an overview of our findings. We will also inform the scientific community of our results by publishing them in journals.

Thank you for your consideration of this request. If you have any questions, or require additional information, feel free to call Dr. Darrin Lehman (Project Director) or Mr. Kenneth Hemphill (Project Coordinator) at our project office: (604) 822-2613.

Best wishes,

Kenneth Hemphill, M.A.
Doctoral Candidate

encls.