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**THE INFORMATION NEEDS AND INFORMATION-SEEKING PATTERNS
OF WOMEN COPING WITH AND ADJUSTING TO
MULTIPLE SCLEROSIS**

by

Lynda M. Baker

Graduate School of Library and Information Science

Submitted in partial fulfilment
of the requirements for the degree of
Doctor of Philosophy

**Faculty of Graduate Studies
The University of Western Ontario
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ABSTRACT

Multiple sclerosis (MS) is a chronic neurological disease with an unpredictable course and not known cause or cure. Coping strategies of people with MS may therefore yield insights into information-seeking patterns. This study of information preferences was based on Miller's (1980) theory of information-seeking, which states that some people (monitors) cope by actively seeking information, while others (blunters) reject information. In this study, 251 female MS clinic patients were classified through the Miller Behavioral Style Scale (MESS) as either monitors or blunters and by the length of time since diagnosis. It was hypothesized that monitors (in contrast to blunters) would be more interested in information regardless of phase of the disease, format or specificity of information. In Part One of this study, 160 women completed a mail survey designed to assess their interest in and desire for information on 29 topics relevant to MS, as well as the preferred formats of this information. The results revealed that monitors expressed preferences for more information than did blunters in earlier phases of the disease, while blunters became interested and wanted information in later phases of the disease. Videos, magazines, pamphlets and books were the most preferred formats for information on multiple sclerosis. Physicians and spouses were the most common human resources, though preferences varied with topic and format. In Part Two, an additional 93 women with MS, also classified as monitors or blunters were asked to assess a general or a specific pamphlet on one of two topics (fatigue or treatment of acute attacks). More monitors than blunters rated the pamphlet they had received as relevant, regardless of the specificity of information. This study contributes to the development of a methodology for studying information-seeking patterns and suggests that information providers (e.g., MS societies, health care professionals and librarians) may need to consider general orientation to information as well as phase of the disease in order to meet the information needs of women with MS.

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CHAPTER 1

INTRODUCTION, LITERATURE REVIEW and PROBLEM STATEMENT

Multiple sclerosis (MS), a chronic inflammatory disease of the central nervous system, affects many people in the colder climates of the world. Scientific and medical research on this disease has been extensive since the mid-nineteenth century when Charcot first identified its clinical and pathological features (McFarlin & McFarland, 1982). Although the cause of MS has mystified scientists and physicians for many years, current research seems to support the theory that MS is an autoimmune disease, that is, a disease in which an individual's immune system attacks the self (Steinman, 1993). Although no cure has yet been found, promising treatments are emerging, such as Beta interferon, a drug which has been found to reduce exacerbation rates significantly, as well as the severity of the exacerbations in people with relapsing-remitting MS (The IFNB Multiple Sclerosis Study Group, 1993, p. 655; Multiple Sclerosis Society of Canada, 1993, p. 4). The lack of firm medical and scientific knowledge about the disease creates a series of problems for medical practitioners such as elusive diagnosis and a lack of certainty with respect to the particular form of the disease and its prognosis. In addition, treatments can be aimed only at relieving symptoms, not curing the disease. For people with MS, the ramifications of this lack of knowledge can be severe. The diagnostic process may be long and fraught with frustration. Uncertainty becomes a major factor in their lives, since the prognosis and outcome cannot be determined. Furthermore, these people face social problems including isolation, loss of identity and self esteem; economic problems arising from changes in career aspirations, loss of employment and medical expenditures; and psychological burdens such as shame, guilt, humiliation and fear. Register (1987) stated that fear of the unknown, or uncertainty, is "the single most frightening feature of chronic illness" (p. 183). This may be particularly true for people with MS.

For the library and information scientist interested in the role of information in disease and health, MS provides an opportunity for studying that role in the process of coping and adjusting to a chronic disease, replete with uncertainty from the pre-diagnosis period through the course of the disease. The purpose of this research was to assess the general orientation to information of women in three different time periods of the disease process, in an attempt to understand how their orientation to information affected their information needs in each of these phases.

Overview of Multiple Sclerosis

Multiple sclerosis, a debilitating neurological disease, damages the insulation or myelin sheath that surrounds the nerve fibers in the brain and the spinal cord. This myelin sheath is a fatty substance that enhances "the velocity with which nerve impulses are conducted along the fibers" (Whitaker, 1987, p. 14). Where the sheath is destroyed, hardened plaques of varying sizes form and the resulting symptoms correspond with the location of these lesions in the central nervous system (CNS). The plaques cause a slowing or the complete obstruction of the nerve impulses and thus "any nervous system activity (such as vision, strength, sensation and coordination) is diminished or lost" (Whitaker, 1987, p. 13).

MS is a chronic disease that strikes women more than men, affects Caucasians more than other racial groups, and is predominant in colder climates north and south of the equator. According to the MS Society of Canada (MSSC), over 50,000 Canadians have MS, while the U.S. National Multiple Sclerosis Society (NMSS) estimates the number affected at 250,000. Although cases have been reported in both younger and older age groups, MS usually strikes adults between the ages of 20 and 40.

The Diagnostic Process

Multiple sclerosis is a complicated disease to diagnose. One reason for this is that the onset is insidious and the symptoms can be erratic and vague. Since the initial symptoms may be fleeting, patients often delay seeking medical advice. Instead, they ignore their symptoms or attribute them to some other cause such as the flu, overwork, or injuries. When they finally do seek medical help, they frequently encounter physicians who cannot find any physical basis for their symptoms (Davis, 1973). Many physicians, including neurologists (i.e., specialists in diseases of the nervous system), have little experience with MS and very often misdiagnose the disease (Poser & Aisen, 1987). Consequently, a confirmed diagnosis of MS may take years. During this time, patients often become frustrated upon hearing that their symptoms are not indicative of a disease or after receiving treatments that do not alleviate their problems. They often engage in "physician shopping" hoping to find a physician astute enough to interpret their symptoms or they turn to other sources to find their own answers (Robinson, 1988).

A diagnosis of MS is dependent upon both the patient's history and a series of neurological tests documenting the presence of lesions. The physician must delve into the patient's history to discover prior problems and symptoms that may be indicative of MS. However, meticulous history-taking is a time- and labour-intensive task and often is not undertaken in a busy family practice setting. In addition to providing a history, the patient must undergo a series of neurological tests. These tests may include a lumbar puncture (a painful procedure used to obtain cerebrospinal fluid from the spinal cavity), evoked visual or auditory response studies (a recording is made of the electrical responses from the cerebral cortex), and a computer tomography scan (a radiologic technique for generating an image of the tissue density in slices approximately one centimetre thick). Most of these tests are inconclusive. However, since 1982, magnetic resonance imaging (MRI), a scanning technique powerful enough to detect very small lesions in the CNS, has been used in the diagnosis of MS. By 1987 the use of MRI as a

diagnostic tool for this disease had received support in the medical literature, since it provides clear evidence of plaques in the brain and spinal cord (Poser & Aisen, 1987). Unfortunately, not all patients are able to benefit from this diagnostic tool. For example, in Canada, there are very few MRI scanners and some of these are dedicated exclusively to research (Multiple Sclerosis Society of Canada, 1991). In the U.S., accessibility to MRI scanners is not a problem as they are available throughout the country (National Multiple Sclerosis Society, 1989); however, costs can be prohibitive (MRI scans range from \$500 to \$1000 per patient). As a result, many physicians are reluctant to order a scan early in the diagnostic process, using, instead, the more inconclusive tests. Poser and Aisen (1987) explained this behaviour, noting that "it is often more valuable and certainly less expensive simply to observe the patient over a period of weeks or even months than to perform a series of diagnostic procedures that in the early stages of the disease may only indicate that some central nervous system disease is present" (p. 30). An obvious disadvantage of this approach, however, is that it perpetuates uncertainty for the patient with MS.

Uncertainty Factors Associated with MS

One thing that is clear about MS is that uncertainty permeates nearly every aspect of this disease. As will become evident in the following sections, one finds uncertainty not only in the diagnostic process, but also in the course and prognosis or outcome of the disease, as well as in the absence of any specific form of treatment. Further, the incomplete medical knowledge about MS perpetuates the public's ignorance about this disease.

Diagnosis. Since most of the diagnostic tests are inconclusive, some patients never receive a confirmed diagnosis of MS, especially when a MRI scan is not done. Furthermore, it appears that physicians are still debating whether a person suspected of having MS should be informed before a definitive diagnosis is available. Mooney,

Mushlin and Phelps (1990) used a cost benefit analysis model to study the dilemma of when to inform patients. They recommended immediate use of MRI when "the quality of life for waiting equals [emphasis added] the quality of life while labelled as having MS" (p. 86). Although the benefit may be small, they emphasized that the physician must weigh the value of reassuring people with a negative diagnosis with the anxiety caused by providing a positive diagnosis. They are continuing to study "the value that patients [emphasis added] place on earlier diagnosis ...to assess the impact of the diagnostic information on their well-being" (p. 90).

Course and prognosis of the disease. In addition to the uncertainties involved in diagnosing MS, the course of the disease varies, making a patient's prognosis impossible to determine. To date, four basic patterns of disease development have been identified:

a) benign: Approximately 20% of people with MS exhibit this form of the disease, wherein the exacerbations are few and they are followed by complete or nearly complete recovery. Exacerbations are defined as "the sudden or relatively sudden onset of new symptoms that last for at least one day" (Scheinberg & Smith, 1987, p. 50).

b) relapsing/remitting: This pattern, affecting 25% of the MS population, is similar to the benign, except that patients may experience some symptoms such as weakness or imbalance during the exacerbations. Again, recovery tends to be complete or nearly complete.

c) relapsing/progressive: Forty percent of people with this disease have clear-cut attacks or exacerbations from which recovery is incomplete, leading to moderate to severe disability and significant reductions in their activities.

d) chronic progressive: Although this is the most severe pattern of MS, only 15% of the people are afflicted with this progressive form of the disease, which is characterized by unclear exacerbations and no remissions. In other words, the symptoms continue to worsen, causing a steady decline in functional ability. Severe disability can occur in a short period of time.

At diagnosis, the pattern of disease that will develop cannot be determined. Thus, the course and prognosis of MS are unpredictable making it unlike other chronic diseases such as Alzheimer's or rheumatoid arthritis. Because people with multiple sclerosis have no idea how the disease will affect them, they cannot undertake any definite emotional or physical preparation for what is to come. Instead, people with MS live in a constant state of uncertainty.

General lack of knowledge. Another source of uncertainty arises from the public's general lack of knowledge about MS. In 1973, Davis observed that MS was not a disease familiar to the public, "so that when patients are told of this diagnosis, many have very little understanding of what it is they have or what might be in store for them in the future" (p. 8). Four years later, Cunningham (1977) reiterated the same theme. For example, when the Canadian and American MS societies mount their campaigns for research money, the advertisements usually portray a person with the disease sitting in a wheelchair. The reason for this is that compassion for victims is viewed as an essential component of fund raising. However, as noted above, very few (15%) people with MS become wheelchair bound. As a result, the public often receive a limited and somewhat distorted view of the disease.

One measure of the level of public awareness of any disease is the degree to which the media focus attention on particular problems. In an effort to test this, an online search of the periodical database MAGAZINE INDEX was conducted to determine the frequency with which articles about MS appear in popular magazines, such as Prevention, Health, Newsweek, Good Housekeeping, Science, Scientific American, and Science News. Over a period of approximately 28 years, only 200 articles on MS appeared in popular magazines; a small number when compared with 6119 articles on cancer, 671 on hypertension and 754 on diabetes mellitus that appeared in the same magazines over the same time period. Of the 200 articles on MS, many were devoted to the ways that various celebrities coped with the disease, as well as to new discoveries of

therapies or medications for MS. Thus, it would seem that, in comparison with other diseases, the general public receives considerably less information about MS through the mass media. Despite this lack of general knowledge, both Robinson (1988) and Stewart and Sullivan (1982) reported that people have used these sources to diagnose themselves by comparing their symptoms with those reported in these magazines.

Interestingly, very little research has looked at the content of information on MS available to the public. Therefore, it is not clear how material on multiple sclerosis, published by the MS societies or appearing in popular publications, affects people in either the pre- or the post-diagnostic periods. Further, the type and amount of information that patients want has yet to be determined. In 1984, Simons warned that the literature available on MS may cause "preparatory depression" or anxiety in newly diagnosed patients because it portrays possible future losses, such as career and family goals, as well as current losses. He also noted that "the person with MS is also made aware through the literature of the lack of certainty in MS prognosis and the fact that he is not expected to develop all these symptoms. It is...this lack of certainty that causes many of the worst reactions through the fear of getting all the possible symptoms" (p. 4). For example, some of the introductory publications of the Multiple Sclerosis Society of Canada and the National Multiple Sclerosis Society (U.S.) contain information on the many problems that can affect the MS person. Given Simons's findings, it is plausible that the inclusion of so much material in these publications may actually increase anxiety and fear, especially in newly diagnosed patients.

Medical treatment. Two medically-related factors contribute to the problem of uncertainty in MS. The absence of any "cure" for the disease does little to alleviate an already uncertain future for people with multiple sclerosis. Instead, the disease is treated symptomatically with medications that may or may not be effective. The second factor, especially for Canadian patients with MS, involves the new drug Beta interferon. While this drug may be available for use in the United States in 1994, it may be years before

most Canadian patients will have access to it, as the drug company who will be manufacturing and supplying it "is just about to submit" the necessary paper work to the Health Protection Branch of the Canadian government to obtain approval for use of the drug in Canada (Multiple Sclerosis Society of Canada, 1993, p. 4). Thus, the uncertainty continues for Canadian patients who are left wondering if they will be in the "ideal" condition to receive this drug when it becomes available in this country.

Summary

To summarize, MS can be seen as a continuous stressful situation from the first onset of symptoms. For the patient and the physician, diagnosis can be a long, difficult, and frustrating experience. No cure exists, thus compounding the stress. The course and the prognosis are beyond the limits of medical and scientific knowledge. Finally, it is possible that some of the information made available to people with MS may actually increase rather than reduce their level of anxiety.

The Role of Information in Coping and Adjusting to Stressful or Uncertain Events: A Review of the Literature

This section will introduce two general theories about how people manage stress or uncertain life events and the role that information plays in the process of coping. Some comparisons to MS will be made where relevant; however, coping specifically with MS will be discussed in more depth in the next section.

People encounter stressful events at various points in their lives. To deal with these events, many employ different coping and adjusting techniques so that the stress does not consume them. In other words, they use some method to maintain a sense of balance in their lives. The coping and adjusting process has attracted the attention of

researchers from many different disciplines. One theory suggests that people evaluate each stressful event encountered and react accordingly. Stress is seen as a bidirectional, continually changing interaction between the person and her/his environment and thus, should be studied "in the particular person-environment relationship in which it is embedded" (Folkman, 1984, p. 840). The other theory proposes that people develop a standardized or characteristic style of responding and, therefore, behave similarly each time a stressor is encountered (Miller, 1980). The role that information plays in these theories is quite interesting and will be examined more fully below.

The Non-Standardized Approach

How a person responds to a stressful encounter depends on the situation and on her/his ability to cope with it at that time. Since no standardized way of coping exists, what a person finds stressful at one point in her/his life may not be stressful at another. The reason for the different responses at different times involves the appraisal process. People appraise every novel situation they encounter and based on their appraisal, decide first if, and then how, they can cope with it. Appraisal is a "mediating cognitive process allowing the individual to distinguish between something potentially harmful from something potentially beneficial" (Lazarus, Averill & Opton, 1974, p. 259). This process gives the person time to process the information, judge the relevance of the situation to her/his well-being and then decide on the coping strategy that "is most nearly suited to the complex geometry of costs and gains" (p. 291). When the necessary experience or knowledge to cope with a particular situation is missing, stress results. According to Lazarus and Folkman (1984), "the degree of stress depends mainly on the appraisal of how much appears to be at stake in the transaction...and the relative power of the environmental demand to do harm, compared with the power of the person to prevent or manage such harm" (p. 290). It is through the appraisal process that the person determines how her/his own resources measure up to the demands of the stressful

situation and ultimately how much control she/he has over the situation. The key factors in managing stress, then, are the appraisal process as well as personal control, i.e., "cognitive and/or behavioral efforts to exercise or seek control in [a stressful] encounter" (Folkman, 1984, p. 844). This model suggests that people actively participate in problem solving in an effort to reduce and control the stress.

In the case of multiple sclerosis, each exacerbation of the disease has the potential for causing stress. According to the non-standardized theory, whether or not stress occurs and how intense the stress is perceived to be depend on people's appraisal of the particular episode and their resources for handling another flare-up of the disease. Although people with MS have no control over the occurrence, duration and severity of these exacerbations, Brooks and Matson (1982) observed that the more autonomous people were, the greater their sense of control over the disease. Conversely, frequent exacerbations and decline in physical mobility negatively affected their perceived ability to control the disease. However, in general, these authors found that despite the cumulative effects of MS, many people felt a sense of control over their disease. It appears that despite the uncertainties associated with MS, people can and do exert control, thereby managing the stress associated with the disease.

Function of coping. Folkman (1984) and Martelli, Auerbach, Alexander and Mercuri (1987) noted that coping has two major functions: getting one's emotions under control (emotion-focused coping) and managing the problem causing the distress (problem-focused coping). These coping strategies can be used concurrently or sequentially. According to Martelli et al. (1987), emotion-focused coping strategies (e.g., denial, wishful thinking or minimizing the threat) are more valuable in the earlier stages of coping, whereas problem-focused strategies become more useful in the latter stages when they can influence long-term outcomes (p. 201). In problem-focused coping, the individual exerts some effort to control the situation "through problem solving, decision making and/or direct action" (Folkman, 1984, p. 845). It is in the problem-focused

coping stage that information seeking becomes more apparent, although as Lazarus and Folkman (1984) pointed out, information searching can be used as an "emotion-focused strategy to bolster a decision already made and so to sustain morale" as well as a "problem-focused strategy to find out what has to be done" (p. 285).

Given this theory, a question that begs clarification is what happens in high stress situations where there is little hope of changing the outcome. The evidence suggests that people most often use emotion-focused coping in these situations (Folkman, 1984; Martelli et al., 1987; Mattlin, Wethington & Kessler, 1990). Mattlin and his colleagues, looking at short-term versus long-term stress, observed that coping strategies used to manage stress in long-term situations were very different from those used in response to acute stresses. They found that people coping with chronic illnesses were more likely to use the emotion-focused coping strategy of escape-avoidance, where avoidance was described as "things" people did to distract themselves from the situation. Interestingly, this finding is not supported in the studies on coping with and adjusting to MS.

According to the research of the Matson and Brooks team (1977, 1987), people with this disease pass through the emotional phase to problem solving in order to regain control of their lives. Phillips (1986) found that throughout the disease, people used both emotion- and problem-focused strategies. Thus, it is possible that some people with MS may remain in the avoidance mode of coping for an extended period, while others will pass from the emotion- to the problem-focused stage and become more active in managing their own health care. Regardless of the phase of coping and adjusting, people with MS may seek information in an attempt to reduce their feelings of uncertainty and regain some personal control, for as Cohen and Lazarus (1979) pointed out, information seeking is one of the "most basic forms of coping" in conditions of ambiguity (p. 221). One purpose of this research, then, was to examine the information preferences of women with MS, in order to determine whether the preferences for certain topics of information varied according to the stage of the disease.

The Standardized Approach

Of more interest to this research project is the second theory on coping with stressful events which depicts a more standardized approach, wherein people either want information in order to handle an uncontrollable event or they turn away from it because information is perceived to increase their levels of anxiety. People who adopt this approach for handling stress and uncertainty can be divided into two groups, those who seek a lot of information (monitors or vigilants), and those who reject information (blunters or avoiders) and use distraction as a method of "blunting" the impact of stress (Miller, 1990). The research on vigilance and avoidance is substantial. Since the focus of this research project concerns only monitoring and blunting behaviour, discussion is limited to current research on monitors and blunters.

In their article on monitoring and blunting behaviour, Miller, Combs and Stoddard (1989) put forth two hypotheses which "account for when information, coping and control are preferred and stress-reducing and when they are not" (p. 108). The first hypothesis, "minimal", involves the issue of control, and while control is not within the realm of this study, the hypothesis is of interest. Basically, Miller and her colleagues (1989) stated that people "are motivated by a desire to minimize the maximum danger to themselves" and seek and prefer control "when having control allows them to put an upper limit on how bad the situation can become" (p. 108). Of more direct relevance to this study is the second hypothesis which concerns monitoring and blunting. According to these authors, in the face of an aversive event that is controllable, "high monitoring and low blunting are the main responses and information is preferred" while the reverse is true in situations that are not controllable (pp. 108-109). However, in some studies, this pattern of response to controllable or uncontrollable situations has not been found to prevail. For instance, Miller and Mangan (1983) studied women undergoing colposcopy, an uncomfortable pelvic examination that requires the use of a magnifying lens to inspect the cervical tissue for evidence of cancer (Dorland's Illustrated Medical

Dictionary, 1988, p. 362). The authors were interested in the relationship between the women's desire for information and their emotional response to colposcopy. Forty women completed the Miller Behavioral Style Scale (MBSS), a measure designed to identify monitors and blunterners. Half the monitors and half the blunterners were assigned randomly to either a high information group (HIG) or a low information group (LIG). The HIG received "voluminous preparatory information", while the LIG received little information. Both the monitors and the blunterners in the HIG reacted adversely to the overload of information. The monitors experienced high anxiety, depression and a longer recovery period, whereas the blunterners continued to have increased heart rates long after the termination of the exam. These results indicated that too much information increased the women's distress levels by forcing them to confront too many possible dangers. Thus, Miller and Mangan (1983) concluded that the amount of preparatory information should be consistent with the patient's coping style.

The finding that monitors experienced more distress during and after the colposcopy than did blunterners, plus evidence of similar responses reported from other studies, prompted Miller (1990) to suggest that "there are alternative modes for coping with aversive events ...and that the most adaptive modes for coping with uncontrollable threat may involve cognitive avoidance and blunting of threatening cues" (pp. 107-108). To address the question of whether people who have chronic disorders "which are characterized by prolonged, high levels of physiologic and subjective arousal" are more "prone to exhibit a high monitoring ...style of coping" (p. 108), Miller (1990) compared twenty-five patients with high blood pressure (hypertension) to a control group with normal blood pressure readings (normotensive). Both groups completed the Miller Behavioral Style Scale (MBSS). The results showed that over two-thirds of the hypertensive patients were monitors, whereas three-quarters of the normotensives were blunterners. Miller observed that although the results were preliminary, people with hypertension "tend to monitor and scan for threat-relevant cues, even when the situation

is uncontrollable" (p. 109). According to the author, "these results make sense" since monitors "typically seek out threat-relevant information about aversive events" (p. 110), whereas blunTERS turn away from this type of information. This finding is interesting in that multiple sclerosis is also an unpredictable and uncontrollable situation. If Miller identified a large number of people with hypertension as monitors, it is also possible that a greater number of women with MS will exhibit monitoring rather than blunting behaviour, since MS is characterized by its unpredictability and is uncontrollable.

In a more recent study of women undergoing colposcopy, Barsevick and Johnson (1990) looked at the women's information-seeking behaviour as it related to their preference for information and behavioural involvement as well as their emotional response to the procedure. The authors defined information seeking as "actions used to obtain knowledge of a specific event or situation" (pp. 3-4). Ten days before the colposcopy exam, the participants were informed that an information sheet on the procedure was available upon request. The authors felt that "offering the information sheet would not be a true indicator of information seeking [behaviour] because the participant could agree to accept the information sheet out of politeness" (Barsevick & Johnson, 1990, p. 4). Immediately after the procedure, the women completed the Miller Behavioral Style Scale (MBSS) and the Krantz Health Opinion Survey-Information subscale (KHOS-I) to determine their preferences for information, as well as the Krantz Health Opinion Survey-Behavioral subscale (KHOS-B) to measure their behavioural involvement.

The authors reported that there was a low correlation between the MBSS and KHOS-I, but no correlation between either of these preference for information measures and KHOS-B, the preference for involvement measure. Also, while a positive correlation was noted between the number of questions asked and KHOS-I, no correlation was found between MBSS and the number of questions asked. Finally, the women who requested an information sheet scored higher on the KHOS-B than did those who had not

asked that the information sheet be mailed to them, supporting a relationship between information seeking and desire to participate in health care.

The absence of any correlation between the MBSS and the number of questions asked and the low correlation between the two preference for information measures led the authors to "suggest that this scale is not a sensitive indicator of preference for information and involvement in health care situations" (p. 6). Also, Barsevick and Johnson found "no difference in the negative or positive emotion scores" between the women who requested the information sheet and those who did not (p. 6), whereas Miller and Mangan (1983) found that women who had obtained a considerable amount of information about colposcopy had negative emotional responses. The fact that Barsevick and Johnson did not "impose" information on the patients (the term used by Miller, 1980, p. 164) may explain the different results.

The colposcopy studies are useful because they suggest that in order for information to have a positive effect, it must be sought by the individual when that individual perceives a need for it. For information to be beneficial and therapeutic, an individual has to find the right information in the right amount at the right time. In this research project, the interest in and the amount of information women with multiple sclerosis wanted at three different time periods in the disease process was assessed. Since both blunders and monitors were identified in this population, the findings have implications for physicians and other health professionals, health educators and the Multiple Sclerosis Society, all of whom dispense information to people with this disease.

Content of Information

What has not been addressed in these studies, to date, is the content of the information given to patients. As patients can have adverse reactions to medications, so it seems that they can also have adverse reactions to information. In addition, presenting information written in medical jargon to patients may create a barrier to their

understanding and actually cause rather than alleviate fear and anxiety. If patients do not understand medical terminology, they may need an opportunity to discuss the information they receive with a health care professional in order to resolve any misconceptions. However, in none of these studies are these important concerns raised. Therefore, one must ask if the results would have been the same if the information had been geared more specifically to the needs of the patients.

Auerbach, Martelli and Mercuri (1983) found specificity of information to be an important issue. In their study, patients scheduled for dental extraction surgery were divided into two groups, those who had a high preference for information and those who indicated a low preference, based on a median split of KHOS-I subscale scores. The patients with a high preference for information were found to adjust much better when given specific information over general information, whereas those with a low preference for information responded slightly better with general information than with specific. Again, this suggests that information should be tailored to meet an individual's needs, and that general information may be appropriate for those who do not express a desire for information, while specific information may be appropriate for those who do. In this research project, the preference of women with MS for general and specific information was examined in relation to their scores on the Miller Behavioral Style Scale.

Summary of Literature on Coping and Adjusting

The literature on coping and adjusting clearly defines the role of information in this process. In the first set of studies discussed above, the type of information was the important factor. People sought information during the emotion-focused coping period in order to get their emotions under control, a necessary precursor to active involvement. Information seeking, however, became more prevalent in the problem-focused coping stage, when the information could help the individual assume some personal control. The second set of studies examined how varying amounts of information affect people who

are facing stressful events in their lives. Some people sought information when they encountered a stressor, while others did not. For those in the information-seeking group, information was more helpful if the content was specific and the information was tailored to their needs. Conversely, people with a low preference for information found general information more suitable to their needs. As none of the studies discussed above examined chronic stressful situations such as those encountered by people with multiple sclerosis, this research project addressed the interest, amount and depth of information women with MS wanted throughout the disease process.

Multiple Sclerosis and Information Seeking

To date, only one study (Phillips, 1986) has examined the information-seeking behaviour of people with MS, although other studies have identified types of sources and the nature of information people with MS have used in various time frames. For example, Stewart and Sullivan (1982) and Robinson (1983, 1988) presented evidence that information-seeking behaviour begins during the pre-diagnostic period. Although very little work has been done on how patients receive the diagnosis, Robinson (1983) described how patients found out they had MS, who told them the diagnosis and how they reacted. He found that many people discovered they had MS through channels other than the attending physician, such as reading their own charts or talking to other health professionals. Robinson also noted that women, more often than men, were not told the diagnosis face-to-face, but were informed by spouses or other members of the family. In the post-diagnostic period, Brooks and Matson (1987) discussed the information-seeking behaviour of people with MS as they attempted to cope with and adjust to the disease. These few studies will be described in more detail below.

Using a structured interview technique, Phillips (1986) studied the information-seeking behaviours of a cross section of 50 people who had had MS for one to twenty

years. Several of her findings are of interest to this study, the first of which describes the coping methods used by her subjects. From the list of 40 coping methods on the Jalowiec Coping Scale, the participants selected how often (never=1; almost always=5) they used each method. Of the five most frequently used coping strategies, hope (an emotion-focused coping method) ranked first, followed by four problem-focused coping strategies, including thinking a problem through, being objective, drawing on past experiences and finding meaning in the situation (p. 88). Overall, Phillips found that people coping with and adjusting to MS did not use emotion-focused coping significantly more often than problem-focused coping (p. 72). That is, they used "many coping strategies to deal with the stress produced by the disease" (p. 85).

To determine "the information seeking behaviors of patients with multiple sclerosis at various times during their disease process" (p. 4), Phillips compared the participants' preference for topics at the time of diagnosis with the information they wanted at the time of the interview. The "time since diagnosis" was limited to two categories: less than or equal to five years and greater than five years (p. 55). She found no significant differences between their past and present information needs. Although noting that some people had trouble recalling the information they wanted at the time of diagnosis, she found that 21% of the people remembered not wanting any information at that time, while 48.5% wanted information of a biological nature and 18.2% wanted sociological information. At the time of the interview, people's interest remained somewhat the same; that is, they wanted biological (66%), sociological (10%) and emotional (6%) information. Finally, Phillips found that the participants used a variety of sources to obtain information about multiple sclerosis. In order of descending frequency of use, the sources included neurologists, the MS Society, pamphlets, other people with MS, books from the library, friends, social workers, clergy and siblings.

Although the three other studies mentioned above did not focus on the information needs and seeking behaviours of people with MS, they provide valuable

insight into topics of interest, sources of information and the time frames in which people sought information. The information-seeking activity of people with MS during the pre-diagnostic period was discussed by Stewart and Sullivan (1982) who studied the illness behaviour of sixty individuals diagnosed with the disease. These authors, identifying three distinct phases from the onset of symptoms to diagnosis, found information-seeking activity to be quite high only in the first two phases. In the first phase, labelled "nonserious," patients did not pay much attention to their vague symptoms, classifying them as ailments or minor illnesses. Information seeking for most patients consisted of discussions with family and friends. Only half of the patients consulted a physician, but not for the MS symptoms, which often were discussed along with other illnesses for which they were being treated.

In the "serious" phase, when symptoms resisted treatment or worsened, information seeking became quite important and thus more easily recognized. Patients sought more medical help (physician shopping) in search of answers and a treatment that worked. Stewart and Sullivan noted that the frequent misdiagnoses resulted in feelings of uncertainty, confusion and frustration and caused a strain in the patients' relationships with physicians, relatives and friends. These findings are consistent with other studies that have found that patients' hostility is often directed towards physicians during the pre-diagnosis period, primarily because of their unwillingness to convey the diagnosis (VanderPlate, 1984; Robinson, 1983, 1988). Further, friends and relatives were more apt to accept the diagnosis provided by the physicians while the patients did not, culminating in strained relations and causing patients once again to look for their own answers (Stewart & Sullivan, 1982). According to these authors, patients sought answers in popular literature, medical texts and through family or friends with a nursing or medical background. In his study of 750 people with MS, Robinson (1983) found that approximately one-quarter of them had used these various resources to discover the cause of their symptoms.

Stewart and Sullivan saw "diagnosis" as the last phase, when the final tests were carried out and the diagnosis was confirmed. The authors did not report any information-seeking behaviour in this phase, a finding that may not be surprising because the patients received the information (i.e., the diagnosis of MS) that they had been seeking. Although these authors did not explain the information-seeking behaviour of their subjects in terms of coping and adjusting, it appears that these people were trying to adjust to a series of stressful events by seeking information from many channels and using it to cope with the unknown. Once the diagnosis had been confirmed, they no longer needed the same type of information.

Literature on coping with and adjusting to MS in the post-diagnostic period is much more abundant and thus, the role that information plays in this process is more defined. The ground work on coping with and adjusting to MS was done by the team of Matson and Brooks. In 1974, Matson and Brooks did an exploratory study of a sample of people with MS ($n=174$) to determine how they had adjusted since diagnosis. Self concept was used as the indicator of adjustment, where self concept was defined as "the image one holds in one's 'mind's eye' of oneself" (Matson & Brooks, 1977, p. 245). The findings suggest that most of the adjustment had taken place in the first ten years of the disease and that while self concept seemed to improve over time, it was mediated by the degree of impairment.

Based on these findings, Matson and Brooks (1977) proposed a four-stage model of adjustment to MS. Newly diagnosed patients entered Stage I (denial) immediately. Denial has been classified as part of the emotional-coping process, a process that usually precedes problem-oriented coping (Martelli et al., 1987). In this stage, patients sought information through different medical channels, in an attempt to find a physician who would dispute the diagnosis. Weisman and Worden (1976-77) defined this information-seeking behaviour as a completely defensive activity, wherein patients sought more information in order to question the diagnosis and find a more acceptable answer. In

Stage II (resistance), Matson and Brooks found that once people acknowledged the possibility of having MS, they anxiously sought information about the disease and a cure. Patients also turned to others with the same disease and participated in classes or groups "to garner any information which may be helpful" (~ 250).

In the first two stages, information seeking is an overt activity, whereas in the third stage, affirmation, this behaviour is much more difficult to identify. Affirmation was defined as the time when an individual had accepted the diagnosis and had started constructing a new self concept. During this stage, patients explained MS to others in their environment, a behaviour Davis (1973) described as normalization, i.e., an attempt by the individual with MS to alter "the perspective of the other so as to be more compatible or in better alignment with his" (p. 18). At this point, then, people with MS want others to understand that the disease has not taken over their total identity. Thus, the act of telling others about MS can be viewed as information-seeking behaviour, in so far as these people are seeking feedback from those to whom they have revealed their condition.

The final stage, integration, occurred when the person fully accepted the illness, dealt with exacerbations with minimal emotion and spent energy on matters other than the disease. Matson and Brooks found that, in this period, patients recognized some beneficial aspects of their condition, for example, more intimate relations with family and friends, a reorganization of their value system and a deeper sensitivity to life in general. The authors did not indicate that any information was needed during this prolonged stage. It is conceivable, however, that throughout the disease, some people might want to keep up-to-date on MS research and new treatments. Indeed, Robinson (1988) found that keeping up-to-date with medical news helped people with the disease make sense of the future.

In a more recent article summarizing the findings of their two previous studies, Brooks and Matson (1987) provided a description of the information needs and

information-seeking behaviour from the patients' perspectives. For example, information given by the physician was seen as inadequate (Brooks & Matson, 1987, Stewart & Sullivan, 1982; Robinson, 1987), even though as Robinson (1987) noted, communication between the doctor and the patient was essential since it could be "the only available form of treatment in many chronic diseases" (p. 252). However, good communication between these parties may be difficult to maintain since many "patients desire life-encompassing direction" which may be beyond the scope of the individual physician (Brooks & Matson, 1987, p. 84).

In addition, Brooks and Matson (1987) presented evidence that patients resented the lack of information about the illness. They wanted practical information that would help them live with their condition (Brooks & Matson, 1987; Maybury & Brewin, 1984). In order to find this information, patients used various channels, for example, books, literature published by the multiple sclerosis societies, government publications, medical journals found in public libraries and other MS patients (Brooks & Matson, 1987; Gorman, Rudd & Ebers, 1984; Mechanic, 1977). However, Scheinberg, Kalb, LaRocca, Geisser, Slater and Poser (1984) cautioned that much of the information on MS available to the lay person is inadequate, since it may contain incomplete information, "inaccurate reports of recent discoveries of potential etiologic agents, near-miraculous forms of treatment, cures or descriptions of research in progress" (p. 212). Regardless of the problems with the information itself, for patients, this gathering of information from different sources served to enhance their confidence in discussions with the medical staff, in decisions about self treatments and in managing their everyday lives (Brooks & Matson, 1987). In addition, patients felt that information helped them "achieve relief from illness uncertainty" (p. 85).

Although many researchers agree with the Matson and Brooks model of coping, some do not. For example, in his book on MS, Robinson (1988) argued with this four stage coping process, pointing out that there is "little evidence of such a transition being

a common pattern," and a lack of "any clear link between degree of physical disability, length of time with the disease, and the stage reached in the model" (p. 33). Robinson contended that since "no empirical research has yet substantiated" the Matson and Brooks model, it should be viewed with skepticism (p. 33).

Robinson (1988) mentioned that in one of his earlier studies of MS, most people used a "fighting" strategy in response to the disease, which he attributed to the existence of a "special relationship" between body and mind, wherein both entities worked together to beat the disease. People who fought the disease were seen as taking an active role in their health care and at the same time, were receiving personal benefits from this "vigorous and unyielding state of mind" (p. 34). Having said this, he conceded that those who used resistance may be more visible socially and further, that fighting may coexist with other strategies. In other words, he assumed that most people with the disease did not employ one predominant method in coping with and adjusting to MS.

It is possible to think of fighting as both an emotional and a problem-solving strategy: emotional in the sense that people are angry at themselves for getting ill and at the disease for changing their lives and their self-image; and problem focused because information and knowledge about MS are required in order to take a proactive approach. Viewed in this way, the Robinson model of coping and adjusting becomes a "microversion" of the Matson and Brooks model and not a total departure from it. Unlike Matson and Brooks (1977), Robinson does not focus on information or discuss how it can help a person wage the fight. However, it seems apparent that the person who uses this fighting strategy would need information to wage an informed battle against the disease.

Self-Help Groups

One source of information frequently mentioned in studies of adjustment to MS is other people with the disease, very often found in self-help groups. Although such

groups have been documented as sources of information, their usefulness is still being debated. Some authors (Brooks & Matson, 1987; Mator, 1989) found them to be very helpful; others (Maybury & Brewin, 1984) did not. In a general study of self-help groups, Mechanic (1977) considered them beneficial only on a short term basis.

In a study supporting the utility of mutual-help groups, Maton (1989) observed a positive association between friendship and group satisfaction among patients with MS. He attributed this finding to the fact that many patients with this disease experienced disruptions in their social and work relationships and therefore joined these groups to construct a new social network. Matson and Brooks (1977) observed that only after patients had accepted the diagnosis, however minimally, did they seek other patients and become active in programs. Being in these groups allowed the members to judge their own progress and setbacks (Brooks & Matson, 1987). Mechanic (1977) echoed the same theme, observing that patients joined self-help groups "to arrive at some prognostic information concerning their problem and some indication of how they compare with others" (p. 81). At first, patients may be relieved to find others with whom they can share experiences and information. In this context, self-help groups can be viewed as a positive resource for information, encouragement and assistance for people recently diagnosed with MS. However, in the long term, Mechanic concluded these groups may have a negative effect on the individual's identity since belonging to the group continually reinforces the disability. Maybury and Brewin (1984) also stated that the more contact MS people had with able-bodied people, the better their self-esteem and psychological health, especially during the early years of this disease.

The Maybury and Brewin (1984) study is interesting for two other reasons. It was the only study to report a negative relationship between information and adjustment, and second, the validity of one of their measures of adjustment can be called into question. Using a small sample of patients ($n=36$), Maybury and Brewin observed the effect of increased knowledge of MS on adjustment. First, they assessed the participants'

knowledge of MS through a questionnaire constructed from information in a British MS Society booklet "So you have MS"? Although younger and better educated patients were found to have more knowledge of MS, substantial gaps existed in their understanding of the disease. For example, they did not know that research on the etiology of the disease was still being done. Further, they were unaware of what type of help to expect from a doctor, what happens during remission and what factors make the symptoms better. The level of patients' knowledge about their disease was not found to correlate with either measure of self-reported adjustment used in this study, i.e., self-esteem or the General Health Questionnaire (GHQ). The authors concluded that knowledge of MS gleaned from a textbook does not result in adjustment, and that what would help the adjustment process is "practical matters of direct relevance for the patient trying to manage his or her condition" (p. 374). The second issue involves the use of the GHQ to measure adjustment. This instrument was originally designed as a screening device to measure minor psychiatric disturbances (Maybury & Brewin, 1984). LaRocca (1984) stated that many researchers have looked for patterns that characterized the MS patient and have used measures "ordinarily employed to assess psychiatric illness" (p. 439). Disagreeing with the use of these measures, LaRocca claimed that results were often contradictory "because adjusting to a chronic illness does not necessarily represent psychopathology in the usual case" (p. 439). Thus, the use of the GHQ to measure adjustment to MS may explain why Maybury and Brewin obtained results that differed from those reported in other studies.

Summary of the Literature Review on MS

Viewed from the perspective of the literature on both coping and adjusting and on MS itself, this disease can be seen as a multistage illness in which each stage involves emotion- and problem-focused coping and adjustment as well as information seeking. For people with MS, the coping process, and thus information needs, may vacillate in

accordance with the exacerbations and remissions of the disease. Since none of the studies reviewed identified the participants' state of health, more research needs to be done to compare the information needs of people during periods of exacerbations and remissions.

In the post-diagnostic period, both Phillips (1986) and Brooks and Matson (1987) noted that people with MS needed a wide range of information including physiological, medical, sociological and psychological. Phillips (1986) also found that not all people wanted information at the time of diagnosis, a finding which may be explainable in terms of monitoring and blunting; that is, the people who did not want information may have been blunting the traumatic effects of the diagnosis. In these studies, the ratio of women to men was at least 2:1, and their information needs were reported in the aggregate. It is conceivable that not only may the information needs of women and men with this disease differ, but also that their general orientation to information, i.e., their monitoring and blunting patterns, may vary somewhat according to gender. Therefore, this research project involves only women with multiple sclerosis. This study represents an attempt to identify the general orientation to information (blunting or monitoring) of a sample of women with MS, as well as the effects of their orientation to information on their interest in and the amount of information they seek throughout the course of the disease in order to determine how that information relates to the coping and adjusting process.

Information and Information Seeking

Definitions of Information

Although the term "information" has been used frequently throughout this literature review, no definition, as yet, has been accepted, partly because none of the authors of the studies previously discussed provided one. The concept of information is very difficult to define, because information can mean different things to different

people. For example, Rohde (1986) and Stevens (1986) have defined information as factual data, a piece of advice, an opinion or a message transmitted to another person. Whittemore and Yovits (1974) described information as "data of value in decision making" (p. 31), while for Faibisoff and Ely (1976), information is a set of symbols which have potential meaning for the receiver. Dervin (1977) has defined information more broadly, stating that information was any thing the person found to be informing, where any "thing" could be interpreted as a conversation, a book, a phone number, to name a few examples. Whether something can be considered informing depends on the person's interpretation of it or as Dervin, Harlock, Atwood and Garzona (1980) explained, "information does not inform unless the individual can make personal sense of it and personal sense can only be made when information can be processed in the frame of personal understandings" (p. 592).

To ascertain what women with MS find informing, it is necessary to understand how they define their worlds, that is, to study their needs within a situational context. Since their worlds have changed or are in the process of changing as a result of the disease, it is likely that their information needs will reflect the current state of their physical and/or emotional health. Therefore, for this research project, the definition of information proposed by Dervin will be the operational definition, because it is broad and it allows information to be studied in a situational context.

Reasons for Seeking Information

Various reasons have been put forth in the psychological literature to explain why people seek information. Several theories relevant to the MS situation have been selected from this literature for discussion.

Information and personal control. According to the psychological literature, people generally seek information to reduce uncertainty and to gain or regain personal control both emotionally and intellectually in order to participate in decision making.

This desire to participate, described by psychologists as the act of taking personal control, is regarded as a positive forward move in the coping and adjusting process. According to Burger (1989), control is defined as the "perceived ability to significantly alter events" (p. 246). However, given the uncertainty of MS and the inability to alter the course of the disease, it is plausible that some people with this disease would not be interested in assuming control. Interestingly, the findings of Brooks and Matson (1987) do not support this postulate. They found that many MS patients expressed the desire for information in order to have some control over their treatment, although they were ready to relinquish much of that control to the medical team when their condition worsened.

Burger (1989), Folkman (1984) and Averill (1973) observed that in the past, psychologists viewed being in control as stress reducing and therefore beneficial. For instance, Maslow (1963) wrote that the desire for information and thus control over the events in one's life were basic psychological needs, noting that "man does have a need to know and ...a need to understand, which are profoundly rooted in his biological nature" (p. 111). He further stated that "ignorance makes real choice impossible" (p. 116), since "knowledge and action are frequently synonymous" (p. 122). "When we know fully and completely, suitable action follows automatically and reflexly" (p. 112). Control, viewed from this perspective, appears to be a goal towards which one should strive. However, is control always a good thing?

According to Burger (1989), current literature on personal control and coping reflects a change in this philosophy. The prevailing view is that control is not always a positive experience; it can increase anxiety instead of reducing it, especially in situations where the "perceived probability of obtaining desired outcomes" is decreased (p. 247). Steele, Blackwell, Gutmann and Jackson (1987) observed that "the exercise of personal control carries heavy responsibility and risk" (p. 19). Thus, patients who are seriously ill may not want to or may be incapable of accepting the responsibilities and hazards which are a part of personal control (Steele et al., 1987; Blanchard, Labreque, Ruckdeschel &

Blanchard, 1988). Folkman (1984) too agreed that "control can be a mixed blessing when exercising it exacts costs in other areas" (p. 845), and Averill (1973) reported that "no simple relationship exists between personal control and stress" (p. 300).

Burger (1989) further stated that if the outcome is perceived to be poorer when the individual is in control, control is more likely to be relinquished. Ende, Kazis, Ash and Moskowitz (1989) reported similar results. In their study of 312 patients attending a primary care clinic, Ende and his colleagues found that the majority of patients preferred more decision-making power during minor illnesses than during major ones. Steele and his colleagues (1987) noted that the variations in the amount of control or active participation chosen by patients depended on the patients' understanding and interpretation of their illness experiences and their abilities to cope. These authors postulated that patients' preference for more control may occur later in the illness when they have acquired a better understanding of the situation and felt more confident in their ability to cope.

In the MS situation, women who seek information may want it for the purpose of regaining control, for as one chronically ill person stated "When you find out that you are chronically ill, you start striving for some kind of acceptance ...But you can't have that unless you're in control, and you're not in control unless you have knowledge" (quoted in Register, 1987, p. 186). In times of exacerbations, some women may relinquish control to the medical establishment but may want it back when they start feeling better. It appears from the literature on MS and chronic illnesses that most people do not want to remain "emotional invalids", but want to have as normal a life as possible within the disease parameters (see, for example, Register, 1987; Robinson, 1988).

Information and uncertainty. Although some people may use information to gain control, other people may seek information to reduce their feelings of uncertainty. Miller, Brody and Summerton (1988) reported that people's information-seeking behaviour did "not appear to be initiated in order to undertake controlling actions but rather in order to

reduce uncertainty and concomitant arousal" (p. 147). Basing their conclusion on the fact that some of people in their study tended to play a very passive role in their health care, the authors concluded that the people who expressed a desire for a lot of information about a medical procedure did so in order to reduce their stress. Therefore, information seeking was not to gain control and participate in medical decision making, but to reduce uncertainty and the distress resulting from it.

In another study, Mishel (1984) found a strong association between lack of information and uncertainty, which she defined as an event or a situation that "cannot be adequately structured or categorized because sufficient cues are lacking" (Mishel, 1981, p. 258). Using the Mishel Uncertainty in Illness Scale, the author studied 100 male medical patients. She found that the lack of information about their illness, treatment and hospitalization contributed to feelings of uncertainty that resulted in stress for these patients. In addition, she reported that the lack of information was strongly related to unpredictability. The results of this study provide more support for the theory that people may seek information to reduce stress caused by uncertain and unpredictable events.

Although outside the focus of this research project, the influence of information on uncertainty in MS would be interesting to study, as uncertainty is a constant factor in this disease, and available literature on this disease can increase anxiety (Simons, 1984). Since the effects of MS information on uncertainty may be dependent upon the depth of information and the stage of the disease, it is necessary first to ascertain the specificity of the information people desire at the various stages of the disease process before addressing the effectiveness of that information on their uncertainty levels. It is plausible that the information people request may reduce their uncertainty because it is tailored to their immediate information needs.

Information and sense making. An entirely different perspective on why people seek information has been proposed by Dervin, a communications specialist. According to her theory, people seek information only when they need to make sense of an event,

that is, when they realize there are gaps in their knowledge, preventing them from solving the problem at hand, making an informed decision or understanding the situation in which they find themselves. Normally, people do not recognize that gaps exist in their personal store of knowledge until a particular situation arises, prompting them to recall what they know of the topic. If what is already known satisfies the requirements of the situation, no further information seeking takes place. Conversely, when the retrieved information is not adequate for handling the new situation, a gap is identified and the person sets out to find some way of increasing her/his knowledge in order to bridge the gap. According to Dervin (1983), information seeking and use are "constructing" activities because the person looks for information and uses it to construct her/his own personal sense of the situation or event.

In health-related situations, it is likely that gaps exist in most lay people's knowledge of diseases. Attempts to educate the public about health issues and various diseases through the mass media have resulted in a large amount of literature on some "popular" diseases. As a result of the sheer volume of information, many people may recall some details about these popular diseases if asked (Pratt, 1956). Sense-making theory leads one to expect, however, that despite this generally high level of available information, most people probably do not know a great deal about health conditions unless they have an immediate and personal need to know. For most people then, gaps exist in their knowledge of many diseases, and as noted above, for less "popular" health conditions such as MS, the gaps in the lay person's knowledge may be quite extensive.

Another factor contributing to gaps in knowledge about a health condition is poor communication between physicians and patients. As noted above, from the perspective of the person with MS, physician-patient communication is often characterized as inadequate. Patients often receive too little or too much information from physicians, which may arise from physicians' tendency to adopt a "generic approach" to patients rather than changing their behaviours or communication styles to accommodate

individual patients. As a result, all patients are likely to receive the same type of information (Campbell, Mauksch, Neikirk, & Hosokawa, 1990; Street & Buller, 1988), or the same amount of information, that is, too much or too little, depending on the physician's belief about how much information a patient should receive. For instance, in a British study of patients with MS, Robinson (1983) found that physicians were more reluctant to inform female patients that they had MS than they were to tell their male patients. He explained this behaviour in terms of consequences for the physicians, stating that doctors giving a diagnosis of MS to female patients would be inconvenienced or made uncomfortable by "the likely immediate emotional reactions", which "may be difficult and time consuming for medical staff to cope with" (p. 12). Therefore, it seems that patients who are seeking information at various times during the disease process may be hampered by too much or too little material, by the physician's inability to handle the patient's emotional responses, and by information that is not tailored to their specific needs.

Reasons for Not Seeking Information

The reasons why some people do not seek information have not received much coverage in the literature noted above. For instance, Robinson (1983) did not explain why some people in his study did not want to hear their diagnosis, nor did Phillips (1986) provide reasons why some participants did not want information at the time of diagnosis. However, Mishel (1988) does provide some insight into this behaviour, observing that the uncertainty associated with an illness has to be managed in some way in order for the person to adapt to the disease. People manage the uncertainty either through inference or illusion. The former involves an evaluation of the uncertainty based on past experiences and is "built on personality dispositions, general experience, knowledge and contextual cues" (p. 228). On the other hand, illusion involves the "construction of beliefs" that usually have a positive outlook. Illusions are seen as

appropriate in situations where the outcome is uncontrollable and negative, such as in multiple sclerosis. Faced with these negative factors, people create illusions of hope in order to turn the negative situation into a positive one. Mishel (1988) further explained this behaviour by stating that the "...lack of information, a type of uncertainty, allows people to create illusions and thus a more positive outcome, i.e., hope" (p. 230). Support for this theory can be found in Phillips' study (1986), as people cited "hope" as the coping method they most frequently used.

Summary of Information and Information Seeking

If information is viewed as any "thing" a person finds informing, then information can be seen as a very subjective experience in which some people will want to share and others will not. In other words, people have to want to know about their situation and secondly, they must be able to see a "thing" as informing, as something that will solve an internal problem, help them to make sense of their situation, relieve their uncertainty or help them regain personal control. Other people will shy away from informational sources or will not put any inadvertently acquired information to use. For these people, information may destroy an illusion, thereby eliminating any sense of control they may have over their situation. Russell (1989) explained this behaviour in people with MS by pointing out that the instability and unpredictability of the disease offer those afflicted a "continual source of hope: namely disbelief that one's body will continue to decline in physical abilities" (p. 282).

Statement of Research Questions and Hypotheses

Research Question for Part One of the Study

What are the information needs and information-seeking patterns of women with

multiple sclerosis at three different time periods of the disease process? In order to determine if the information needs and seeking patterns of women with MS changed throughout the course of the disease, three distinct time periods were chosen: the newly diagnosed period, i.e., diagnosis to six months post-diagnosis; the active coping stage, i.e., two years post-diagnosis (Cunningham, 1977); and the "acclimated" stage, i.e., five years post-diagnosis (Williams, 1984).

This general question can be made more specific by addressing its components:

1. Are there women in the population of people with MS who can be identified as monitors or blunders?
2. What is the nature or content of the information sought at these different time periods?
3. Will the content of this information reflect the woman's stage in the coping and adjusting process?
4. What patterns of information seeking emerge?

Hypotheses for Part One of the Study

As noted previously, there are basically two methods of coping with and adjusting to stress: the standardized approach, that is, people use the same reactive method to every stressor, or the non-standardized approach, wherein people appraise each stressful event and act accordingly. Regardless of the approach taken, many people, faced with a stressful event such as the diagnosis of multiple sclerosis, respond emotionally and then adjust to the situation by using problem-solving strategies. Information has been identified as a key factor in the coping and adjusting process.

Miller (1980) has identified monitors as people with a high preference for information, whereas blunders are those who do not seek information. In her recent study of hypertensive patients, Miller (1990) found most people with this chronic disorder to be monitors. Although hypertension may not as debilitating a disease as multiple sclerosis, the diseases have some characteristics in common, such as unpredictability and

lack of personal control. It was expected that, in this sample of women with MS, monitors would want more information than blunters.

Hypothesis 1.1: Throughout the course of the disease, women with a high preference for information would be more interested in and want more information than women with a low preference for information.

Hypothesis 1.2: Throughout the course of the disease, women with a high preference for information will want more information about MS in any format than will women with a low preference for information.

Research Question for Part Two of the Study

What depth of information (general or specific) do women want in the early coping and adjusting period which, for the purpose of this project, will extend from diagnosis to two years post-diagnosis?

Hypothesis for Part Two of the Study

Auerbach, Martelli and Mercuri (1983) found that people with a high preference for information adjusted better when given specific information, whereas those with a low preference for information responded slightly better with general information. Since Miller (1990) found that monitors with hypertension wanted more information than did blunters, it was hypothesized that, in the active coping years (i.e., diagnosis to two years post-diagnosis), women who showed a high preference for information would want both specific and general information, whereas women who showed a low preference for information would want general information.

Hypothesis 2.1: In the active coping phases of the disease, women with a high preference for information will want both general and specific information, while women with a low preference will prefer general information.

Significance of the Research Project

The study of the information needs and information-seeking patterns of women with multiple sclerosis has both theoretical and practical implications. From a theoretical perspective, the results of this research project will contribute new insights into the role of information in the coping and adjusting process that has been depicted by psychologists, sociologists and health professionals. The findings of this research project will build on Miller's work by ascertaining if the monitoring and blunting patterns of coping exist in long-term stressful and uncertain situations.

Library and information science professionals have studied the information needs and information-seeking behaviours of various groups of people, but few have examined the needs of people with chronic illnesses (for example, see Marshall, 1979). Therefore, the results of this project will add a new dimension to the body of literature on this topic.

From a practical standpoint, ascertaining that monitors and blunters exist in the MS population will help health professionals, health educators and the multiple sclerosis societies. Physicians and health educators may need to be alerted to the fact that some people want information, while others do not. Knowing this can help health professionals tailor information to the needs of their patients. Further, the results of this study may suggest that instead of sending generic packages of information to women with MS, the multiple sclerosis societies should send more appropriate material based on the person's general orientation to information (monitoring or blunting), as well as the length of time the person has had MS.

CHAPTER 2

RESEARCH DESIGN AND METHODOLOGY

The contents of this chapter include a detailed description of the methodology used in this study. After a brief description of both parts of the study is presented, the study sites and choice of subjects are discussed. The remaining sections describe the instruments used to collect the data and the characteristics of the respondents in each part of the study.

Overview of Research Design

Part One. As noted in Chapter 1, the topics of interest to people with MS, identified by other researchers, range from physiology to economics. Given the wide variety of known information needs, this study attempted to determine if the need for information about any of these topics changed over the course of the disease and how the women's general orientation to information affected their interest in these topics, the amount of information they wanted and their preference for particular formats. The women's general orientation to information was measured by two scales, the Miller Behavioral Style Scale and the Krantz Health Opinion Survey-Information subscale. As noted in Chapter 1, the length of time a woman had had MS determined the group to which she was assigned: diagnosis to six months post-diagnosis (Phase 1); two years post-diagnosis (Phase 2); and five years post-diagnosis (Phase 3).

Part Two. The purpose of the second part of this study was to examine the relationship between the women's general orientation to information, length of time with MS and the depth of information (general or specific) they preferred about the disease. General and specific versions of pamphlets were prepared on two topics of interest to women with MS, namely fatigue and treatment of acute attacks. Each participant received one of these pamphlets, plus a short questionnaire designed to determine her

reaction to the pamphlet and the Miller Behavioral Style Scale, which was used to measure general orientation to information. In this part of the study, the length of time with MS was limited to the active coping phase. More specifically, one group would consist of newly diagnosed women and those who had been diagnosed for up to six months (Phase 1), while the second group would include women who had been diagnosed for two years (Phase 2).

Sampling

The Clinic Settings

Selection of MS clinics. Participants in the study were obtained through two MS clinics in southwestern Ontario (Clinic A and Clinic B). Because patients attend these clinics more for medical reasons than for information-gathering purposes, (although the latter activity may be on an attendee's agenda), clinics were considered a better source of participants than the registries of the MS Society which have been used in other MS investigations (the important role of the Society is to provide MS information to its members). The MS clinics also provided access to patients who fell into the time frames dictated by this study, making the research project more manageable.

Two problems associated with clinic-based MS studies have been identified in the medical literature. One problem concerns the diffuse geographical base of many clinics, as patients are often referred to these clinics from a wide geographic area for tests, diagnosis or treatment. In Ontario, there are five MS clinics serving the needs of people with this disease. Although each clinic has its own specific catchment area, the clinics chosen for this study are known to overlap somewhat because of their proximity and thus, provide a more homogeneous base from which to select patients. The second problem involves the biases of physicians in the community. Since all physicians in the community may not refer their patients to the local MS clinic, clinic populations may not

be truly representative of the known population of patients with a certain disease (Weinshenker, Bass, Rice, Noseworthy, Carriere, Baskerville & Ebers, 1989). However, in a study comparing the clinic populations of a MS clinic in British Columbia with one in Ontario, the authors stated that "the clinic populations are representative of the general MS population" (Sadovnick, Eisen, Ebers & Paty, 1991, p. 1193). Thus, the generalizability of the findings of this study may be limited only to other women with MS registered with the thirteen MS clinics in Canada. Still, this may represent a fairly large population of women with the disease, since the Canadian MS clinics have a mandate "to assess patients for diagnostic purposes, to monitor and manage the course of MS over time, and to conduct research" (Sadovnick et al., p. 1193).

The final argument for choosing MS clinics was based on the need for diagnostic certainty. Since there are three levels of diagnosis (possible, probable and confirmed), it was essential to ensure that the women selected for this study had a confirmed diagnosis of MS. Problems encountered in establishing level of diagnosis will be discussed below. In addition, a decision had been made to exclude from the study women who were experiencing an acute exacerbation or who had cognitive problems. Information of this nature was easier to obtain from the patient's chart or from the staff of the MS clinics than it would have been through membership lists of the MS Society.

The investigator wrote a letter to the medical director of each MS clinic describing the study and asking permission to include his patients in this project (see Appendix D). A copy of the appropriate questionnaire was included for their perusal. Both directors had been apprised of the study by their clinic staff members who had expressed an interest in the study and permission to undertake the research was granted.

Construction of Sampling Frame

Selection of the subjects for both parts of the study was guided by four criteria. The subjects had to be female, have a confirmed diagnosis of MS, could not be suffering

from an acute exacerbation nor could they have any cognitive problems. The requirement that only female subjects be selected for this study stems from the fact that multiple sclerosis strikes more women than men (Multiple Sclerosis Society of Canada, 1991). Although estimates of the ratio of females to males vary somewhat between 2:1 (Hader, Elliot & Ebers, 1988) and 3:1 (Cook, 1985 quoted in Monks & Robinson, 1989), it is clear that women are more often afflicted by this disease than men. Because women and men may want different information to help them cope with the disease, (see, for example, Belenky, Clinchy, Goldberger & Tarule (1988)), the present investigation focussed only on women with MS.

Women were excluded from the study for two disease-related conditions, that is, having cognitive problems or suffering from an acute exacerbation. Cognitive problems caused by the demyelination process associated with multiple sclerosis may affect comprehension, while those suffering from an acute exacerbation may have been too ill to participate and being in the throes of an exacerbation may have altered significantly their usual response to the disease.

Although the study was designed to include only those with a confirmed diagnosis of MS, an insufficient number of women, particularly in the newly diagnosed category, were identified in the clinic samples. Therefore, the sample was extended to include women with a probable diagnosis of MS. For all potential subjects with a probable or confirmed diagnosis, the researcher verified through an examination of the records that the diagnosis had been discussed with the patient.

This discussion of the diagnosis became an important factor in this study for another reason, that is, date of diagnosis. Both MS clinics are primary care facilities as well as referral centres. In other words, people who belong to these clinics have been diagnosed either by the neurologists in the MS clinics or by physicians in the communities who send their patients for confirmation of the diagnosis. The referral cases caused problems for the researcher in that the patient may have known or suspected that

she had MS for many years, but just recently received a probable or confirmed diagnosis based on more recent diagnostic tests. Since the parameters of the study required that diagnosis be made within distinct time periods, extensive searching of the referral records was necessary in order to ensure correct identification of the time frame of the disease. For the purpose of this study, a decision was made to accept the first date on which a physician discussed the diagnosis of MS with the patient as the official starting date of the disease.

To this point, the discussion of the construction of the sampling frame has dealt with issues pertaining to both parts of the study. In the next two sections, specific issues relevant to each part of the study will be discussed.

Selection of subjects: Part One. The subjects for Part One of the study were selected from Clinic A. In addition to the date and level of diagnosis problems discussed above, the length of time with MS became problematic. In other words, an insufficient number of subjects met the "stage of disease" criterion. Therefore, the time frame for having MS was expanded as follows: instead of six months, the newly diagnosed group was increased to include women who had been diagnosed for up to one year (March 1991 to March 1992); the second group was increased to include women who had been diagnosed for two to three years, (1989 to 1990); and the third group was extended to include those diagnosed for five to seven years (1985 to 1987).

Four women were excluded from the study, including one who was experiencing cognitive problems according to the staff and three who were geographically inaccessible. A total population of 414 potential subjects for this study were identified: 78 in the newly diagnosed group (Phase 1); 160 in the 2-3 year time frame (Phase 2); and 176 in the 5-7 year period (Phase 3).

Selection of subjects: Part Two. During the selection process at Clinic B, two problems were encountered. The first problem involved locating a sufficient number of patients whose date of diagnosis coincided with the proposed time frames of diagnosis to

6 months (the newly diagnosed) or 2 years (the end of the active coping stage). Since very few women had been diagnosed within these specific time periods, the length of time with MS had to be adjusted. Women with a diagnosis of three years or less (January 1989 to the date of selection) were included, allowing for the creation of three time frames: Phase 1, diagnosis to 12 months post-diagnosis; Phase 2, 13-23 months post-diagnosis; and Phase 3, 24-36 months post diagnosis. Most of the patients' charts contained a summary sheet that included both the date of diagnosis and notes by a staff member indicating a discussion of the diagnosis had taken place. A list of 82 potential subjects was compiled. However, on the recommendation of the staff member, two names were deleted from the list: one woman did not speak English and the other was known not to want information about MS.

The second problem concerned the number of potential subjects, eighty being insufficient to have a minimum sample size of 10 responses per cell. Therefore, since Clinics A and B are known to have similar populations (Staff member, Clinic B, personal communication, May, 1992), a decision was made to increase the sample size by adding the names of the women from Clinic A who had been listed, but not randomly selected, for inclusion in Part One of the study. Seventy-five women from Phases 1 and 2 were added to the 80 from Clinic B for a total of 155 subjects.

Data Collection: Part One

The first part of the study examined the relationship between the women's general orientation to information and their interest in various topics of relevance to people with MS, the amount of information wanted on these topics and their preference for format.

Construction of the questionnaire. The questionnaire was composed of five different instruments (see Appendix A). The Miller Behavioral Style Scale (MBSS) was used to measure general orientation to information, identifying monitors and blunders (Miller, 1980). The Information subscale of the Krantz Health Opinion Survey (KHOS-I)

was also used to measure general orientation to information, identifying those with a high and low preference for information (Krantz, Baum, & Wideman, 1980). The remaining three instruments were designed to elicit information on women's interest in various topics, the amount of information they desired on these topics and the preferred format for the information. Instructions for completing each section of the questionnaire were included. At the end of the questionnaire, the person's age and level of education were requested. The scales were packaged in counterbalanced order (five different ways) to eliminate possible response bias.

Description of the scales. In this study, the Miller Behavioral Style Scale has been used to determine whether, in the face of stress, people avidly seek information (i.e., are monitors) or avoid it (i.e., are blunters). The MBSS is composed of four short scenarios, each followed by eight declarative sentences. The subjects are instructed to choose all the statements that best described their reactions to the particular situation. Three different types of scores can be obtained from this scale. The monitoring scores (Mscore) are calculated by adding all the respective responses selected by the participants. People who obtain scores above the mean are considered to be high monitors, while those whose scores fall below the mean are low monitors. The same procedure is used to determine high and low blunters (Miller, 1987). In this study, the monitoring and blunting scores were used only to compare women with MS with other groups tested by Miller. The third score is obtained "by subtracting the total number of items endorsed on the blunting subscale from the total number of items endorsed on the monitoring scale" (Miller, 1992). The mean is used to divide subjects into monitors and blunters. This third score (hereafter referred to as MBscore) was used to divide the study participants into the monitor and blunter groups described in Part One and Part Two of this study.

The MBSS has been validated in a laboratory setting with undergraduate students who faced either a physical or a psychological threat. Faced with the threat of an electric shock, students could choose to listen either to a channel providing information about the

shock or to one playing music. Using analysis of variance, Miller (1987) found "a significant main effect for coping style on listening time. Overall, high monitors and low blunters spent significantly more time listening to the [information channel] than low monitors and high blunters did. Interestingly, this effect was strongest using scores on the blunting subscale, $F(1,28) = 19.26, p < .001$ " (p. 348). Similar results were noted in the experiment involving "ego-threatening cognitive tasks" (Miller, 1987, p. 349). Students could check the quality and speed of their performance by "attending as often as they wished to a light that signaled how well they were performing relative to previously established norms and to a clock that indicated how much time had passed" (p. 349). Checking the clock or the light indicated a preference for information, while the opposite behaviour indicated a preference for distraction. An analysis of variance revealed "a significant main effect for coping style on how frequently subjects looked up at the lights. Overall, high monitors and low blunters looked up at the lights significantly more often than low monitors and high blunters did. Interestingly, this effect was strongest using scores on the monitoring subscale, $F(1,38) = 37.43, p < .001$ " (p. 350). Similar results have also been found in studies of people undergoing medical procedures, such as the Miller and Mangan (1983) study of women undergoing colposcopy described above. In addition, consistent findings of monitors wanting more information than blunters have been reported by other authors who have used the MBSS in medical settings (Miller, 1992).

Another scale used to measure general orientation to information was the Krantz Health Opinion Survey (KHOS). This 16-item instrument asks subjects to choose an option (agree/disagree) that reflects their beliefs about different approaches to health care. The Information subscale (KHOS-I) includes seven items which reflect preference for information style.¹ The mean of the scores on the Information subscale was used to

¹ The other nine items on the KHOS measure the respondent's desire for involvement in health care and are not within the purview of this study.

separate the participants into two groups: women with a high preference for information and those with a low preference for information. For ease of discussion, these two groups will be referred to as high information scorers and low information scorers, respectively.

On the scales assessing interest in different topics and the amount of information wanted, 29 topics on a wide variety of physiological, psychological, social and economic issues known to be relevant to people with MS were listed. These topics were culled from publications of the MS societies in Canada and United States, as well as from biographies of women with MS or other chronic diseases. On both measures, the participants were asked to indicate, on 5-point scales, their level of interest in each topic and amount of information wanted.

The format measure included the same 29 topics, but was designed to permit the respondent to express her preference for different formats in which information could be delivered. In addition, space was made available for the respondent to name human sources she would consult for personal questions on each topic.

Pretesting the questionnaire. Five women who had had multiple sclerosis for varying lengths of time pretested the questionnaire. While none of the women expressed concern about the length or the content, one woman did suggest some changes to the topics. Based on her suggestions, a topic was added and another amended on the interest, amount and format measures.

Distribution of questionnaires. The questionnaires were distributed in such a way that each of the three subject groups, i.e., the newly diagnosed women, those in the active coping stage, and those who had had MS for 5-7 years, was exposed to an equal representation of the five formats in order to eliminate possible response bias. A numeric code, stamped in the lower right hand corner of the questionnaire and on the envelope, ensured anonymity. Sixty women randomly selected from Phase 1 (i.e., newly diagnosed women) and 100 from each of Phases 2 (i.e., women in the active coping stage) and 3 (i.e., women who had had MS for 5-7 years) were mailed questionnaire packages

containing the following items:

- a) a letter from a staff member of Clinic A (this staff member is well known to all clients of this clinic). This letter introduced the researcher and the project, ensured confidentiality and advised the participants to complete it at their leisure (see Appendix D);
- b) a cover letter from the researcher describing the purpose of the project. The letter also advised the subjects of their right to refuse to participate in the study and their right to withdraw from the study at any time, as well as ensuring anonymity. General instructions stated that it must be the person with MS who responded to the questionnaire, not a family member, although the latter may physically fill out the forms (see Appendix D);
- c) the questionnaire and a stamped envelope addressed to the researcher (see Appendix A).

Response rate. As the return rate of the questionnaires was both high and fast, no follow-up notices were deemed necessary. A total of 160 (61.5%) completed questionnaires were returned. The response rate from Phase 1 was 36 (60%), from Phase 2, 67 (67%) and from Phase 3, 57 (57%).

Characteristics of the respondents. The women ranged in age from 18 to 78 years ($M= 41.02$; $SD=11.02$). Their education ranged from eighth grade to six years of postsecondary education ($M= 13.23$ years; $SD=2.44$). No significant differences were found in age or education between the three groups, that is, between the women who were in different stages of the disease.

As mentioned above, the MBSS and the KHOS-I were used to determine the women's general orientation to information. The scores for each scale are reported in Table 1. One-way analyses of variance revealed no differences in mean scale scores for women in the three different phases of the disease.

Table 1: Mean, Median, Standard Deviation and Range of Scores for MBSS and KHOS-I: Part One

Scale	n	Mean	Median	Standard deviation	Range of scores
Mscore	158	8.84	9.00	2.93	1 to 15
Bscore	158	4.48	4.00	2.45	0 to 11
MBscore	158	4.36	5.00	3.86	-7 to 13
KHOS-I	160	4.54	5.00	2.03	0 to 7

Note: Two women did not complete the MBSS. Monitors ($n=81$); blunterns ($n=77$); high information scorers ($n=82$); low information scorers ($n=78$).

Data Collection: Part Two

The second part of the study involved the women's general orientation to information and their reactions to a general or a specific pamphlet on a particular topic.

Construction of the pamphlets. The staff members at the MS clinics were asked to name some issues of concern to people who had been fairly recently diagnosed with MS (i.e., within the first three years). From the list of topics provided, two were chosen: treatment for acute exacerbations and fatigue. Two pamphlets were written on each of these topics: a general and a specific pamphlet on the treatment of acute attacks and a general and a specific one on fatigue. In order to write the four pamphlets, a variety of sources were consulted, ranging from material written for the layperson with MS to medical books and articles on fatigue and treatments of exacerbations. The general pamphlets provided a basic overview of the etiology, physiology and treatments of the conditions, but did not include any precise information. Conversely, the specific pamphlets provided as detailed information as is available on the etiology, physiology and treatments, naming drugs of choice and dosages. The final versions of the pamphlets were read and approved by the Medical Director of Clinic B and the staff members of both clinics (see Appendix D).

Pretesting the pamphlets. The four pamphlets were pretested by thirty-four

students from the Graduate School of Library and Information Science: general pamphlet on treatment ($n=8$), general pamphlet on fatigue ($n=8$), specific pamphlet on fatigue ($n=8$), specific pamphlet on treatment ($n=10$). The students were asked to rate the level of language (lay versus technical), the tone of pamphlet (nonreassuring versus reassuring), and the nature of information provided in the pamphlet (general versus specific) on 7-point scales (low=1; high=7). No significant differences were revealed by two-way analyses of variance (ANOVA) for level of language or tone of article by topic (fatigue or treatment) and type (general or specific). In other words, this lay audience did not experience any problems reading or understanding the language in the pamphlets, nor evaluating the tone of the pamphlet as reassuring. And, as intended, they found the specific pamphlets ($M=5.11$) to provide more specific information than the general pamphlets ($M=3.94$), $F(1,30) = 5.49$, $p=.03$. Similarly, the women who participated in Part Two of the study also noted a significant difference between the general and the specific pamphlets. A four-way ANOVA revealed a significant main effect for depth of information, $F(1,69) = 5.08$, $p=.03$. In other words, the study participants found the specific information pamphlets ($M=2.83$) to be significantly different from the general information pamphlets ($M=2.35$).

Construction of questionnaire. The questionnaire package for Part Two of the study consisted of the Miller Behavioral Style Scale (MBSS) described above, either the general or the specific pamphlet on one of the two topics (fatigue or treatment of acute attacks) and a short questionnaire designed to ascertain the participant's response to and satisfaction with the depth of information included in the pamphlet (see Appendix B).

The questionnaire was pretested with twelve women with MS. Three women rated each version of one pamphlet. No problems with the readability of the pamphlets or the construction of the questionnaire were encountered during this pretest.

Distribution of questionnaires. Packages containing one randomly selected pamphlet, the MBSS scale and the questionnaire were mailed to 155 subjects: 42 women

in Phase 1 (diagnosis to 12 months post-diagnosis); 47 women in Phase 2 (13 to 23 months post-diagnosis); and 66 women in Phase 3 (24 to 36 months post-diagnosis) (see Appendix B). Two letters, similar in content to the letters for Part One of the study, accompanied the questionnaires. The letter from the staff member of Clinic B introduced the researcher and the study and guaranteed confidentiality. The letter from the researcher outlined the purpose of the study, advised subjects of their right not to participate or to withdraw from the study at any time and guaranteed anonymity (see Appendix D). In addition, the person with MS was asked to answer the questions, although a friend or family member could record their responses. A stamped addressed envelope for easy return of the questionnaire was also included in the package.

Response rate. Since the questionnaires were mailed out in early summer, the response rate was slow but good. No follow-up notices were necessary. Ninety-five (61.3%) completed questionnaires were returned: 26 (62%) in Phase 1; 28 (60%) in Phase 2; and 41 (62%) in Phase 3.

Characteristics of respondents. The demographic information requested on the questionnaire included age and highest grade completed in school. The women ranged in age from 20 to 69 years ($M=37.53$; $SD=9.81$) and their education ranged from fifth grade to seven years of postsecondary education ($M=13.73$ years; $SD=2.80$). No significant differences in age or education were found between the women who were in different stages of the disease or who had received the different topics.

As in Part One of the project, the Miller Behavioral Style Scale was used to determine monitors and bluntners. The monitoring, blunting and MBscores are reported in Table 2.

Table 2: Mean, Median, Standard Deviation and Range of Scores for MBSS: Part Two

Scale	n	Mean	Median	Standard deviation	Range of scores
Mscore	93	9.14	10.00	2.92	2 to 15
Bscore	93	3.85	3.00	2.37	0 to 9
MBscore	93	5.29	5.00	3.69	-4 to 13

Note: Two women did not complete the MBSS. Monitors ($n=46$); blunters ($n=47$).

Comparison of MS Women in Part One and Part Two

The women who participated in Part One of the study were found to be significantly older ($M=41.02$) than the women in Part Two ($M=37.53$), $t(254) = 2.62$, $p=.01$. Also, their blunting scores were higher ($M=4.48$) than were those of the women in Part Two ($M=3.85$), $t(251) = 2.01$, $p=.05$. No differences were noted in levels of education, their monitoring scores or their MBscores.

Comparison of MS Women with Other Groups Tested with MBSS

The monitoring and blunting scores of the women with MS are reported in Table 3, along with the scores of other patients and non-patients Miller tested with the MBSS. The women who participated in this study appear to be similar in their general orientation to information to primary care patients, that is, people who are either acutely ill or chronically ill but experiencing a flare-up that requires medical care for a short period of time.

Insert Table 3 about here

Table 3: Comparison of the Means of Groups Tested with MBSS

	MS Women Part One \bar{n} = 158	MS Women Part Two \bar{n} = 93	Primary Care Patients \bar{n} = 118*	Asymptomatic HIV+ Gay Men \bar{n} = 40*	Gynecology Patients Colposcopy \bar{n} = 100*	Gynecology Patients Laser \bar{n} = 50*	Junior and Senior Under- graduates \bar{n} = 100*	Junior and Senior Under- graduates \bar{n} = 240*	Freshmen Under- graduates \bar{n} = 85*
Monitoring Score	8.84	9.14	8.10	10.29	10.13	10.10	10.11	10.13	10.00
Blunting Score	4.48	3.85	3.63	4.18	4.09	3.70	4.78	4.58	3.80

* (S. Miller, personal communication, June, 1991)

Summary of Methodology

The purpose of this study is to determine the relationship between general orientation to information and the information needs of women who have had multiple sclerosis for varying lengths of time. Part One of the study was designed to examine the effects of orientation to information and length of time with MS on women's interest in various topics, the amount of information wanted and their preference for formats. Part Two was designed to determine the reaction to general and specific information of women who have had MS up to three years and who have different orientations to information.

CHAPTER 3

ANALYSES AND RESULTS OF PART ONE: THE TOPICS AND FORMATS PREFERRED BY WOMEN WITH MS

This chapter reports the results of the analyses of the data collected during Part One of the study. The data set consisted of responses to the Miller Behavioral Style Scale (MBSS), the Krantz Health Opinion Survey-Information subscale (KHOS-I), as well as the Interest, Amount and Format questionnaires. In this chapter, the effects of general orientation to information and length of time with MS (three different time periods) on interest in, amount of information wanted, and preference for format for 29 topics relevant to people with MS was assessed. As noted in Chapter 2, the three different time periods of the disease included: Phase 1—newly diagnosed to one year; Phase 2—the active coping stage (2-3 years); and Phase 3—the acclimated stage (5-7 years). Of the 160 women who returned the questionnaires, 77 were blunters and 81 were monitors. Two women did not complete the MBSS.

Interest and Amount of Information

The hypothesis formulated for this part of the study postulated that regardless of their length of time with MS, women whose general orientation to information is vigilance or monitoring would be more interested in and want more information about their disease than women whose general orientation to information is that of avoidance or blunting. To address this hypothesis, two 5-point scales were used to ascertain the subjects' interest in and desire for information on 29 topics. As shown in Appendix A, a score of 1 indicated that a respondent was not interested in or wanted no information, while a score of 5 indicated that the respondent was extremely interested or wanted all information on that topic. For ease of discussion, these scales will be referred to as the "Interest" and "Amount" questionnaires. Total interest (TIS) and total amount (TAS)

scores were obtained by adding the individual scores for each topic on each questionnaire. The highest attainable score is 145.

Table 4: Mean, Median, Standard Deviation and Range of Scores for Total Interest Score and Total Amount Score

	Mean	Median	Standard Deviation	Range
TIS (n=150)	104.86	107.00	23.44	8-145
TAS (n=153)	104.78	108.00	23.78	4-145

The results of the two-way ANOVAs revealed that neither length of time with MS nor general orientation to information as reflected in MBSS and KHOS-I scores was associated with the women's overall interest in these 29 topics or the amount of information they wanted. Since no differences were found to exist between monitors and blunterns (MBSS) or low and high information scorers (KHOS-I), the hypothesis that monitors and high information scorers would be more interested in and want more information than would blunterns and low information scorers was not supported at this macro level of analysis. However, the finding did prompt two questions: (1) did any association exist between MBSS, KHOS-I and the total interest and total amount scores; and (2) did any differences exist between monitors and blunterns or low and high information scorers in terms of individual topics of information?

Association between General Orientation to Information, TIS and TAS

An attempt was made to address the first question by calculating Pearson r correlation coefficients, the results of which are reported in Table 5. Years of education and age were included. It was not surprising to find a significant correlation between TIS and TAS, $r=.62$, $p = .01$, i.e., between the women's total interest in and the amount of information they wanted on the 29 topics. However, the presence of a weak but

significant correlation between TIS and MBscore, $r=.21$, $p = .05$, indicates some tendency for monitors to be more interested, generally, than blunters in the topics included on the questionnaire. The amount of information wanted by the women appeared to decrease with their age, as suggested by the weak but significant negative correlation between TAS and age, $r= -.17$, $p = .05$.

Another finding is worthy of note. The KHOS-I and MBscore were not significantly correlated, indicating that these scales measured different aspects of the women's orientation to information. For example, although a weak but significant correlation between education and the KHOS-I subscale suggested that better educated women had a somewhat greater preference for information, no similar correlation was noted between MBscore and education.

Table 5: Pearson r Correlation Coefficients for Education, Age, MBscore, KHOS-I, TIS and TAS

	Education	Age	MBscore	KHOS-I	TIS
Education	1.00				
Age	-.13	1.00			
MBscore	.03	-.08	1.00		
KHOS-I	.23**	-.01	-.10	1.00	
TIS	-.06	-.12	.21*	.02	1.00
TAS	-.04	-.17*	.05	.01	.62**

* $p < .05$; ** $p < .01$

The finding of a significant albeit weak negative correlation between TAS and age suggested that further investigation might be worthwhile. Was age or level of education associated with the women's interest in the 29 topics or the amount of information they desired? To find out, additional Pearson r correlation coefficients were calculated; only the significant results are reported in Table 6.

Table 6: Pearson r Correlation Coefficients for Age and Education with Interest and Amount, by Topic

	Age Interest	Age Amount	Education Amount
career choices	-.38**	-.36**	
employer relations	-.34**	-.33**	
pregnancy	-.55**	-.53**	
sexual problems	-.17*	-.19*	
pain	.20*		
relations with physicians	.22**	.20*	
mutual support groups	.22**		
living aids	.20*	.19*	-.17*
biographies	.21*		
MS Society	.25**	.19*	-.21**
stress, alcohol, smoking		-.23**	
religious material		.18*	
understanding caregiver role			-.18*
government agencies			-.26**
effects of overheating			-.22**

Note: No significant correlations between education and interest were found for any of the 29 topics.

* $p < .05$; ** $p < .01$

Since the average age of the women in this study was 41 years, it was perhaps not surprising to find that, relative to other topics, they were less interested in or desired less information on topics such as career choices, employer relations, pregnancy and sexual problems. Age was also negatively correlated with the amount of information the women wanted on the effects of stress, smoking, and alcohol on MS, indicating perhaps (a) an experiential knowledge of the effects of these three variables on the disease or their general well-being, or (b) the irrelevance of one (or more) of these variables to the respondent. In fact, when answering this question, some women scratched out the word(s) 'smoking' or 'alcohol', thus deleting the variable on which they did not want information. Instead, the women indicated more interest in and wanted more information on pain, relations with physicians, mutual support groups, living aids, biographies,

religious materials and the Multiple Sclerosis Society.

The women's level of education was associated with the amount of information they wanted on five topics. Specifically, less educated women wanted more information on living aids, MS Society, understanding the caregiver role, government agencies and the effects of overheating, a condition which may worsen symptoms for many people with this disease.

Differences between Low and High Scorers on a per Topic Basis

Prompted by the absence of significant differences between monitors and blunters (as reflected by the MBSS scores) or between low and high information scorers (as reflected by the KHOS-I scores) and total interest and total amount scores, all topics were analyzed individually. That is, an attempt was made to ascertain if any differences existed between low and high scorers on MBSS or KHOS-I over the three time periods by performing two-way analyses of variance (ANOVA) for the interest and amount scores for each of the 29 topics. Again, the results indicated that the MBSS and KHOS-I were measuring different aspects of the women's general orientation to information. Monitors and blunters (using the MBSS measure) differed significantly from one another in their response to four topics (uncertainty, memory problems, hereditary aspects of MS and understanding the caregiver role), while low and high information scorers (using the KHOS-I measure) differed significantly from one another on seven topics (mutual support groups, pain, muscle spasticity, employer relations, friendships, MS Society and living aids).

Only these eleven topics for which significant results were obtained are discussed here, organized by scale. A posteriori testing was done on the significant results using the Tukey-Kramer (TK) procedure, which is recommended for nonorthogonal contrasts when "sample n 's are unequal...but the basic assumption of normality and homogeneity of variance ...are tenable" (Kirk, 1982, p. 119).

Results of the two-way ANOVAs using MBSS. The discussion in this section is limited to the results of two-way analyses of variance on the four topics (two physiological and two psychological) for which significant results were found using MBSS. In addition to the discussion, the results of the findings are also summarized in Table 7. As noted in Chapter 2, the mean of the MBscores ($M=4.36$; $n=158$) was used to divide the women who participated in this part of the study into monitor and blunter groups.

Uncertainty:

In multiple sclerosis, the uncertainty about the course, prognosis and treatments makes coping with the disease more difficult. Few studies have addressed the issue of uncertainty specifically in MS, although the term is often used in conjunction with the disease. This topic was included in the questionnaire to determine how much of a concern it was for these women with MS.

Measuring interest in the topic of uncertainty revealed a significant interaction between MBtype² and length of time with MS, $F(2,135) = 3.07$, $p=.049$. Pairwise comparisons revealed that newly diagnosed monitors ($M=4.94$) were more interested in information about uncertainty than either newly diagnosed blunters ($M=4.13$) or the monitors in Phase 3 ($M=4.24$).

Memory problems:

For amount of information wanted about memory problems, a significant interaction between MBtype and length of time with MS was found, $F(2,143) = 4.19$, $p=.017$. Blunters ($M=4.63$) in Phase 3 wanted more information than the monitors in this phase ($M=3.63$). These same 5-7 year blunters ($M=4.63$) also wanted more information than

² Whereas the term MBscore has been used to describe the range of monitoring/blunting scores, the term MBtype denotes actual monitors and blunters.

newly diagnosed blunters ($\underline{M}=3.47$). In fact, blunters in Phase 3 of the disease appeared to want more information on memory problems than did any other group.

Hereditary or genetic aspects of MS:

For interest on the topic of heredity, a significant interaction was obtained between MBtype and length of time with MS, $F(2,138) = 4.97, p=.01$. Monitors in Phase 1 ($\underline{M}=4.71$) and blunters in Phase 2 ($\underline{M}=4.52$) were significantly more interested in information on heredity than were blunters in Phase 1 ($\underline{M}=3.38$).

Understanding the caregiver role:

A significant interaction between MBtype and length of time with MS was found for interest on the topic of understanding the caregiver role, $F(2,133) = 4.27, p=.016$. The newly diagnosed monitors ($\underline{M}=3.94$) were significantly more interested in information on the role of the caregiver than were the newly diagnosed blunters ($\underline{M}=2.81$).

Table 7: Summary of the Results of ANOVAs using MBSS Interest or Amount by MBtype by Length of Time with MS

Topic	Interest/ Amount	Interaction/ Main effect	MBtype	Phase of Disease
uncertainty	interest	interaction	monitors	1
memory problems	amount	interaction	blunters	3
hereditary aspects	interest	interaction	monitors blunters	1 2
caregiver role	interest	interaction	monitors	1

Note: In the column, MBtype, the group who was more interested in or wanted more information on the topic is listed, while the number in the last column designates the group's length of time with MS.

Summary of the MBSS Results

From these findings, it appears that blunters in the newly diagnosed group wanted

somewhat less information on some topics than monitors at this phase of the disease. Interestingly, however, for two topics (hereditary aspects and memory problems), blunters became more interested or wanted more information after having coped with the disease for several years.

Results of the two-way ANOVAs using KHOS-I. As noted above, low and high scorers on the KHOS-I subscale differed significantly from one another on 7 topics. Again, the mean of the KHOS-I was used to divide the participants into high and low information scorers ($M=4.54$; $n=160$). The discussion in this section is limited to the seven topics for which significant results were revealed by two-way ANOVAs, including physiological and social topics. The results are also displayed in Table 8.

Mutual support groups:

A significant main effect for general orientation to information, $F(1,142) = 4.84$, $p=.029$, revealed that low information scorers ($M=3.67$) wanted more information on the topic of mutual support groups than high information scorers did ($M=3.17$), regardless of phase of disease.

Pain:

For amount of information wanted on pain, there was a significant main effect for general orientation to information, $F(1,143) = 7.34$, $p=.008$. Again, low information scorers ($M=4.13$) wanted significantly more information on this topic than did high information scorers ($M=3.56$), regardless of phase of disease.

Muscle spasticity:

For the amount of information wanted on muscle spasticity, there was a significant main effect for general orientation to information, $F(1,143) = 4.46$, $p=.036$.

Regardless of phase of disease, low information scorers ($M=4.56$) wanted more information on muscle spasticity than did high information scorers ($M=4.23$).

Multiple Sclerosis Society:

A significant main effect for general orientation to information was observed for amount of information wanted on the MS Society, $F(1,141) = 5.20$, $p=.024$. Again, the same pattern was observed. Low information scorers ($M=3.97$) wanted significantly more information on the MS Society than did high information scorers ($M=3.50$), regardless of phase of disease.

Living aids:

The final topic for which a significant main effect for general orientation to information was observed for amount of information was living aids, $F(1,142) = 4.16$, $p=.043$. Once again, regardless of phase of disease, low information scorers ($M=3.51$) wanted significantly more information on this subject than did the high information scorers ($M=3.01$).

Employer relations:

For interest in the topic of employer relations, a significant interaction was found between KHOS-I and length of time with MS, $F(2,135) = 3.22$, $p=.043$. Both high information scorers in Phase 2 ($M=3.38$) and low information scorers ($M=3.35$) in Phase 3 were significantly more interested in information on employer relations than were high information scorers in Phase 3 ($M=2.36$).

Friendships:

For interest in literature on friendships, there was a significant interaction between KHOS-I and length of time with MS, $F(2,136) = 3.12$, $p=.047$. In Phase 3, low

information scorers ($M=3.70$) expressed more interest in this topic than did high information scorers ($M=2.96$). In addition, a significant difference was noted between high information scorers in Phase 2 ($M=3.91$) and Phase 3 ($M=2.96$), the former showing more interest in information on friendships than the women who had been diagnosed for five years or more.

Table 8: Summary of the Results of ANOVAs using KHOS-I Interest or Amount by KHOS-I by Length of Time with MS

Topic	Interest/ Amount	Interaction/ Main effect	KHOS-I	Phase of Disease
mutual support groups	amount	GOTI	low	n/a
pain	amount	GOTI	low	n/a
muscle spasticity	amount	GOTI	low	n/a
MS Society	amount	GOTI	low	n/a
living aids	amount	GOTI	low	n/a
employer relations	interest	interaction	high	2
			low	3
friendships	interest	interaction	high	2
			low	3

Note: GOTI=significant main effect for general orientation to information.

Summary of KHOS-I Results

Paradoxically, it seems, the women whose scores on the KHOS-I suggested that they had a low preference for information actually wanted more information than those who scores suggested that they had a high preference for information. Where significant interactions occurred between the length of time the women had had MS and their general orientation to information (i.e., employer relations and friendships), both high and low scorers were found to be interested in these topics. However, high information scorers were interested in the topics earlier in the disease process than were low information scorers.

Length of Time with MS

Since the time frame within which topics are important to women with MS is an important aspect of this study, it is necessary to discuss the two topics for which women's interest in or preference for amount of information varied, depending on the phase of the disease, rather than on their orientation to information in general. Using the MBSS measure, a two-way ANOVA, examining the amount of information wanted by the women on the topic of education and support for family members, revealed a significant main effect for length of time with MS, $F(2,140) = 5.75, p=.004$. Pairwise comparisons revealed that women in Phase 2 or the active coping stage ($M=4.28$) wanted more information on the topic of education and support for their family members than did the women who had had MS for 5-7 years ($M=3.54$).

Using the KHOS-I measure, a two-way ANOVA, examining interest in nutritional information, revealed a significant main effect for length of time with MS, $F(2,141) = 3.29, p=.040$. Newly diagnosed women ($M=4.29$) expressed more interest in nutritional information than did the women who had had MS for 5-7 years ($M=3.46$).

The findings reveal in what stage of the disease these two topics become important. In the first year of having the disease, nutritional information seems to be of interest, while information on education and support for family members appears to be desired after the women have coped with MS for two to three years.

Topics of Greatest and Least Interest to Women with MS

Not all topics were of interest to the women who took part in this study. Tables 9 and 10 list the topics in descending order of preference, i.e., from those in which the greatest overall interest was indicated to the least, and those topics for which the greatest amount of information was requested to those for which the least information was requested. On average, the topics which seem to generate the most interest and requests for information are the physiological topics, such as fatigue and the hereditary aspects of

MS, while those of least concern are topics relating to careers, pregnancy and religion.

Table 9: Topics Ranked by Interest

Topic	Total number of responses	Mean	Standard Deviation	# and % of "extremely interested" responses
fatigue	146	4.49	.96	102 (69.9%)
hereditary aspects	146	4.28	1.17	96 (65.8%)
hidden disability	147	4.33	1.13	96 (65.3%)
muscle spasticity	147	4.34	1.00	91 (61.9%)
uncertainty	143	4.34	.98	87 (60.8%)
gen info on MS	148	4.17	1.20	89 (60.1%)
exercise	147	4.18	1.07	83 (56.5%)
overheating	146	4.10	1.24	81 (55.5%)
nutrition	147	3.97	1.27	78 (53.1%)
insurance	146	3.97	1.29	76 (52.1%)
stress	145	4.03	1.21	75 (51.7%)
emotional behaviour	142	4.15	1.06	73 (51.4%)
govt agencies	144	4.00	1.25	73 (50.7%)
memory problems	143	3.97	1.26	72 (50.3%)
bowel/bladder	147	4.03	1.22	74 (50.3%)
educ/support family	144	3.86	1.27	65 (45.1%)
pain	142	3.90	1.18	61 (43.0%)
relations with MD	143	3.81	1.28	61 (42.7%)
MS Society	145	3.86	1.19	61 (42.1%)
sexual problems	144	3.49	1.45	54 (37.5%)
biographies	146	3.59	1.31	50 (34.2%)
mutual support	143	3.48	1.33	48 (33.6%)
friendships	142	3.49	1.35	43 (30.3%)
living aids	147	3.14	1.53	43 (29.3%)
caregiver role	140	3.29	1.36	40 (28.6%)
employer relation	141	3.00	1.57	37 (26.2%)
career choices	136	2.96	1.53	34 (25.0%)
pregnancy	140	2.18	1.62	27 (19.3%)
religious literature	144	2.51	1.46	25 (17.4%)

Table 10: Topics Ranked by Amount of Information Requested

Topic	Total number of responses	Mean	Standard Deviation	# and % of "want everything" responses
fatigue	150	4.47	1.01	106 (70.7%)
hereditary aspects	149	4.48	.96	105 (70.5%)
muscle spasticity	149	4.39	.96	96 (64.4%)
uncertainty	148	4.31	1.11	95 (64.2%)
gen info on MS	150	4.11	1.30	93 (62.0%)
hidden disability	147	4.11	1.28	86 (58.5%)
insurance	148	4.03	1.33	84 (56.8%)
bowel/bladder	150	4.07	1.29	85 (56.7%)
exercise	150	4.15	1.15	85 (56.7%)
emotional behaviour	147	4.12	1.19	83 (56.5%)
overheating	148	4.16	1.19	83 (56.1%)
stress	146	4.10	1.21	79 (54.1%)
govt agencies	149	3.97	1.35	80 (53.7%)
memory problems	150	3.97	1.32	80 (53.3%)
nutrition	149	3.94	1.27	76 (51.0%)
pain	149	3.83	1.34	70 (47.0%)
educ/support family	144	3.95	1.21	68 (46.3%)
MS Society	147	3.73	1.33	63 (42.9%)
sexual problems	148	3.48	1.52	60 (40.5%)
relations with MD	150	3.66	1.29	53 (35.3%)
mutual support	148	3.41	1.43	52 (35.1%)
biographies	148	3.50	1.36	52 (35.1%)
caregiver role	147	3.33	1.45	49 (33.3%)
living aids	148	3.25	1.50	47 (31.8%)
friendships	148	3.34	1.46	43 (29.1%)
employer relation	143	2.97	1.62	40 (28.0%)
career choices	144	2.95	1.59	39 (27.1%)
pregnancy	145	2.12	1.62	29 (20.0%)
religious literature	148	2.36	1.49	25 (16.9%)

Summary of Findings on Interest in and Amount of Information Wanted on the 29 Topics

The information needs of the women who participated in this study correspond to those reported in other studies, (see, for example, Phillips, 1986, and Brooks & Matson, 1987). In those studies, the authors reported that people with MS needed information in the following topic categories: physiological, social, psychological and economic. According to these authors, the primary information needs of people with MS concern the disease process and its long term effects. The results of this study support these earlier findings, as the topics of greatest interest to the women who participated in this study were physiologically-oriented. While some psychological and economic topics generated considerable interest (e.g., hidden disability, uncertainty, insurance and government agencies from whom financial support can be obtained), other similarly oriented topics did not garner much interest (e.g., biographies, religious material and career options). In addition, socially related topics, such as friendships or mutual support groups, were of little interest to the women in this study.

Interest in and the amount of information wanted on the various topics was also examined from the perspective of the women's general orientation to information as well as the length of time they had had the disease. When general orientation to information was the only significant factor affecting interest or amount, low information scorers, rather than high information scorers, as measured by KHOS-I, appeared to want more information about some topics. However, a different picture emerged when both the women's general orientation to information (as measured by MBSS) and length of time they had had MS were taken into account. It seems that newly diagnosed monitors were somewhat more interested in or wanted more information on some topics than did blunters in the same phase of the disease. Further, monitors, as well as high KHOS-I scorers, appeared to want more information or to be more interested in these topics earlier in the disease process than did blunters and low KHOS-I scorers. In a general sense, disease phase appeared to have little relationship to the women's interest in and

desire for more information, except for two topics: women in the first two stages of the disease appeared to be somewhat more interested in or to want more information on education and support for family members and nutrition than did the women who had been coping with MS for a longer period of time, i.e., 5-7 years.

Before turning to a discussion of the women's preferences for format on the 29 topics, it is necessary to comment on the two scales used to determine the women's general orientation to information, since they measured different aspects of their orientation to information.

Comparison of the MBSS and KHOS-I for assessing general orientation to information of women with MS. In this study, an attempt was made to ascertain if the general orientation to information of women with MS was associated with their interest in and desire for more information on 29 topics known to be relevant to people with this disease. Two scales were used to measure this general orientation to information, the Miller Behavioral Style Scale and a more health-related measure, the Krantz Health Opinion Survey.

The value of the Miller Behavioral Style Scale (MBSS) and the Krantz Health Opinion Survey-Information subscale (KHOS-I) must be judged on the information they provided about the women with MS and their information needs. Although the MBSS and the KHOS-I measured different aspects of the women's general orientation to information, some comparisons can be made between the two scales. First, the women's general orientation to information, as measured by both MBSS and KHOS-I, revealed a similar number of high and low scorers: the MBSS included 81 monitors and 77 blunners (two women did not complete the MBSS), whereas the KHOS-I revealed 82 high information scorers and 78 low information scorers. Although there were slightly more high scorers than low scorers on both measures, the differences were not significant. Second, for some topics, similar patterns were observed, that is, high scorers wanted information in earlier stages of the disease, whereas the reverse was noted for low

scorers. However, that was where the similarity between the measures ended, as the KHOS-I showed low information scorers wanting more information than high information scorers, while the MBSS revealed that monitors were more interested in information than were blunters.

The different findings of these two measures may be a result of the design of the KHOS. According to the authors, Krantz, Baum and Wideman (1980), the KHOS was meant to be used in routine medical situations and the questions "do not refer to severe or traumatic illnesses" (p. 980). The statements on the questionnaire may have been too general to have allowed the women to respond from their own situation as people with a chronic illness. In other words, the questions may not have been perceived by the women as relevant to a medical situation related to their multiple sclerosis, but to a less serious or acute situation. Their patterns of communication may be quite different during routine medical care than they are for MS-related care. Decisions about how to answer the questions (i.e., from a healthy or MS perspective) may have confounded their responses. Thus, a general health-related questionnaire may not be reliable when it is used in chronic disease situations.

Although one author, Steptoe (1989, 1991), has voiced concern with some of the scenarios included on the MBSS, they are fairly general and most people could associate with them through personal experience or vicariously through the mass media. Because these scenarios are familiar, people can indicate responses they would normally use in that situation. In other words, the MBSS allowed the women in this study to portray their reaction to the threatening events within the context of their having MS. Thus, the MBSS may reflect the women's general orientation to information more accurately than the KHOS-I because the scenarios had no connection with their MS.

Format Preferences for Information

The hypothesis concerning format preferences postulated that throughout the disease, monitors would want more information in any format than would blunders. Respondents were asked to express their preference for different formats in which information could be delivered on various topics. These formats included print (books, pamphlets, medical articles or popular magazine articles), audiocassette, video or "other." Overall, "other" formats were suggested only infrequently by the participants and those they did mention included newspapers, TV programs, newsletters, children's books, seminars and classes.

Participants were also asked to indicate from whom they would like to receive information. These human sources were categorized as: physicians, health professionals, social workers, the MS Society, people with MS, spouse, family, friends and other. Physicians included neurologists, family practitioners or anyone else with an MD degree. The health professional category included nurses, dietitians, occupational or physical therapists, and health or sports experts. Family included relatives by blood or marriage. Spouses or partners were singled out as a separate category because these people occurred frequently in the subjects' responses. Support groups as well as "another person with MS" or a "friend with MS" were coded as MS person, whereas the category, friends, was restricted to friends not qualified by the words MS. The "other" category included all the individuals who did not fit into any of the other eight categories, such as clergy, insurance agents, lawyers, home care, fitness instructor. In most cases, the "other" people suggested as human resources were appropriate to the topic. For example, members of the clergy were cited as a resource for religious or spiritual material, insurance agents for information on insurance questions and experts for information on the genetic aspects of MS. Some unexpected responses also turned up, such as travel agent for the effects of overheating; "myself" in response to the pain and fatigue topics;

Dr. Roy Swank for nutritional information and Dr. Ruth on sexual problems. Librarians were mentioned by three respondents as sources of information on biographies or autobiographies of women with MS.

Preference for Type of Format

The data collected from the Format questionnaire provided an opportunity to examine the women's preferences for information from a general, as well as a specific topic by topic, perspective. A discussion of the general preference for print or human sources precedes a more detailed discussion of the format preferences for each topic.

Four categories were created to reflect the subjects' responses to each topic. The categories and the results are outlined in Table 11. For many topics, more blunters than monitors in Phases 1 and 2 indicated they did not want information from any source. More newly diagnosed blunters than monitors wanted information from human sources, whereas in Phases 2 and 3, the groups are reversed. The preference for print sources of information reveals a different pattern. More newly diagnosed monitors than blunters preferred print sources, while in Phases 2 and 3 of the disease, monitors preferred print sources less often than did blunters. In the final category, more monitors than blunters indicated both print and human sources for the various topics.

Table 11: Overview of Sources Chosen by Blunters and Monitors in All Three Phases of the Disease

Phase of disease	General orientation to information	No sources indicated	Human sources only	Print sources only	Both print and human sources	Total
1	Blunters	187	17	67	251	522
	Monitors	79	9	71	334	493
2	Blunters	378	17	208	383	986
	Monitors	205	28	160	564	957
3	Blunters	253	21	164	287	725
	Monitors	294	27	103	475	899

In order to test for significant differences between blunters and monitors for type of sources chosen, binomial z tests were done on each of the three formats for both monitors and blunters in all three phases of the disease (see Table 12). According to Sprinthall (1990), binomial z tests are used to identify "the differences between two independent *sample* proportions" (p. 432) and can be used "if both samples have an N of at least 100" (p. 432).

Table 12: Results of Binomial z Tests for Differences between Blunters and Monitors for Types of Sources

Phase of disease	No sources indicated	Human sources only	Print sources only	Both print and human sources
1	8.43**	1.46	.77	-6.49**
2	8.29**	1.78	2.47*	9.05**
3	.932	.13	5.94**	5.39**

** $p = .01$; * $p = .05$

As outlined in the last column, the results of the z tests reveal that in all three phases of the disease, monitors wanted more information from both print and human sources than did blunters, thus supporting the hypothesis that monitors would want more information regardless of format. The results also reveal that in the first two phases of the disease, significant differences existed between blunters and monitors, that is, more blunters preferred no information than did monitors. Interestingly, however, after the first year of having MS, more blunters than monitors preferred print sources.

Preference for Format Measured by MBtype and Length of Time with MS

In order to ascertain if monitoring or blunting and length of time with MS were associated with the women's format preferences, loglinear analyses were conducted for each of the 14 formats for each of the 29 topics (the "other" formats were not included in these analyses). The format for each topic was coded as book1, pamphlet1, book2, pamphlet2, etc., so that each format would be tied to each topic.

Loglinear analysis is a method of measuring the effect of two or more categorical independent or "explanatory" variables on one dependent or "response" dichotomous variable (Fienberg, 1980). Marascuilo and Busk (1987) defined it as "... a way to study main effects and interactions for multidimensional contingency tables with categorical data" (p. 443). Although loglinear analysis is likened to a two-way ANOVA, it is a "chi-square-based measure" that "attempts to identify the structure underlying a set of categorical variables" (DiLeonardi & Curtis, 1988, p. 179). In this study, the dependent dichotomous variable was the format for each topic, for example, book1 (yes or no), while the independent categorical variables were MBtype (blunters or monitors) and length of time with MS (Phases 1, 2 or 3). Since it was necessary to run four hundred and six analyses to address the question of format preferences, only the significant results are reported. The Likelihood Ratio Chi Square (G^2) and the Pearson Chi Square (X^2) for each significant result are included, although Fienberg (1980) suggests that the Pearson is

preferable to G^2 in cases of small or empty cell counts.

To provide some order to the discussion of the results, the topics have been organized into physiological, psychological, social and economic categories. Within these categories, the topics are ranked according to percent of interest as recorded in Table 9 above. Given the volume of results to report, figures for each significant result have been drawn both to provide a visual representation of the information and to reduce the need in many cases for lengthy explanations. Figures that portray more unusual results have been given numerical notations and are included in the text, while those with more standard results were given alphanumeric notations and can be found in Appendix C. In addition, since the significant interaction for all results is between the women's general orientation to information and the length of time with MS, these two phrases will not be repeated when each interaction is discussed.

Physiological Topics

Fatigue:

Fatigue is a major problem for people with MS, who often describe their fatigue as overwhelming. Thus it was not surprising to find a high level of interest (70% of the respondents) in this topic, or that the participants wanted information in all print formats, on audiocassettes and videotapes as well as from physicians, family and spouses.

For both books and medical articles on fatigue, significant interactions were found between general orientation to information and length of time with MS (see Table 13). All newly diagnosed monitors selected books, while only 56.3% of newly diagnosed blunters preferred this format. In Phases 2 and 3, more blunters than monitors wanted information on fatigue in book form (see Figure A1).

Preference for medical articles on fatigue was higher for both newly diagnosed monitors (100%) and those in the second or active coping phase of the disease (89.7%) who displayed more interest in medical articles than did blunters in the same time

periods. However in Phase 3, blunters wanted more information in this format than did monitors (see Figure A2).

Table 13: Fatigue: Loglinear Analysis Summary Table for Books and Medical Articles

Format	df	n	G ²	p	X ²	p
books	2	139	14.40	.001	11.63	.003
medical articles	2	139	6.81	.033	5.07	.079

Some respondents indicated their spouses as resources for information.³ However, the results show that the longer they had the disease, the less often the women indicated this source, $G^2(2, n=139) = 6.54, p=.038$; $X^2(2, n=139) = 7.31, p=.026$. In other words, more newly diagnosed women (29%) referred to spouses than did the women in Phases 2 (13%) or 3 (10.2%) of the disease (see Figure A3).

Preference for pamphlets, $G^2(1, n=139) = 5.60, p=.018$; $X^2(1, n=139) = 5.52, p=.019$, and popular magazine articles, $G^2(1, n=139) = 5.36, p=.021$; $X^2(1, n=139) = 5.24, p=.022$, was associated with MBtype (see Figures A4 and A5). In all three phases of the disease, monitors preferred these two print formats for information on fatigue more than blunters did. The same pattern held for both audiocassettes, $G^2(1, n=139) = 3.99, p=.046$; $X^2(1, n=139) = 3.92, p=.048$, and videos, $G^2(1, n=139) = 5.23, p=.022$; $X^2(1, n=139) = 5.13, p=.024$ (see Figures A6 and A7). Finally, more monitors than blunters preferred physicians, $G^2(1, n=139) = 4.65, p=.031$; $X^2(1, n=139) = 4.56, p=.033$, and family members, $G^2(1, n=139) = 4.94, p=.026$; $X^2(1, n=139) = 4.13, p=.042$, as human sources of information about fatigue. In fact, no blunters in Phase 3 of the

³ It is unclear if the respondents were suggesting spouses or family members as sources of information or if they were indicating their desire to speak to these people about problems such as fatigue. For the purpose of this chapter, the spouse or family member will be considered as a source of information, but a more complete discussion of this issue will be undertaken in the last chapter.

disease indicated family members as a possible source for information on fatigue (see Figures A8 and A9).

Hereditary or genetic aspects of MS:

The second topic of major concern to the participants was the hereditary or genetic nature of MS. Researchers have indicated that although MS is "not directly inherited... it clearly does occur in people who are genetically susceptible" (Reingold, 1992, p. 7). Not surprisingly, therefore, 60% of the respondents said they were interested in this topic and preferred this information in such formats as pamphlets, popular magazine articles, audiocassettes, videos, as well as from physicians.

For popular magazine articles on the genetic nature of MS, there was a higher percentage of monitors than blunters in Phase 1 who indicated a preference for this format. However, in the other two phases of the disease, the percentage of blunters was higher than that of monitors (see Figure B1), resulting in a significant interaction, $G^2(2, n=134) = 6.84, p=.033$; $X^2(2, n=134) = 6.43, p=.044$.

MBtype was associated with preference for one print format, pamphlets, $G^2(1, n=134) = 4.74, p=.029$; $X^2(1, n=134) = 4.66, p=.031$, and for both audiocassettes, $G^2(1, n=134) = 5.78, p=.016$; $X^2(1, n=134) = 4.61, p=.032$, and videos, $G^2(1, n=134) = 10.31, p=.001$; $X^2(1, n=134) = 9.63, p=.002$. Monitors wanted more information in these formats than did blunters (see Figures B2, B3 and B4). However, no blunters in Phase 1 indicated audiocassettes as a preferred format for information on hereditary or genetic aspects of MS. Not surprisingly, the only human source preferred for information about the hereditary or genetic aspects of MS was physicians $G^2(1, n=134) = 5.08, p=.024$; $X^2(1, n=134) = 5.31, p=.021$, as more monitors than blunters wanted information from doctors on this topic (see Figure B5).

Muscle spasticity or weakness:

Fifty-seven percent of respondents expressed interest in the topic of muscle spasticity. Human resources were preferred over print and included physicians, social workers, health professionals, another MS person and the MS Society. In addition, audiocassettes were selected as a format of choice for the delivery of information on muscle spasticity or weakness.

Significant interactions were noted for both MS Society and MS person (see Table 14). Only monitors in Phases 1 and 2 and blunters in Phase 3 indicated their preference for obtaining information on muscle spasticity from the MS Society (see Figure C1). Similar variations in interest were noted for another person with MS as a informational resource. That is, only monitors in Phase 1 and blunters in Phases 2 and 3 indicated that they preferred to obtain information on muscle spasticity from another person with the same disease (see Figure C2).

Table 14: Muscle Spasticity: Loglinear Analysis Summary Table for MS Society and MS Person

Format	df	n	G ²	p	X ²	p
MS Society	2	139	6.49	.039	4.99	.082
MS Person	2	139	11.42	.003	8.98	.011

Length of time with the disease was associated with women's preference for information from social workers and health professionals (see Table 15). The newly diagnosed group (22.6%) wanted to talk to social workers more than did the women in Phase 2 (5.1%) or Phase 3 (2.0%) (see Figure C3). For health professionals, the order was reversed. The longer the women had the disease, the more interested they were in talking to health professionals, as the percentage in Phase 3 was the highest (28.6%), dropping to 22% for Phase 2 and 6.5% for newly diagnosed women (see Figure C4).

Table 15: Muscle Spasticity: Loglinear Analysis Summary Table for Social Workers and Health Professionals

Format	df	n	G ²	p	X ²	p
Social workers	2	139	11.27	.004	12.92	.002
Health professionals	2	139	6.72	.035	5.98	.050

More monitors than blunters, in all phases of the disease, preferred an audiocassette format for information on muscle spasticity, $G^2(1, n=139) = 4.05, p=.044$; $X^2(1, n=139) = 3.96, p=.047$ (see Figure C5). Similar findings were noted for physicians, that is, physicians were the preferred source of information about this topic for more monitors than blunters, $G^2(1, n=139) = 4.43, p=.035$; $X^2(1, n=139) = 4.34, p=.037$ (see Figure C6).

General information on MS:

Although "general information on MS" is a broad topic and could be construed as ambiguous, it was included because it reflects the content of many of the introductory pamphlets produced by the MS Society. General information on MS can also be found in popular magazine articles and autobiographies, where most authors do not go into any depth about the disease. Interest in this topic ranked fourth in the list of topics at 60.1%.

MBtype was found to be associated with the choice of two formats in which information on this topic could be delivered, namely popular magazine articles, $G^2(1, n=143) = 6.04, p=.014$; $X^2(1, n=143) = 5.96, p=.015$, and videos, $G^2(1, n=143) = 9.64, p=.002$; $X^2(1, n=143) = 9.54, p=.002$. Again, regardless of stage of disease, monitors wanted more information in these two formats than did blunters (see Figures D1 and D2). In addition, more monitors indicated family members as sources of information about MS than did blunters, $G^2(1, n=143) = 4.01, p=.045$; $X^2(1, n=143) = 3.19, p=.074$. In fact, no blunters in Phase 3 of the disease indicated family as a source of general information

about multiple sclerosis (see Figure D3).

Length of time with MS was associated with the women's preference for spouses as informational resources, $G^2(2, n=143) = 10.64, p=.005$; $X^2(2, n=143) = 9.48, p=.009$. The women in Phase 2 or the active coping stage (32.8%) most often suggested talking with their spouses, followed by newly diagnosed women (25%). Very few women in the 5-7 year range (8%) suggested their spouses (see Figure D4).

Exercise, fitness and yoga:

Since individual exercise programs, fitness routines, yoga and Tai Chi are frequently recommended for people with MS, it was not surprising that 57% of the participants were interested in information on these topics.

Significant interactions were found for both medical articles and health professionals. In the case of medical articles, the percentage of monitors in Phase 1 who wanted to read medical articles was greater than that of blunterners in the same phase of the disease. However, in Phases 2 and 3, the pattern is reversed, that is, the percentage of blunterners was slightly higher than that of monitors, $G^2(2, n=134) = 6.23, p=.044$; $X^2(2, n=134) = 5.90, p=.052$ (see Figure E1).

For health professionals, a slightly different pattern was observed. For instance, only in Phase 2 was the percentage of monitors higher than that of blunterners. The newly diagnosed blunterners were the only ones in this phase to think about health professionals as sources of information, as no monitors indicated any health professional. Similarly in Phase 3, more blunterners than monitors considered health professionals as relevant sources of information on exercise, fitness or yoga, $G^2(2, n=134) = 6.85, p=.033$; $X^2(2, n=134) = 5.63, p=.066$ (see Figure E2).

The choice of books as a format for information on exercise was associated with MBtype, $G^2(1, n=134) = 6.86, p=.009$; $X^2(1, n=134) = 6.87, p=.009$. What is interesting about this result is that blunterners wanted more books on exercise than did monitors in all

three phases of the disease (see Figure 1).

Insert Figure 1 about here

The preference for pamphlets on exercise was associated with length of time with MS, $G^2(2, n=134) = 5.46, p=.065$; $X^2(2, n=134) = 6.31, p=.043$. The women in Phase 1 (51.6%) were less interested in pamphlets on exercise than were either the women in Phase 2 (77.6%) or Phase 3 (75.6%) (see Figure 2).

Insert Figure 2 about here

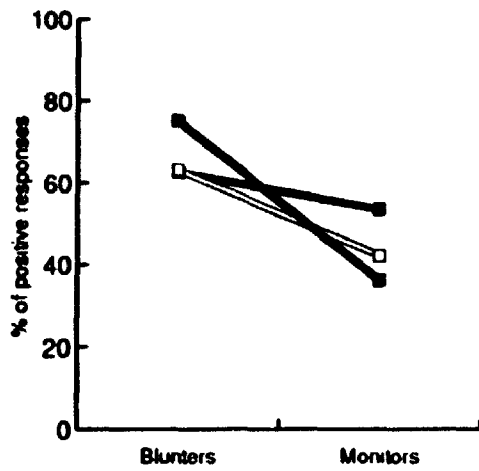
Effects of overheating (hot baths, sunbathing):

Overheating, which can cause MS symptoms to worsen, was of interest to 56% of the respondents. The women's preference for audiocassettes, videos and medical articles, as well as for physicians, spouses and friends was associated with MBtype. For information about overheating, both audiocassettes (see Figure F1) and videos (see Figure F2) were preferred by more monitors than blunters in all three phases of the disease (see Table 16).

Table 16: Effects of Overheating: Loglinear Analysis Summary
Table for Audiocassettes and Videos

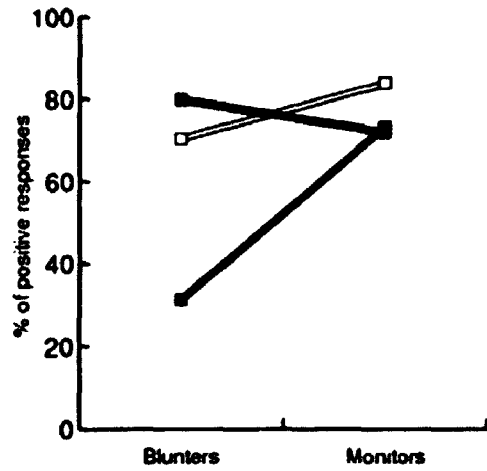
Format	df	n	G ²	p	X ²	p
audiocassettes	1	129	11.60	.001	8.91	.003
videos	1	129	4.35	.037	4.35	.037

There were three human sources from whom the participants preferred to receive information: physicians, spouses and friends. As noted above, their choices were



$G^2(2, n = 134) = 6.858, p = .009$
 $X^2(2, n = 134) = 6.865, p = .009$

Figure 1: Books



$G^2(2, n = 134) = 5.46, p = .065$
 $X^2(2, n = 134) = 6.31, p = .043$

Figure 2: Pamphlets

associated with MBtype. Physicians were the preferred sources for information on the effects of overheating for more monitors than blunters in all three phases of the disease, $G^2(1, n=129) = 6.21, p=.013$; $X^2(1, n=129) = 6.21, p=.013$ (see Figure 3).

Insert Figure 3 about here

Similarly, more monitors than blunters indicated their preference for spouses, $G^2(1, n=129) = 5.91, p=.015$; $X^2(1, n=129) = 5.89, p=.015$, and friends, $G^2(1, n=129) = 5.63, p=.018$; $X^2(1, n=129) = 4.47, p=.035$ as informational resources about the effects of overheating (see Figures F3 and F4).

The only print source for which a significant main effect for MBtype was revealed was medical articles. In Phases 1 and 3, more monitors than blunters preferred medical articles on the topic of overheating, whereas in Phase 2, the reverse was noted, i.e., more blunters than monitors preferred medical articles $G^2(1, n=129) = 4.64, p=.031$; $X^2(1, n=129) = 4.48, p=.034$ (see Figure 4).

Insert Figure 4 about here

A significant main effect for length of time with MS was also noted for audiocassettes. The longer the women had MS, the more interested they were in audiocassettes on this topic, $G^2(2, n=129) = 6.01, p=.050$; $X^2(2, n=129) = 4.95, p=.084$. That is, the women in Phase 3 (18.6%) preferred audiocassettes more than did those in Phase 2 (10.7%) or Phase 1 (10%) (see Figure F5).

Nutritional information:

Various diets, such as the gluten-free diet, have been touted as a way to retard the progression of multiple sclerosis. Judy Graham and Dr. Roy Swank, among others, have

**Table 18: Nutrition: Loglinear Analysis Summary Table
for Social Workers and Health Professionals**

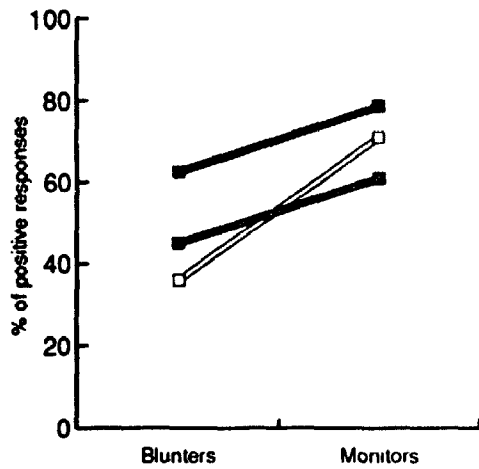
Format	df	n	G ²	p	X ²	p
social workers	2	127	6.92	.031	6.11	.047
health professionals	2	127	6.77	.034	6.82	.033

Effects of stress, smoking or alcohol:

Preference for medical articles on stress, smoking or alcohol was similar in Phases 1 and 3, but not in Phase 2, resulting in a significant interaction $G^2(2, n=126) = 9.58, p=.008$; $X^2(2, n=126) = 7.75, p=.021$. All newly diagnosed monitors who responded to this question wanted to read medical articles on these topics, whereas only 64.3% of blunters in the same time period indicated that they wanted information in this format. In Phase 3, a similar preference was observed. However, in Phase 2, the pattern was reversed, as more blunters than monitors indicated an interest in medical articles on the effects of stress, smoking and alcohol (see Figure 5).

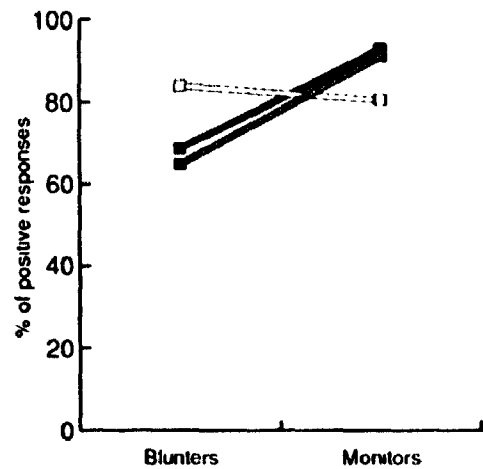
Insert Figure 5 about here

The women's preference for audiocassettes for information on these topics was associated with MBtype, $G^2(1, n=126) = 7.06, p=.008$; $X^2(1, n=126) = 5.73, p=.017$ (see Figure H1). Similar findings were noted for both spouses (see Figure H2) and family (see Figure H3 and Table 19). In all cases, monitors wanted more information than did blunters. In fact, very few blunters indicated audiocassettes or either of the human sources for information on stress, smoking or alcohol.



$G^2(1, N = 129) = 6.21, p = 0.03$
 $X^2(1, N = 129) = 6.21, p = .013$

Figure 3: Physicians



$G^2(1, N = 129) = 4.64, p = .031$
 $X^2(1, N = 129) = 4.48, p = .034$

Figure 4: Medical Articles

Effects of Overheating
 Phase 1 ● Phase 2 □ Phase 3 ■

written books on dietary regimes for people with MS. In their autobiographies, some authors with MS have discussed various diets they have found helpful. Since some believe a link exists between control of MS and diet, it was not surprising to find that 53.1% of the respondents were extremely interested in information on nutrition.

Significant interactions were found for books and popular magazine articles (see Table 17). Similar patterns were noted for both of these print formats; that is, more newly diagnosed monitors than blunters preferred these formats. However, in the later stages of the disease, blunters preferred these two formats for information on nutrition more than monitors did (see Figures G1 and G2). A significant interaction was also revealed for spouses $G^2(2, n=127) = 5.46, p=.065$; $X^2(2, n=127) = 5.98, p=.050$. Only three groups indicated they wanted to talk to their spouses about nutrition, including blunters in Phase 1 and monitors in both Phases 2 and 3 (Figure G3).

**Table 17: Nutrition: Loglinear Analysis Summary
Table for Books and Popular Magazine Articles**

Format	df	n	G ²	p	X ²	p
books	2	127	9.97	.007	7.68	.021
popular articles	2	127	10.38	.006	9.71	.008

The longer the women had had MS, the less interested they were in obtaining nutritional information from social workers (see Table 18). In other words, newly diagnosed women (20.7%) preferred to discuss this topic with social workers more often than did the women in Phases 2 (9.8%) or 3 (4.3%) (Figure G4). The results were different in the case of health professionals (see Table 18), as the women in Phase 2 (33.3%) and Phase 3 (17%) preferred talking to health professionals, including dietitians or nutritionists, more than did the newly diagnosed women (10.3%) (Figure G5).

Table 18: Nutrition: Loglinear Analysis Summary Table for Social Workers and Health Professionals

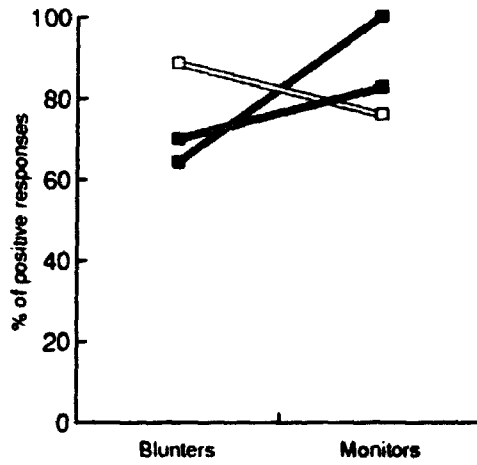
Format	df	n	G ²	p	X ²	p
social workers	2	127	6.92	.031	6.11	.047
health professionals	2	127	6.77	.034	6.82	.033

Effects of stress, smoking or alcohol:

Preference for medical articles on stress, smoking or alcohol was similar in Phases 1 and 3, but not in Phase 2, resulting in a significant interaction $G^2(2, n=126) = 9.58, p=.008$; $X^2(2, n=126) = 7.75, p=.021$. All newly diagnosed monitors who responded to this question wanted to read medical articles on these topics, whereas only 64.3% of blunters in the same time period indicated that they wanted information in this format. In Phase 3, a similar preference was observed. However, in Phase 2, the pattern was reversed, as more blunters than monitors indicated an interest in medical articles on the effects of stress, smoking and alcohol (see Figure 5).

Insert Figure 5 about here

The women's preference for audiocassettes for information on these topics was associated with MBtype, $G^2(1, n=126) = 7.06, p=.008$; $X^2(1, n=126) = 5.73, p=.017$ (see Figure H1). Similar findings were noted for both spouses (see Figure H2) and family (see Figure H3 and Table 19). In all cases, monitors wanted more information than did blunters. In fact, very few blunters indicated audiocassettes or either of the human sources for information on stress, smoking or alcohol.



$G^2(2, n = 126) = 9.58, p = .008$

$X^2(2, n = 126) = 7.75, p = .021$

Figure 5: Medical Articles

Effects of Stress, Smoking or Alcohol

Phase 1 ● Phase 2 ◻ Phase 3 ●

**Table 19: Effects of Stress: Smoking or Alcohol: Loglinear Analysis
Summary Table for Spouses and Family**

Format	df	n	G ²	p	X ²	p
spouses	1	126	9.75	.002	15.72	.000
family	1	126	3.94	.047	3.04	.081

Preference for two sources of information, one print format and one human source, was influenced by length of time with MS. Women in Phase 2 (87.3%) wanted to read pamphlets on the effects of stress, smoking or alcohol more than did the women in Phase 3 (74.4%) or in Phase 1 (60.7%), $G^2(2, n=126) = 7.48, p=.024$; $X^2(2, n=126) = 7.58, p=.023$ (see Figure H4). A different pattern was noted for social workers. That is, it was the newly diagnosed women (21.4%) and those in Phase 2 (18.2%) who wished to receive information from social workers more than did the women in Phase 3 (2.3%), $G^2(2, n=126) = 10.01, p=.007$; $X^2(2, n=126) = 7.31, p=.026$. Interestingly, an equal number of newly diagnosed monitors and blunders indicated social workers as sources of information on this topic (see Figure H5).

Memory problems or forgetfulness:

Since memory may be affected by the demyelination process, it is not surprising that this topic was a cause of concern to many of the respondents in this survey (45%). Significant interactions were found for two formats, namely popular magazine articles and medical articles (see Table 20). In all phases of the disease, monitors more often than blunders wanted to read popular magazine articles and medical articles for information on these topics. The only exception to this was in Phase 2, where the percentage of blunders who wanted information from medical articles was slightly higher than the percentage of monitors (see Figures I1 and I2).

**Table 20: Memory Problems: Loglinear Analysis Summary
Table for Popular Magazine Articles and Medical Articles**

Format	df	n	G ²	p	X ²	p
popular articles	2	123	6.44	.040	6.00	.050
medical articles	2	123	7.23	.027	5.41	.067

The choice of physicians as sources of information about memory problems was associated with length of time with MS in that the longer the women had had the disease, the less often they preferred this source, $G^2(2, n=123) = 6.74, p=.034$; $X^2(2, n=123) = 6.50, p=.039$. In other words, women in Phase 1 (74.1%) referred to doctors more often than did the women in Phase 2 (52%) or Phase 3 (43.5%) (see Figure 13).

The preference for friends as informational sources was associated with MBtype, $G^2(1, n=123) = 6.24, p=.012$; $X^2(1, n=123) = 4.67, p=.031$. More monitors than blunters in all three phases of the disease suggested friends as sources of information about memory problems or forgetfulness (see Figure 14).

Bowel and bladder problems:

Bowel and bladder problems are common in people with MS and slightly more than 50% of the respondents were "extremely interested" in this topic. Although a significant interaction for spouses was found, $G^2(2, n=131) = 5.80, p=.055$; $X^2(2, n=131) = 6.80, p=.033$, only three groups indicated their spouses as sources of information: blunters in Phase 1 and monitors in Phases 2 and 3 (see Figure 11).

The length of time with MS was associated with the women's preference for talking to health professionals, $G^2(2, n=131) = 7.82, p=.020$; $X^2(2, n=131) = 7.45, p=.024$. While no newly diagnosed women indicated a preference for health professionals as sources of information on bowel and bladder problems, more women in Phase 3 (13.7%) selected health professionals than did women in Phase 2 (3.6%) (see

Figure J2). Finally, MBtype was associated with the women's choice of both audiocassettes and videos as outlined in Table 21. The pattern was the same for both formats, that is, monitors preferred these formats more often than did blunters (see Figures J3 and J4).

**Table 21: Bowel and Bladder Problems: Loglinear Analysis
Summary Table for Audiocassettes and Videos**

Format	df	n	G ²	p	X ²	p
audiocassettes	1	131	5.79	.016	5.45	.020
videos	1	131	7.99	.005	6.62	.010

Pain:

According to literature published by the MS Society, some people with MS may experience some pain during the course of the disease (Multiple Sclerosis Society of Canada, 1991). However, this topic was of interest to only 43% of the women in this study.

A significant interaction was found for medical articles, $G^2(2, n=123) = 6.10$, $p=.047$; $X^2(2, n=123) = 4.52$, $p=.105$. A higher percentage of monitors than blunters preferred to read medical articles for information about pain in Phases 1 and 3, but not in Phase 2, where slightly more blunters than monitors selected this format. Medical articles were of particular interest to monitors in Phase 1, as all who responded chose this format. On the other hand, blunters in this same time frame were the least interested in medical articles on pain (see Figure K1).

A significant interaction was also noted for spouses, $G^2(2, n=123) = 11.23$, $p=.004$; $X^2(2, n=123) = 8.55$, $p=.014$. Whereas the newly diagnosed blunters were very interested in talking with their spouses about pain, no newly diagnosed monitors suggested this source. In Phase 2, no blunters indicated spouses, while monitors did. In

Phase 3, monitors indicated this source more often than blunters (see Figure K2).

The preference for A/V formats was associated with MBtype (see Table 22). In all three phases of the disease, more monitors than blunters indicated their preferences for obtaining information about pain via audiocassettes and videos (see Figures K3 and K4).

Table 22: Pain: Loglinear Analysis Summary Table for Audiocassettes and Videos

Format	df	n	G ²	p	X ²	p
audiocassettes	1	123	6.87	.009	6.48	.011
videos	1	123	5.97	.015	5.72	.017

Sexual problems associated with MS:

Although interest in this topic was not high (37.5%), respondents indicated their preferences for information from books and pamphlets, as well as from physicians and social workers.

A significant interaction was noted for books, $G^2(2, n=105) = 10.62, p=.005$; $X^2(2, n=105) = 9.36, p=.009$. All newly diagnosed monitors who responded to this question preferred this format, whereas the percentage of newly diagnosed blunters preferring books was less. In Phases 2 and 3, the reverse was observed, that is, there was a higher percentage of blunters than monitors who indicated books as the format of choice for information on sexual problems (see Figure 6).

 Insert Figure 6 about here

In addition, a significant interaction was revealed for social workers, $G^2(2, n=105) = 9.06, p=.011$; $X^2(2, n=105) = 7.50, p=.023$. There was a higher percentage of

blunters than monitors in Phase 3 who preferred to receive information about sexual problems from social workers, whereas in Phases 1 and 2, the percentage of monitors was higher than the percentage of blunters (see Figure 7).

Insert Figure 7 about here

The women's preference for pamphlets, $G^2(1, n=105) = 8.26, p=.004$; $X^2(1, n=105) = 8.35, p=.004$, as well as for physicians, $G^2(1, n=105) = 4.08, p=.043$; $X^2(1, n=105) = 4.06, p=.044$, was associated with MBtype, as more monitors than blunters wanted to read pamphlets or speak to their doctors about sexual problems (see Figures 8 and 9).

Insert Figures 8 and 9 about here

The length of time the women had had MS was also associated with their preference for pamphlets on sexual problems, $G^2(2, n=105) = 6.62, p=.037$; $X^2(2, n=105) = 7.06, p=.029$. Newly diagnosed women preferred this format less often (58.3%) than did the women in Phase 2 (84.8%) and Phase 3 (74.3%) of the disease (see Figure L1).

Independent living aids:

Living aids, such as specially adapted kitchen utensils, lifting aids and transfer seats, have been included in this section because their use results from physiological problems such as muscle weakness. Overall, the participants were not very interested in this topic (29.3%), but those who did answer this question wanted to read books and pamphlets as well as speak with social workers, health professionals and the MS Society, which can provide these aids.

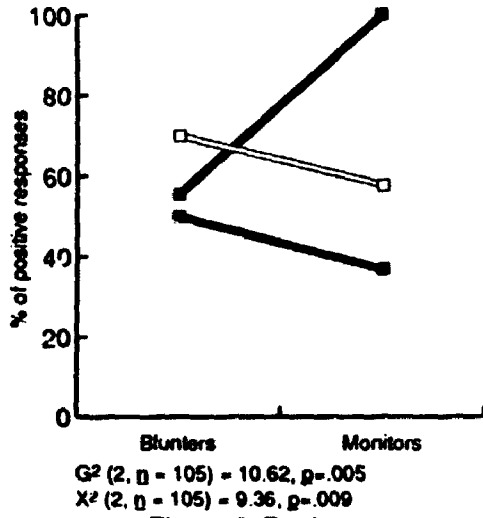


Figure 6: Books

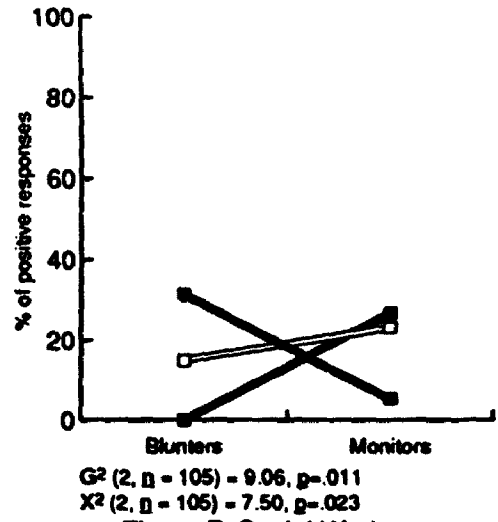


Figure 7: Social Workers

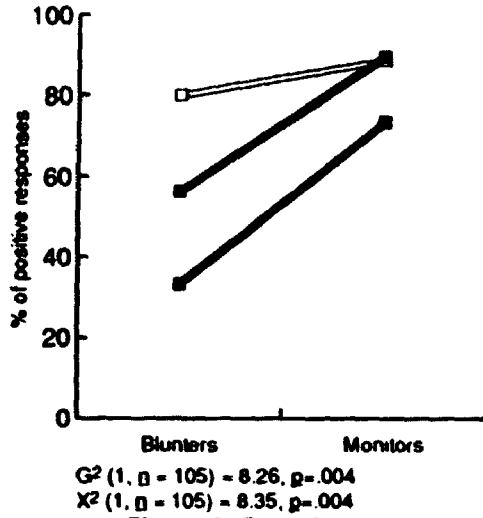


Figure 8: Pamphlets

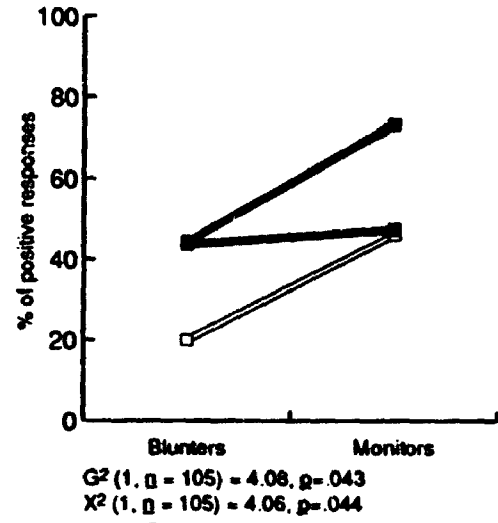


Figure 9: Physicians

Sexual Problems Associated with MS
 Phase 1 ● Phase 2 □ Phase 3 ■

A significant interaction was found only for health professionals, $G^2(2, n=97) = 7.36, p=.025$; $X^2(2, n=97) = 5.60, p=.061$. The group who most preferred these people as sources of information were the monitors in Phase 2, while no blunters in this stage of the disease referred to health professionals. A higher percentage of monitors than blunters was also noted in Phase 1, but in Phase 3, the percentage of blunters was higher than the percentage of monitors (see Figure M1).

The longer the women had had MS, the less they preferred to read books on the topic of living aids, $G^2(2, n=97) = 7.09, p=.029$; $X^2(2, n=97) = 7.98, p=.018$. A similar pattern was observed in relation to the women's preference for seeking information from the MS Society about living aids. In fact, no one in Phase 3 suggested the MS Society as a source of information, $G^2(2, n=97) = 6.11, p=.047$; $X^2(2, n=97) = 4.79, p=.091$. Finally, the women in Phases 1 and 3 preferred to obtain information about this topic from social workers more than did the women in Phase 2, $G^2(2, n=97) = 5.56, p=.061$; $X^2(2, n=97) = 6.13, p=.047$ (see Figures M2, M3 and M4).

While it is tempting to postulate that the newly diagnosed women were just shopping for information rather than actually needing it, the researcher met a recently diagnosed woman who was recovering from an acute exacerbation and using a walker. This case emphasizes the unpredictability of the disease and the difficulty in determining why women are seeking information.

MBtype was found to be a significant factor only for popular magazine articles. More monitors than blunters selected this format for information about independent living aids in all three phases of the disease, $G^2(1, n=97) = 4.68, p=.031$; $X^2(1, n=97) = 4.40, p=.036$ (see Figure M5).

Pregnancy and/or contraception:

Although interest in these topics was found to be low (19.3%), a significant interaction was observed for books, $G^2(2, n=48) = 9.87, p=.007$; $X^2(2, n=48) = 9.56,$

$p=.008$. More monitors than blunters were interested in receiving information on these topics in both Phases 1 and 3, while in Phase 2, the reverse was noted (see Figure 10).

Insert Figure 10 about here

A significant interaction for spouses was also noted $G^2(2, n=48) = 7.48, p=.024$; $X^2(2, n=48) = 7.44, p=.024$. However, it was blunters in Phase 1 who were more interested in talking to their spouses than were newly diagnosed monitors. In the next two phases, no blunters, only monitors, suggested spouses as sources of information (see Figure N1).

Interest in pamphlets for information on these topics was found to be associated with the length of time the women had had MS, $G^2(2, n=48) = 6.17, p=.046$; $X^2(2, n=48) = 6.03, p=.049$. The women in Phase 2 were more interested in receiving information about pregnancy or contraception in pamphlet format than were those in Phase 3 or Phase 1 (see Figure 11).

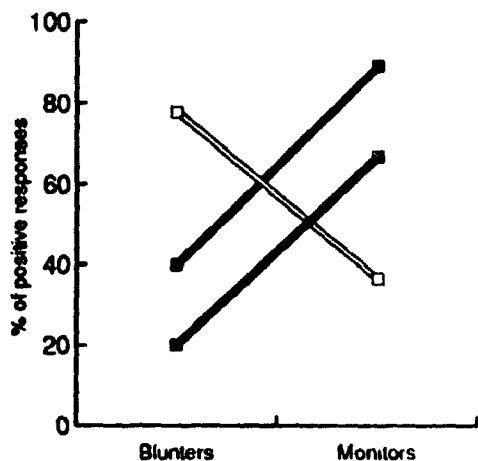
Insert Figure 11 about here

Also on the topics of pregnancy or contraception, preference for video format was associated with MBtype, $G^2(1, n=48) = 4.08, p=.043$; $X^2(1, n=48) = 3.23, p=.072$. Once again, it was monitors who selected this format more than did blunters in all stages of the disease (see Figure N2).

Psychological Topics

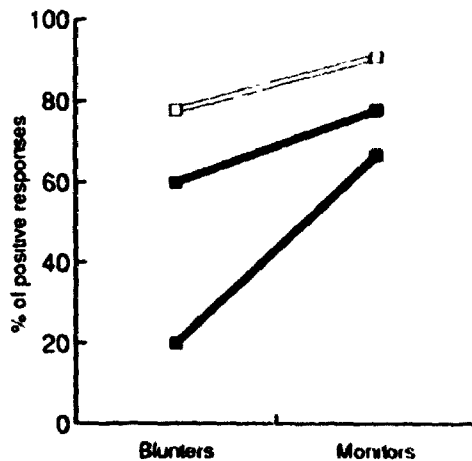
Hidden disabilities:

Many people with MS do not have visible disabilities and thus, do not disclose their illness to others, putting themselves in a delicate situation in which they have to



$G^2(2, n = 48) = 9.87, p = .007$
 $X^2(2, n = 48) = 9.56, p = .008$

Figure 10: Books



$G^2(2, n = 48) = 6.17, p = .046$
 $X^2(2, n = 48) = 6.03, p = .049$

Figure 11: Pamphlets

Pregnancy and/or Contraception
 Phase 1 \leftarrow Phase 2 \leftrightarrow Phase 3 \leftarrow

behave "normally" and yet live within the confines of the disease. It was not surprising, therefore, that 65.3% of the respondents were interested in information on this topic in many formats, including all the print sources and videos, as well as from physicians, family and friends.

The only format for which a significant interaction was found was medical articles, $G^2(2, n=133) = 7.35, p=.025$; $X^2(2, n=133) = 7.00, p=.030$. There was a higher percentage of monitors than blunters in Phase 1 who were interested in reading medical articles on hidden disabilities, while in Phases 2 and 3, the reverse was noted (see Figure O1).

Preference for the remaining three print formats was associated with MBtype (see Table 23). For each format, monitors wanted more information than did blunters (see Figures O2, O3 and O4).

Table 23: Hidden Disabilities: Loglinear Analysis Summary Table for Books, Pamphlets and Popular Magazine Articles

Format	df	n	G ²	p	X ²	p
books	1	133	5.22	.022	5.09	.024
pamphlets	1	133	3.91	.048	3.90	.048
popular articles	1	133	4.32	.038	4.29	.038

Similarly, a significant main effect for MBtype was noted for videos, $G^2(1, n=133) = 4.79, p=.029$; $X^2(1, n=133) = 4.80, p=.028$. Again, monitors wanted more information about hidden disabilities on video than did blunters (see Figure O5). Finally, MBtype was also associated with preference for receiving information about this topic from physicians, family and friends (see Table 24). The same general pattern was observed; that is, more monitors than blunters in all three phases of the disease preferred these three sources of information. In fact, no blunters in Phase 3 wanted to talk to family members, nor did any blunters in Phase 1 indicate friends as sources of information (see

Figures O6, O7 and O8).

Particularly interesting was the finding that physicians were a preferred source of information on how to deal with hidden disabilities. This choice illustrates what has been widely noted in the literature on MS, that is, that people turn to their doctors for answers on everything, regardless of whether or not the issue is likely to be within their knowledge domain.

Table 24: Hidden Disabilities: Loglinear Analysis Summary Table for Physicians, Family and Friends

Format	df	n	G ²	p	X ²	p
physicians	1	133	5.61	.018	5.44	.020
family	1	133	3.89	.049	3.06	.080
friends	1	133	4.73	.030	4.02	.045

Uncertainty

Interest in this topic was quite high (61%). There was one print format, medical articles, for which a significant interaction was found, $G^2(2, n=135) = 12.06, p=.003$; $X^2(2, n=135) = 9.77, p=.008$. Medical articles were preferred by all newly diagnosed monitors who responded to this question, whereas the percentage of blunters who preferred the same format was less. The percentage of monitors in Phase 3 was also higher than that of blunters in the same stage of the disease, but in Phase 2, the reverse was noted (see Figure 12).

Insert Figure 12 about here

Although a significant interaction was also noted for social workers, $G^2(2, n=135) = 10.58, p=.005$; $X^2(2, n=135) = 10.20, p=.006$, a very different pattern of

preferences was observed. Specifically, the percentage of blunterns in Phases 1 and 3 of the disease who wanted to talk to social workers about uncertainty was higher than that of monitors. However, in Phase 2, the opposite was found, as the percentage of monitors was higher than the percentage of blunterns (see Figure P1).

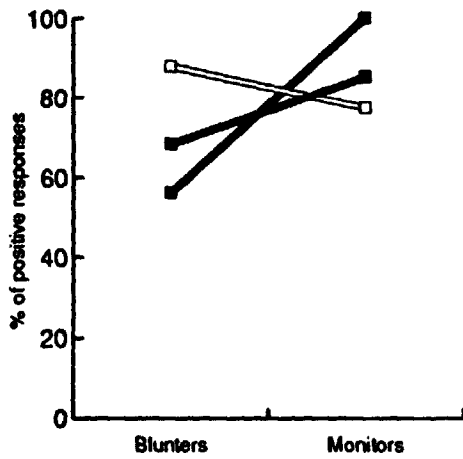
The choice of audiocassettes was affected by MBtype, $G^2(1, n=135) = 5.38$, $p=.020$; $X^2(1, n=135) = 5.05$, $p=.025$. In all phases of the disease, more monitors chose this format for information on uncertainty than did blunterns (see Figure P2). As outlined in Table 25, a significant main effect for MBtype was also observed for physicians and family. The pattern of preference for talking to family members was similar to the pattern noted for audiocassettes (see Figure P3).

The selection of physician as a source of information on uncertainty may reflect the women's need to have some sense of hope in their seemingly hopeless situation. In other words, the doctor is seen as the "only one" who can mitigate the uncertainty with various treatments that have been designed to provide a sense of hope. Thus, more monitors than blunterns in Phases 2 and 3 indicated physicians, but not in Phase 1, where more blunterns (68.8%) than monitors (64.7%) suggested talking to doctors about uncertainty (see Figure 13).

Insert Figure 13 about here

Table 25: Uncertainty: Loglinear Analysis Summary Table for Physicians and Family

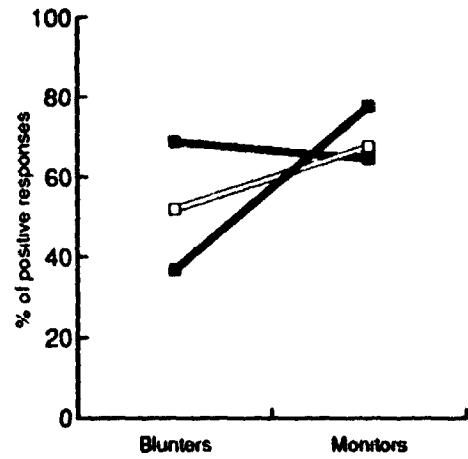
Format	df	n	G ²	p	X ²	p
physicians	1	135	4.00	.046	4.07	.044
family	1	135	7.83	.005	7.92	.005



$G^2 (2, n = 135) = 12.06, p = .003$

$X^2 (2, n = 135) = 9.77, p = .008$

Figure 12: Medical Articles



$G^2 (1, n = 135) = 4.00, p = .046$

$X^2 (1, n = 135) = 4.07, p = .044$

Figure 13: Physicians

Uncertainty

Phase 1 ● Phase 2 □ Phase 3 ■

Emotional behaviour in MS:

Multiple sclerosis plays havoc with the emotions of many sufferers of this disease. As a result, the MS Society has published a booklet entitled "Multiple sclerosis and your emotions" which discusses the more common emotional reactions and how to handle them. Slightly over half of the respondents (51.4%) were interested in information on this topic.

For books and pamphlets, length of time with MS was the factor associated with these choices (see Table 26). Interest in books on emotional behaviour decreased the longer the women had MS. That is, the percentage of newly diagnosed women (77.4%) was highest, followed by those in Phase 2 (63%) and Phase 3 (49%) (see Figure Q1). Preference for pamphlets on this topic ranged from a high of 88% for women in Phase 2 dropping to 77% for those in Phase 3 and 65% for newly diagnosed women (see Figure Q2).

**Table 26: Emotional Behaviour in MS: Loglinear Analysis
Summary Table for Books and Pamphlets**

Format	df	n	G ²	p	X ²	p
books	2	130	6.12	.047	5.99	.050
pamphlets	2	130	6.12	.047	6.32	.043

MBtype affected the women's preference for popular magazine articles and videos. More monitors than blunters selected a video format for information on emotional behaviour, $G^2(1, n=130) = 11.12, p=.001$; $X^2(1, n=130) = 8.99, p=.003$, (see Figure Q3). Although in Phases 1 and 3 more monitors were interested in popular magazines than were blunters, in Phase 2, the opposite was noted, as more blunters (40.7%) than monitors (37.9%) indicated a preference for popular magazines, $G^2(1, n=130) = 4.49, p=.034$; $X^2(1, n=130) = 4.39, p=.036$ (see Figure 14).

Insert Figure 14 about here

Biographies or autobiographies:

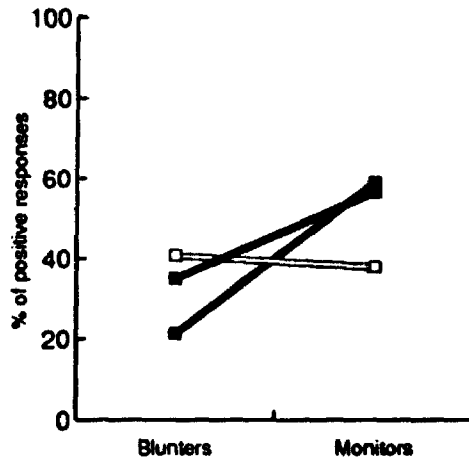
Biographies were included on the questionnaire to determine if women with MS wanted to read about other women with the same disease. The relatively low interest (34.2%) in this topic may suggest the limited usefulness of biographies. The only significant results found were for videos and for the MS Society as a source of information on what biographies are available. Very few women indicated librarians as possible resources for information on available biographies.

The choice of videos was associated with length of time the women had MS $G^2(2, n=105) = 7.59, p=.022$; $X^2(2, n=105) = 7.56, p=.023$. Women in Phase 3 (49%) suggested biographies on video more often than did the newly diagnosed women (31%) or the women in Phase 2 (21.4%) (see Figure R1). A significant main effect for MBtype was associated with the MS Society, in that only monitors referred to the MS Society as a source for information on biographies, $G^2(1, n=105) = 4.57, p=.033$; $X^2(1, n=105) = 3.29, p=.070$ (see Figure R2).

Understanding the caregiver role:

In the pretesting stage of this study, the male partner of a woman who was completing the questionnaire became involved in a discussion of the topics. He felt that many people with MS also need to understand the impact of the disease on caregivers and how their roles are affected. His wife agreed, and the topic was added. Although the overall interest in this topic was relatively low (29%), some women did want to read books and medical articles, view videos and talk to physicians and friends about the caregiver role.

Only for medical articles was a significant interaction noted, $G^2(2, n=82) = 8.40$,



$G^2 (1, n = 130) = 4.49, p = .034$
 $X^2 (1, n = 130) = 4.39, p = .036$

Figure 14: Popular Magazine Articles

Emotional Behaviour in MS
Phase 1 ◀ Phase 2 ◀ Phase 3 ▶

$p=.015$; $X^2(2, n=82) = 8.03, p=.018$. Whereas newly diagnosed blunters were the least interested in this format, monitors in the same time period were the most interested. However, the percentage of blunters was higher than monitors in the other two stages of the disease (see Figure S1). The preference for videos was associated with MBtype, $G^2(1, n=82) = 6.37, p=.012$; $X^2(1, n=82) = 5.01, p=.025$, as more monitors than blunters in all phases of the disease preferred this format (see Figure S2).

Preference for books on this topic was associated with length of time with MS, $G^2(2, n=82) = 7.03, p=.030$; $X^2(2, n=82) = 6.77, p=.034$. The women in Phase 1 (72.2%) indicated books more often than did those in Phase 3 (43%) or Phase 2 (36.1%) (see Figure S3). Length of time with MS was also associated with the women's preference for talking to physicians and friends about this topic (see Table 27). The same chronological order as noted for books was also noted for physicians: Phase 1 (44.4%), Phase 3 (14.3%) and Phase 2 (8.3%) (see Figure S4). And finally, no newly diagnosed women and very few women in Phase 2 suggested talking to friends, while 17.9% of the women in Phase 3 felt that friends were a possible source of information about the caregiver's role (see Figure S5).

**Table 27: Understanding the Caregiver Role: Loglinear Analysis
Summary Table for Physicians and Friends**

Format	df	n	G ²	p	X ²	p
physicians	2	82	9.61	.008	13.57	.001
friends	2	82	8.03	.018	7.55	.023

Religious and spiritual material:

In the research studies discussed earlier, it has been observed that once MS has been accepted, some people seem to find both a sense of inner peace and something positive about having the disease. Also, it is well known that some people turn to religion

in times of stress. Seventeen percent of the women seemed interested in this topic and indicated their preference for two print formats, books and popular magazine articles. In addition, they wanted to talk to their spouses about this topic.

Preference for books was associated with length of time with MS, $G^2(2, n=50) = 6.28, p=.043$; $X^2(2, n=50) = 4.83, p=.090$. Interestingly, the less time the women had had MS, the more interested they were in religious books, as the following percentages show: newly diagnosed women (80%); women in Phase 2 (56%); and women in Phase 3 (47.1%) (see Figure 15).

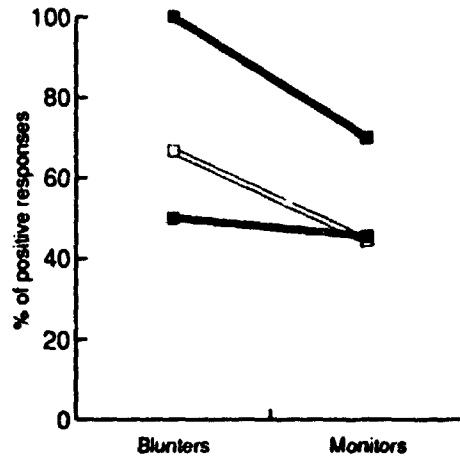
Insert Figure 15 about here

It was not surprising to find that the women's preference for talking to their spouses about religious and spiritual material was associated with MBtype, $G^2(1, n=50) = 4.52, p=.033$; $X^2(1, n=50) = 3.26, p=.072$, since only monitors in all three phases suggested talking to their spouses (see Figure T1). Also, MBtype was associated with preference for popular magazine articles. Although some blunters did indicate popular magazines for religious information, more monitors than blunters preferred this format for information on this topic, $G^2(1, n=50) = 3.86, p=.049$; $X^2(1, n=50) = 3.09, p=.079$ (see Figure T2).

Social Topics

Education and support for family members:

Multiple sclerosis affects not only the patient but also each family member who needs to learn about the disease process and to understand how it will affect her/his life. The MS Society has published some material for family members, but more is directed toward the patient. This topic was included on the questionnaire to determine how relevant the participants felt it was to their situation and to find out what formats suited



$G^2(2, N = 50) = 6.28, p = .043$

$X^2(2, N = 50) = 4.83, p = .090$

Figure 15: Books

Religious or Spiritual Material
Phase 1 ● Phase 2 ◻ Phase 3 ●

the delivery of MS information to their families. Among this sample of women with MS, interest in this topic was moderate (45.1%). The preferred formats included videos, audiocassettes and pamphlets, as well as talking to family members.

The only significant interaction found was for videos, $G^2(2, n=118) = 6.49, p=.039$; $X^2(2, n=118) = 6.11, p=.047$. The percentage of monitors who preferred a video format for information about this topic was greater than the percentage of blunters in each phase of the disease, particularly in Phase 2 (see Figure 16).

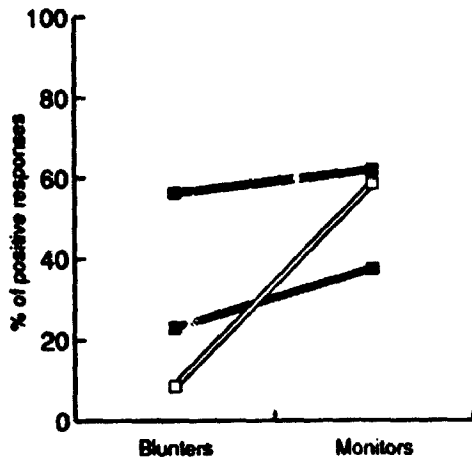
Insert Figure 16 about here

Length of time with MS was associated with the women's preference for audiocassettes, $G^2(2, n=118) = 6.18, p=.045$; $X^2(2, n=118) = 6.44, p=.040$. The order of preference for this format ranged from newly diagnosed women (34.5%) to those in Phase 3 (18.9%) and finally, to the women in Phase 2 (13.5%) (see Figure U1).

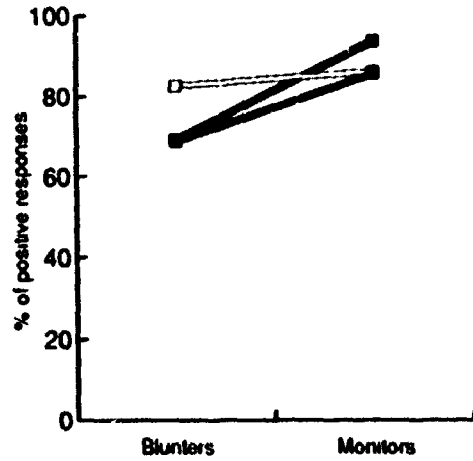
Interest in reading pamphlets containing educational and support information for family members was associated with MBtype, $G^2(1, n=118) = 4.13, p=.042$; $X^2(1, n=118) = 4.06, p=.044$. The popularity of pamphlets for information on this topic is evident from the fairly high response rate of both monitors and blunters. However, in each phase of the disease, more monitors than blunters were noted to prefer this format, especially in Phases 1 and 3 (see Figure 17).

Insert Figure 17 about here

A significant main effect for MBtype was also observed for family members, $G^2(1, n=118) = 3.76, p=.052$; $X^2(1, n=118) = 3.85, p=.050$, as more monitors wanted to speak to family members about this topic than did blunters (see Figure U2).



$G^2(2, n = 116) = 6.49, p = .039$
 $X^2(2, n = 118) = 6.11, p = .047$
Figure 16: Videos



$G^2(1, n = 118) = 4.13, p = .042$
 $X^2(1, n = 118) = 4.06, p = .044$
Figure 17: Pamphlets

Education and Support for Family Members
 Phase 1 \blacklozenge Phase 2 \blacktriangleleft Phase 3 \blacklozenge

Relations with physicians and other health professionals:

Communication problems with physicians have been identified in research studies on people with MS, as noted in Chapter 1. Slightly less than half of the women (42.7%) expressed interest in this topic, suggesting the majority of the women in this study do not experience major problems with physicians or other health professionals, or it may reflect a decrease in problems as time goes on. On the other hand, it could indicate that the women are willing to accept whatever relationship they have with their physicians because they feel so dependent upon them for care. On the questionnaire or in letters to the researcher, some women stated they wished their doctors would listen to them and be more empathic, but only a very few women indicated they would speak to the doctor about their relationship.

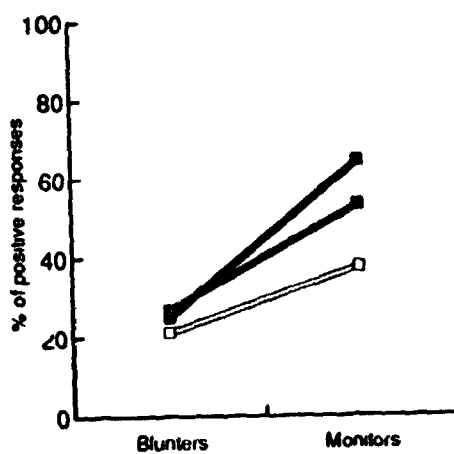
On this topic, there was a significant interaction for pamphlets, $G^2(2, n=95) = 8.53, p=.014$; $X^2(2, n=95) = 8.40, p=.015$. While more monitors in Phases 1 and 2 preferred pamphlets on this topic, more blunters in Phase 3 selected this format (see Figure V1).

A significant main effect for MBtype was observed for popular magazine articles, $G^2(1, n=95) = 6.88, p=.009$; $X^2(1, n=95) = 6.70, p=.010$, as well as for family, $G^2(1, n=95) = 5.52, p=.019$; $X^2(1, n=95) = 4.07, p=.044$. More monitors indicated popular magazine articles (see Figure 18) and family (see Figure V2) than did blunters. In the case of family, no blunters in any phase of the disease chose to talk to family members about their relationship with their doctors.

Insert Figure 18 about here

Multiple Sclerosis Society:

The MS Society, like many non-profit organizations, offers a variety of services to people with MS. Are the women aware of the extent of services and support offered by



$G^2(1, N = 95) = 6.88, p = .009$

$X^2(1, N = 95) = 6.70, p = .010$

Figure 18: Popular Magazine Articles

Relations with Physicians and Other Health Professionals
Phase 1 (●) Phase 2 (□) Phase 3 (■)

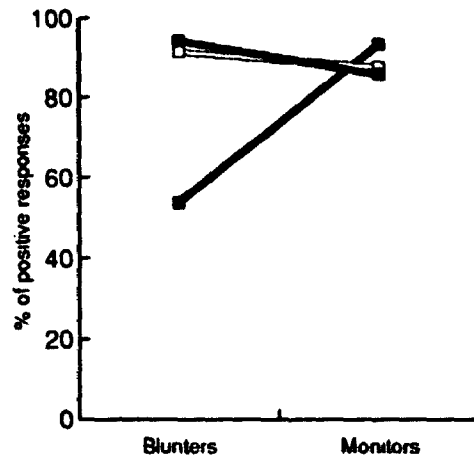
this Society? This question was included to determine if this sample of women with MS perceived a need for information about the organization, how that need changed over the course of the disease, and what formats or sources they preferred. Forty-two percent of the respondents were interested in and wanted information on the MS Society. The preferred formats and sources included pamphlets, videos, physicians and the MS Society itself. A significant interaction was found for each of these formats and sources.

For pamphlets, $G^2(2, n=113) = 6.43, p=.040$; $X^2(2, n=113) = 6.03, p=.049$, a higher percentage of monitors than blunters in Phase 1 wanted information on the MS Society, whereas in Phases 2 and 3, the percentage of blunters was higher than that of monitors. In fact, except for newly diagnosed blunters, all the other respondents considered pamphlets a good vehicle for information about the MS Society (see Figure 19).

Insert Figure 19 about here

As noted above, significant interactions were noted for all formats and sources of information. Video presentation of information on the MS Society was the format of preference for monitors in Phases 1 and 2 and blunters in Phase 3, $G^2(2, n=113) = 11.96, p=.003$; $X^2(2, n=113) = 10.61, p=.005$. Very few blunters in Phase 2 and no blunters in Phase 1 selected this format (see Figure W1).

A similar pattern of responses was noted for physicians (see Figure W2). Only monitors in Phases 1 and 2 wanted to ask their doctors about the MS Society, while in Phase 3, more blunters than monitors thought of talking to their physicians about the MS Society, $G^2(2, n=113) = 6.43, p=.040$; $X^2(2, n=113) = 6.39, p=.041$. And finally, of the respondents who indicated the MS Society as a source of information about itself, the percentage of monitors in Phases 1 and 2 was higher than blunters, while in Phase 3, the reverse was noted, $G^2(2, n=113) = 6.97, p=.031$; $X^2(2, n=113) = 6.84, p=.033$ (see Figure W3).



$G^2(2, n = 113) = 6.43, p = .009$
 $X^2(2, n = 113) = 6.03, p = .010$

Figure 19: Pamphlets

Mutual support groups:

Support groups can be a positive or negative experience for people with MS, as noted in the literature review above. Evidence of ambivalent feelings toward support groups was also noted in the pretesting stage of this study, as some women endorsed support groups, while others refused to attend any meetings. In the sample of women who participated in this study, interest in this topic was relatively low (34%).

For books and videos, significant interactions were found, the results of which are listed in Table 28. The percentage of newly diagnosed monitors who preferred books on this subject was greater than the percentage of blunters. In Phases 2 and 3, the reverse was noted (see Figure X1).

**Table 28: Mutual Support Groups: Loglinear Analysis
Summary Table for Books and Videos**

Format	df	n	G ²	p	X ²	p
books	2	98	6.15	.046	6.28	.043
videos	2	98	6.06	.045	4.52	.105

In Phase 1, only monitors chose videos as a format for information on mutual support groups. Monitors in Phase 2 were slightly more interested in videos than blunters, whereas in Phase 3, the percentage of blunters was higher than that of monitors (see Figure X2).

Friendships:

In some of the biographies read by the researcher, the authors wrote about the importance of friends, being abandoned by friends, or telling friends about the disease. Overall, in this sample of women with MS, interest in this topic was relatively low (30%), although some women added personal comments beside this question. For example, one woman said she had lost all her friends because of MS, while another

stated she had no problems in this area.

A significant interaction was noted for popular magazine articles, $G^2(2, n=94) = 8.57, p=.014$; $X^2(2, n=94) = 6.41, p=.040$. There was a higher percentage of monitors than blunters in all phases. In the newly diagnosed group, no blunters indicated this format, while the percentage of monitors was the highest of all groups. The percentage of monitors in Phase 3 was similarly high, while the remaining groups were more moderate in their choice of popular magazines for information on friendships (see Figure Y1).

MBtype was associated with preference for videos. In all phases of the disease, more monitors than blunters selected videos, $G^2(1, n=94) = 4.97, p=.026$; $X^2(1, n=94) = 3.90, p=.048$, for information on friendships (see Figure Y2).

Economic Topics

Insurance:

Although many women with MS apply for disability insurance, there is a dearth of generic literature on the various types of insurance coverage available. One reason for this, as suggested by a staff member at an MS clinic, is that each case is unique and has to be handled separately. Information about insurance was of considerable interest to the women in this study (52%). The preferred formats, popular magazine articles and videos, chosen by the respondents were somewhat of a surprise. While it is plausible that consumer magazines would carry general articles on insurance, it is more difficult to imagine videos about insurance.

Preference for videos was associated with MBtype, $G^2(1, n=123) = 6.25, p=.012$; $X^2(1, n=123) = 5.87, p=.015$, with monitors being more interested in this format than blunters (see Figure Z1).

A significant interaction was found for popular magazine articles, $G^2(2, n=123) = 8.36, p=.015$; $X^2(2, n=123) = 8.22, p=.016$. The percentage of monitors was higher than the percentage of blunters in both Phases 1 and 3, while in Phase 2, the percentage of

blunters was higher than that of monitors (see Figure Z2).

Government agencies (who they are and how they can help):

Government agencies are similar to insurance companies in that they can offer financial assistance to people with MS. In addition, some agencies may provide other forms of assistance to people with long-term needs. To ascertain if this sample of women needed information on government agencies, this question was included on the questionnaire. The response rate was relatively high (51%) and the preferred formats included popular magazine articles and audiocassettes. The respondents also indicated a desire to speak to physicians and the MS Society about government agencies.

Significant interactions were noted for popular magazine articles, $G^2(2, n=124) = 6.29, p=.043$; $X^2(2, n=124) = 6.26, p=.044$, and the MS Society $G^2(2, n=124) = 6.12, p=.047$; $X^2(2, n=124) = 4.66, p=.097$. Articles in popular magazines were preferred by a higher percentage of monitors in Phases 1 and 3 than blunters. However, in Phase 2, the percentage of blunters who chose popular magazine articles was higher than the percentage of monitors (see Figure AA1). In Phases 1 and 2, more monitors than blunters indicated the MS Society as a resource for information about government agencies, while the reverse was noted for the women in Phase 3 (see Figure AA2).

Women's preference for physicians was influenced not only by length of time with MS, $G^2(2, n=124) = 7.93, p=.019$; $X^2(2, n=124) = 6.77, p=.034$, but also by MBtype, $G^2(1, n=124) = 8.27, p=.004$; $X^2(1, n=124) = 6.66, p=.010$, as more monitors than blunters in all phases of the disease suggested talking to physicians (see Figure AA3). Examining the results by phase of disease, interest in talking to doctors about government agencies was high for the women in Phases 1 (27.6%) and 3 (19.5%) but low for those in Phase 2 (7.4%) (see Figure AA4).

MBtype was also associated with preference for audiocassettes, $G^2(1, n=124) = 8.90, p=.003$; $X^2(1, n=124) = 7.23, p=.007$. Again, more monitors than blunters indicated that audiocassettes would be a good format for information on government agencies (see

Figure AA5).

Employer relations:

Interest in this topic was relatively low (26.2%). The women who responded to this question preferred information in books, popular magazines and on audiocassettes. They also wanted to talk to their spouses about their relationship with their employer.

Significant interactions were noted for books and popular magazine articles (see Table 29). For both these formats, a higher percentage of monitors than blunterns was found in Phases 1 and 3 only. In Phase 2, the percentage of blunterns was higher than the percentage of monitors (see Figures BB1 and BB2).

Table 29: Employer Relations: Loglinear Analysis Summary Table for Books and Popular Magazine Articles

Format	df	n	G ²	p	X ²	p
books	2	80	6.40	.041	6.36	.042
popular articles	2	80	7.71	.021	7.56	.023

A significant interaction was also found for spouses, $G^2(2, n=80) = 6.81, p=.033$; $X^2(2, n=80) = 6.48, p=.039$. There was a higher percentage of blunterns in both Phases 1 and 2 than monitors, who wanted to talk to their spouses about relations with their employers. Although, no blunterns in Phase 3 indicated spouses, 25% of monitors in this stage of the disease did indicate spouses as sources of information (see Figure BB3).

The only format associated with MBtype was audiocassettes, $G^2(1, n=80) = 4.68, p=.031$; $X^2(1, n=80) = 3.87, p=.049$. More monitors than blunterns wanted information on employer relations in this format (see Figure BB4).

Career choices and goals:

Although interest for this topic was also relatively low (25%), the respondents

indicated their preference for information on this topic in three print formats, including books, pamphlets, popular magazine articles. In addition, they wanted to talk to their friends about career choices and goals.

Significant interactions were found for two of the print formats: books and pamphlets (see Table 30). The highest percentage of interest in books on this topic was from newly diagnosed monitors, while the converse was true for newly diagnosed blunters. In Phases 2 and 3, the percentage of blunters was the same (66.7%) and was higher than that of monitors, who were less interested in books on careers (see Figure CC1).

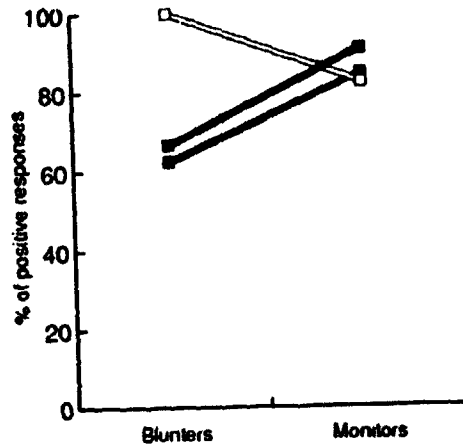
**Table 30: Career Choices and Goals: Loglinear Analysis Summary
Table for Books and Pamphlets**

Format	df	n	G ²	p	X ²	p
books	2	70	7.15	.028	7.09	.029
pamphlets	2	70	6.14	.046	4.94	.085

A significant interaction was noted for pamphlets, as the percentage of monitors in both Phases 1 and 3 was higher than the percentage of blunters in the same phases of the disease. Surprisingly, all blunters in Phase 2 who responded to this question wanted information in pamphlet form, while only 82% of monitors indicated this particular format for information about career choices and goals (see Figure 20).

 Insert Figure 20 about here

Although the response of "friend" as a source of information was scant, a significant interaction was noted, $G^2(2, n=70) = 5.63, p=.060$; $X^2(2, n=70) = 6.18, p=.046$. Only blunters in Phase 1 and monitors in Phases 2 and 3 suggested talking to



$G^2(2, n = 70) = 6.14, p = .046$

$\chi^2(2, n = 70) = 4.14, p = .085$

Figure 20: Pamphlets

friends for information on careers. Since talking to friends about careers is fairly common, one may speculate that age was a factor in the scarcity of this response (see Figure CC2). Finally, preference for popular magazine articles was associated with MBtype, $G^2(1, n=70) = 5.00, p=.025$; $X^2(1, n=70) = 4.88, p=.027$. More monitors than blunters in Phases 1 and 3 chose this format, while in Phase 2, there was a slightly higher percentage of blunters (50%) than monitors (47.1%) (see Figure CC3).

Summary of preference for formats. The results reveal the importance of format in the provision of health care information. The most preferred format was videos, as participants in this study favoured video presentation for 18 of the 29 topics (62%). They also indicated their preference for reading health information in popular magazines (52%), pamphlets and books (49%). Physicians (41%) and spouses (34%) were the most common human resources from whom they were interested in receiving certain kinds of information. The findings also seem to support the results obtained in the "Interest and Amount" section. That is, depending on the topic, monitors seemed to want more information earlier in the disease process, while the reverse holds for blunters. Also, when general orientation to information was the only factor associated with various formats, generally, monitors were observed to want more information than blunters. Overall, the results seem to indicate that, in order to satisfy the considerable information needs of these women with MS, information must be available not only on a wide variety of topics, but also in a variety of formats. In other words, both the content and format of information may require tailoring to meet a woman's specific needs so that she may make sense of her chronic condition.

Summary of Part One

The results obtained in Part One indicate that there are differences between blunters and monitors in their interest in and desire for more information about MS. The differences seem to depend, to some degree, on the particular topic as well as the phase

of the disease with monitors preferring more information than blunterners at earlier phases of the disease. Blunterners, on the other hand, seem to become interested in and want more information later on in the disease process.

Although the women in this study expressed considerable interest in most of the 29 topics, those which garnered the greatest interest were disease-related subjects, particularly fatigue and the hereditary aspects of MS. Topics of little interest to these women concerned careers and employment issues, pregnancy and religion.

Finally, the results revealed the need for information on different topics to be available in more than one format. For the women in this study, the most popular formats for MS information seem to be videos, pamphlets and popular magazine articles, rather than medical articles. Physicians and spouses ranked high on the list of human sources of information, while other people with MS did not seem to be popular as a source of information for these participants. These results emphasize the importance of the vehicle in the delivery of health information and present new challenges to health information providers, including librarians.

In the next chapter, the depth of information preferred by women who are in the first three years of the disease will be examined.

CHAPTER 4

ANALYSIS AND RESULTS OF PART TWO: WOMEN'S PREFERENCE FOR SPECIFICITY OF INFORMATION

This study on the information needs and seeking patterns of women with multiple sclerosis would not be complete without obtaining some indication of the depth of information (general or specific) they preferred. To this end, the second part of the study was designed to ascertain if any association existed between the women's general orientation to information and their preference for general or specific information. It was hypothesized that in the active coping phase of MS (i.e., from diagnosis to three years post-diagnosis) monitors would want both general and specific information, whereas blunters would prefer general information.

While there are many formats in which to package health- or disease-related information, pamphlets seem to be a very common vehicle for the delivery of information of this nature. For example, pamphlets containing information about diabetes mellitus, arthritis, cancer and occasionally multiple sclerosis can be found in pharmacies, supermarkets, libraries and doctors' offices. Therefore, pamphlets were used in this part of the study because this format is a familiar vehicle for health-related information. General and specific pamphlets were written on two topics known to be of relevance to many MS sufferers, namely fatigue and the treatment of acute attacks. Each participant received one of these pamphlets, the Miller Behavioral Style Scale and a short questionnaire designed to elicit her reaction to the pamphlet. Participants were divided into three groups according to the length of time they had had the disease, Phase 1 - newly diagnosed to 12 months ; Phase 2 - 13 to 23 months; Phase 3 - 24 to 36 months.

Preference for General or Specific Information

Although 95 women participated in this part of the study, two did not complete the MBSS. Of the remaining 93, 47 were classified as blunters and 46 as monitors. To

test the hypothesis that monitors would want both general and specific types of information whereas blunters would want only general information, the women were asked to rate the relevance of the information contained in the pamphlet they had received and to provide other opinions on their reactions to the pamphlets (see Appendix B for complete survey).

Relevance. A four-way analysis of variance was carried out for the dependent variable, relevance, where relevance was measured on a 5-point scale ranging from 1 (not relevant) to 5 (very relevant). The independent factors were general orientation to information (monitors or blunters), length of time with the disease (Phase 1, 2 or 3), topic (fatigue or treatment of acute attacks) and depth of information (general or specific). The ANOVA revealed a significant main effect for general orientation to information, $F(1,67) = 4.58, p=.04$. More monitors ($M=3.04$) than blunters ($M=2.57$) rated the pamphlet they had received as relevant to their information needs. Thus, the hypothesis that in the active coping stage of the disease, monitors would want both general and specific information, was supported. Also of interest was the finding of a significant main effect for depth of information, $F(1,67) = 5.84, p=.02$. The women who had received the specific pamphlets ($M=3.07$) found the information to be more relevant than did the women who had received the general pamphlets ($M=2.56$).

The survey which accompanied the pamphlet also included questions designed to assess the women's prior knowledge of the topic they had received, to determine if they wanted more information on that topic and if they would recommend the pamphlet to other people in the same phase of the disease. An attempt was made to gain a better understanding of the women's responses by providing space for them to explain their reactions to the pamphlet they had received. Their responses to these questions form the remainder of this chapter.

Assessment of Prior Knowledge of Topic

Since prior knowledge of a topic may influence one's reaction to it, two questions were included to assess the women's general state of knowledge on the topics in question.

Prior knowledge of the topic. Of the 94 women who responded to this question, the majority of respondents (91.5%) indicated they knew at least something about the topic they had received. Since sources of information are of interest to this study, a brief description of the various sources mentioned by the respondents follows.

Nearly half of the women (46%) stated that they had read books, pamphlets or articles in order to acquaint themselves with this disease. The volume of reading varied from all or most of the books available in local libraries to a few pamphlets. Information about the disease was also obtained from doctors or other health professionals, the MS Society or MS clinics, either in the form of discussions or reading material. Six women cited personal knowledge of MS, as family members also suffered from this disease, while four others credited support groups for additional knowledge about MS. Three women mentioned specific authors whom they found helpful for some of their questions, such as Dr. Roy Swank, a physician who suggests a particular dietary regime for people with MS; Dr. Donald Howland, whose work is unknown to this researcher; and Lynn Risidore, a woman with MS who has written a popular self-help book. Finally, six women stated that part of their knowledge base resulted from their work environment, as registered nurses, nursing assistants or laboratory technicians. Thus, the majority of monitors and blunders had prior knowledge of the particular topic before receiving the pamphlet, having availed themselves of a variety of sources in order to obtain information.

Unanswered questions before reading the pamphlet. The women were asked if they had any questions on the topic prior to reading the pamphlet. If they answered "yes", they were asked to explain their questions. Of the 92 women who responded to

this question, only 30 women indicated that they had questions on the topic of the pamphlet they had received. Crosstabulations showed no significant differences in unanswered questions between monitors and blunters or between women in different phases of the coping stage. In addition, no significant differences were noted for depth of information or topics. Since the nature of the questions posed by the women in all three phases of the disease provides some insight into their information needs, a brief discussion of their questions follows.

Most women who had received the fatigue pamphlets wanted to know about the etiology or cause of fatigue. A few other questions included the relationship between the demyelination process and fatigue, the association between pain and excessive fatigue and the occurrence of fatigue before an exacerbation or seasonal changes.

Questions relating to the pamphlets on treatment of acute attacks ranged from how to identify or prevent exacerbations to what symptoms are treatable, the types of treatments available, the adverse effects of drugs, the seriousness of drug side effects, and the length of time one had to be on drugs. A few women made comments indicative of their need for information about steroids. For example, one woman admitted to a lack of knowledge about Solu-Medrol, a drug mentioned in her specific pamphlet on treatment, while another woman stated that she felt reassured to know that steroids could be used for acute exacerbations.

Helpfulness of the Information Provided in the Pamphlet

The question concerning the helpfulness of the information provided in the pamphlet was directed only at the women who had unanswered questions prior to reading the pamphlet. In other words, the women who did not have unanswered questions before reading the pamphlet were asked to skip this question. As noted above, 30 women indicated they had unanswered questions. Of these 30 women, 28 of them explained how the information had helped or had not helped to answer their questions. An equal number

had received either the general or specific pamphlet. The distribution of their responses is shown in Table 31.

Table 31: Helpfulness of Pamphlets, by Type, to Women who Reported Having Questions

Depth of Information	Not Helpful	Helpful
General Pamphlets	11	3
Specific Pamphlets	6	8

While only three women indicated they had gleaned some information from the general pamphlets, eleven others found the information contained in the general pamphlet too vague to be helpful. Two women were very critical of the general information pamphlets. For example, one wrote, "The information is vague...I honestly felt it was another frustrating piece of literature." The other women echoed her feeling about the vagueness of the information, "It didn't [help]. The pamphlet is so vague that if MS were not mentioned you could be reading about a number of different diseases."

The women who had received the specific pamphlets were more evenly divided in their opinions on the helpfulness of the pamphlet. Some women considered the pamphlets helpful because the information contained therein provided explanations, such as why fatigue occurs and why medication is not required if an attack does not interfere with activities of daily living. However, others found the information not helpful because it was too general or too similar to what they had received from the MS Society. That is, information that was designed to be specific was not necessarily perceived as specific, and in some cases, lacked novelty value.

Desire for More Information

All the subjects were asked if they wanted more information on the topic they had received and what else, if anything, they would like to know. Of the 95 women who

responded to this question, 57 women (60%) indicated they wanted more information. When crosstabulations were carried out, no significant differences in the desire for more information were noted for the women's general orientation to information, length of time with MS, the topic or the depth of information. Of the women who indicated they wanted more information, 39 (63%) stated that they wanted more information on the topic they had received, 16 (28%) asked for other information about MS and two (3.5%) requested information on completely different topics.

Additional information related to the topic of the pamphlet. As noted above, 39 women requested additional information on the topic of the pamphlet they had received. The distribution of responses by topic and depth of information is outlined in Table 32.

Table 32: Additional Information Related to Topic of Pamphlet, by Topic and Depth of Information

Depth of Information	Fatigue	Treatment of Acute Attacks
General Pamphlets	14	9
Specific Pamphlets	8	8

The fourteen women who had received the general pamphlet on fatigue wanted current information on research, drugs and treatments for fatigue, as well as information on how to deal with fatigue, prevent it or combat it. One woman wanted to know what would happen if she ignored her fatigue, while another was interested in the effects of menopause (i.e., hot flashes and loss of sleep) on fatigue. The requests from the eight women who had received the specific fatigue pamphlet were, for the most part, the same. One woman wanted information for her family. Another woman wanted information on the exact [her emphasis] cause of fatigue, while a third respondent listed many questions on fatigue, including the role of stress, amalgam fillings, vitamins, and exercises.

Regardless of the depth of information in the pamphlets about the treatment of acute attacks, most of the participants' requests concerned drug therapy, experimental

drugs, adverse effects of drugs, and current research. A few asked for more information on exacerbations, causes and treatments, how to recognize and prevent them.

Although many of the respondents professed to reading volumes of information on MS, it is not surprising that they still have questions. Many of their requests reflect information needs that are not particularly answerable in print format because of their specificity. That is, the medical information they are requesting often needs to be addressed on a one-to-one basis. In addition, their questions may reflect the fact that what they want to know is just not available.

Other information about MS. In lieu of requesting additional information on fatigue or treatment of acute attacks, 16 women asked for information on other aspects of MS. They wanted information on research and cures for the disease, nerve inflammation or "what technically happens in MS," the hereditary aspects of this disease, pregnancy and childbearing. One woman asked for "positive suggestions" on how to live with MS. As she stated, "clinical information about MS is well documented. Learning to live [her emphasis] with MS is not well documented..." There was also a request for ways of explaining MS to children "so they can understand better."

Information on topics other than MS. Only two women requested information that may or may not be related to MS. For example, one woman wanted to know what permanent damage, other than skin cancers, sunbathing could cause and another woman wanted to know if people who have had TB should not take prednisone. It is possible that this question may have been related to the topic, as she was sent the specific treatment pamphlet which does discuss the use of steroids.

Recommendation of the Pamphlet to Others

The women were asked if they would recommend their pamphlet to others who have had MS the same length of time. Ninety-three women responded to this question: 64 women (69%) indicated they would recommend the pamphlet they had received, 25

(27%) indicated they would not recommend the pamphlet, and four women circled both the "yes" and "no" answers. Crosstabulations revealed no significant differences in recommendations for general orientation to information, length of time with MS or depth of information. However, a significant relationship was observed between their recommendations and the topic received, $\chi^2 (2, N = 93) = 9.72, p=.01$. More women who had received the pamphlet on fatigue (81.6%) indicated they would recommend it than did those who were sent the pamphlet on treatment (54.5%).

Although 93 women responded to this question, not all of them explained their answers. However, from the comments made by 80 (86%) of the women, three themes emerged: the pamphlet contained very little new information; any information about MS is good; and the pamphlets should be given to newly diagnosed patients. A brief discussion of each of these themes follows, as well as a fourth category which contains an assortment of revealing remarks.

Very little new information. Fifteen women (19%) stated that the main reason for not recommending the pamphlets was simply that they found very little new information on these topics. One woman's response spoke for many, as she wrote "I believe that since we have been diagnosed, we know the same or more than the pamphlet." Another woman stated that "Most would already have this information and more, if they have a good relationship with their doctors and had contact with their local MS Society chapter."

Any information is good. More than half of the respondents (50 women or 62%) put forth variations on the theme that "any information is good". Some of them expounded on the importance of having information: to manage one's life around fatigue, to use as a basis for further discussion of treatments with a physician, to refresh one's knowledge about the topics. Others commented on the need for people with MS to learn as much as possible about the disease.

A few women who had received the general pamphlet on fatigue wrote about their feelings of guilt stemming from not having a visible symptom and the difficulty

they have explaining fatigue to others in their lives. For them, the pamphlet legitimized fatigue as a component of MS and they wanted to share this information with others. Another woman made a poignant comment about the specific pamphlet on fatigue. It should be given to others, she said, "so everyone like me knows that they are not forgotten." On a similar note, one woman commented on the value of having specific information in that it gives her a "measure of control and helps her feel not so lost and alone." Some women appreciated the short content, the readability and the "understandable manner" in which the information was presented. Others wanted to share the new information they had gained from the pamphlets.

For new patients. Eleven women (10%) suggested that the pamphlets they received should be given to newly diagnosed patients. As one woman noted, the general fatigue pamphlet would be a quick introduction to the illness. About the specific pamphlet on fatigue, one woman suggested it "might be useful" for the "really newly diagnosed (1-2 months)", while another wrote that if she had received it upon diagnosis, this pamphlet would have helped to relieve her anxiety and to understand what was happening to her body. A few women said it should be given early and be accompanied by additional information. As one woman explained "It would be good in a package of material to be given to a newly diagnosed. It fills an empty niche...I haven't read this type of pamphlet before and it would have been useful in the beginning."

Other comments. The capacity of information to scare people was referred to by seven women who had received the pamphlets on the treatment of acute attacks. One woman said that "any information is better than none" but qualified the statement by adding "...but also don't scare people, they needed [sic] to know about people who still work and have had this for years and doing well." Another woman who answered both "yes" and "no" to this question, commented on the scary aspect of the information in the general treatment pamphlet. She wrote that it "describes severe cases" and since "newly diagnosed patients in this category are few," the pamphlet may worry them. However,

"the title is self explanatory."

Writing about the specific pamphlets on treatment of acute attacks, one woman felt the information in the pamphlet was general enough and "wouldn't scare anyone as to the severity of their case of MS," while another remarked that the pamphlet should be given only to those who are "quite conversant with the topic and are considering these drugs. I would not suggest it be given to people with milder symptoms."

Three other women who also answered both "yes" and "no" to this question were also commenting on the specific treatment pamphlet. One woman stated that the pamphlet could hurt people emotionally if they have not accepted what they have, while another echoed this by stating that some people can "deal with these facts, others don't want to know; depends on the severity of the disease process." The third woman gave explicit reasons for both her answers. People should get the pamphlet "if they do not have access to good medical/clinical information." However, she felt the pamphlet would be "redundant" if they "have taken the responsibility to understand their disease and participated in treatment decisions." These comments seem to support the need to tailor information to the individual's general orientation to information, as well as to her specific information needs.

Summary of Part Two

Several important aspects of the information needs of women with MS were revealed in this part of the study. As predicted, more monitors than blunters found both the pamphlets, whether general or specific, to be relevant to their information needs. Although the majority of women indicated that they knew something about the topics of fatigue and treatment of acute exacerbations before receiving the pamphlet, some still had unanswered questions on both topics. Of the women in this latter category, there were some who did not find either the specific or the general pamphlet helpful.

The comments of the women provide additional insight into their information

needs. Most of their questions or comments concerned causes of and treatments for fatigue or acute exacerbations, indicating the women's continuous search for more definitive information about multiple sclerosis. The number of drug-related questions suggests a need for further education about the drugs used in this disease, including information about dosages and adverse effects. The finding that some topics were of interest to women in both parts of this study (i.e., stress, the hereditary aspects of multiple sclerosis and education and support for family members), while others were not (i.e., pregnancy) emphasizes the importance of assessing information needs on an individual basis. Finally, what some respondents seem to be saying is that the standard pamphlets on MS are not providing enough information to satisfy their information needs and that there is a need for more sophisticated information directed at the lay person. As one woman put it, "I would like to read some new medical evidence that is not so vague about MS. I find this all extremely difficult to deal with when I cannot get any real answers" [her emphasis]. Indeed, as some women pointed out, their information needs may never be satisfied as there are always more questions than answers.

CHAPTER 5

INTERPRETATION AND DISCUSSION

Does a person's general orientation to information affect her interest in and desire for more information, or her preference as to the format or source from which information can be obtained? Do information needs change over the course of multiple sclerosis? How does general orientation to information affect reactions to depth or specificity of information? These questions are addressed in the first part of this chapter. The second section concerns the theoretical contributions of this study to Miller's theory of monitoring and blunting and Dervin's theory of sense making, as well as its practical contributions to health professionals and information providers. Finally, comments on the limitations of this study, suggestions for future research, and the value of this research project conclude the chapter.

The key findings of this study concern the relationship between the women's general orientation to information and their interest in and desire for more information, the specificity of information, the phase of the disease and the formats in which information can be delivered. The findings in each of these areas are discussed below.

General Orientation to Information: Interest and Amount

The women's interest in or desire for more information seemed dependent, to some degree, on the particular topic. That is, although no significant differences were noted between monitors and blunters in their overall interest in or desire for more information, significant differences were observed when each topic was analyzed separately. Only then was it possible to ascertain what factors influenced the women's interest in or desire for more information about the various topics related to MS. The results showed that when the women's general orientation to information was the only factor influencing the amount of information wanted, low information scorers (as

measured by KHOS-I) were observed to want more information than did high information scorers. However, when there was an interaction between general orientation to information and length of time with MS, a different pattern was noted. That is, monitors (as measured by MBSS) and high information scorers (as measured by KHOS-I) were more interested in certain topics and were interested earlier in the disease process than were blunters and low information scorers.

On the Interest and Amount questionnaires, only 15 of the 29 topics seemed to garner a considerable amount of interest. The topics ranged from physiological (fatigue, exercise, effects of overheating on MS symptoms, bowel and bladder problems and general information about MS), to psychological (effects of stress, how to deal with a hidden disability and emotional behaviour) and economic ones (insurance and government agencies). This finding seems to support Phillips' (1986) report of the people in her study who were interested in biological, sociological and emotional information. The high level of interest in these topics may reflect the women's need for current information to help them cope with problems associated with MS or to find effective treatments or therapies that might work for them.

Of these 15 "high interest" topics, only four (uncertainty, muscle spasticity, memory problems and hereditary) were influenced by the women's general orientation to information and/or length of time with MS. For the other 11 topics, no significant differences were observed between monitors and blunters or for length of time with MS, although age and education were noted to affect the amount of information wanted on stress, government agencies and the effects of overheating. Several explanations for the absence of differences between monitors and blunters on these eleven topics are plausible. First, these topics are known to be relevant to people with MS. With the exception of the topic "how to deal with a hidden disability," most of the topics would have been familiar to the women in this study, particularly monitors. Therefore, the absence of differences between the two groups may have been caused by a decrease in

monitors' interest (they had already read literature on these topics) and an increase in blunters' interest (seeing the topics may have stimulated their interest), resulting in a balance that precluded different results.

Another explanation concerns the design of this research project. Unlike other studies that have used the Miller Behavioral Style Scale, in this study, there was no immediate need for the participants to accept or reject information. Instead, the women with MS were asked only to record their level of interest in and desire for information on a wide range of topics. Since the fear of being deluged with information was nonexistent, blunters may have felt less intimidated about recording their actual interest in these topics. Thus, the interest of blunters may have matched the interest of monitors.

Finally, it seems as though women with MS cannot get enough information about certain aspects of the disease. Their continuous search for information may reflect the fact that the information they want does not exist. In addition, their dissatisfaction with the content of the information available to them may send both monitors and blunters shopping for information in an attempt to find something that works for them, such as a treatment or exercise. Their interest in these topics may decrease only when they have found what they are looking for, i.e., a cure for MS.

General Orientation to Information: General or Specific Information

The strength of the MBSS may lie in its ability to differentiate people's preference for specific or general information. The results in Part Two of this study showed that, in the active coping stage (i.e., diagnosis to three years post-diagnosis), monitors preferred both general and specific information, whereas blunters seemed to prefer more general information in the same time period. This finding suggests one explanation for Simons' (1984) statement that available MS literature may cause "preparatory depression" or anxiety. That is, if specific information is given to blunters in the first three years after diagnosis, it may heighten their levels of anxiety or depression, whereas a similar reaction may not occur if that same information was given to monitors.

Not assessing people's general orientation to information before handing out MS literature may cause adverse reactions to that information.

General Orientation to Information: Length of Time with MS

As noted above, women's interest in and desire for more information about nutrition and education and support for family members were the only topics for which significant differences for the length of time with multiple sclerosis were noted. In both cases, women in the earlier phases of the disease process were observed to be more interested in or to want more information than did those in later phases of the disease. For six other topics, the phase of the disease does seem to mediate the role of the women's general orientation to information, i.e., monitors and high information scorers with MS searched for information earlier in the disease process, while for some topics, blunters and low information scorers seemed to wait. For the remainder of topics, the length of time the women had had MS did not seem to affect their interest in or desire for information about the disease. That women with MS need a wide range of information about the disease throughout the course of the disease seems obvious given the unpredictable and uncertain course and prognosis of MS. Since coping with and adjusting to this disease may be a continuous process, information needs do not seem to vary according to length of time the person has had MS. Further examples of the need for the same topics throughout the course of the disease were noted on the Format questionnaire. While newly diagnosed women preferred one format for a topic, such as muscle spasticity, women who had had MS for 5-7 years wanted information on this same topic in another format. Thus, it does not seem possible to state that information on any given topic is needed more by newly diagnosed people than by those who have had MS for many years.

General Orientation to Information: Format

To tailor information to the needs of women with MS, it seems essential to know monitors' and blunters' preference for various formats or sources of information. For

example, although no differences in the use of print sources were noted between monitors and blunterners in the newly diagnosed period (i.e., diagnosis to one year), more blunterners than monitors preferred print sources after having had MS for at least two years. Monitors, on the other hand, indicated a higher preference than did blunterners for both print and human sources of information in all phases of the disease.

The results of the loglinear analyses emphasize the need for MS information to be available in a variety of formats. The women indicated a high preference for video presentation of MS information, perhaps because of the popularity of this medium, or because many people with MS suffer from visual problems or have problems with muscle spasticity. The participants also preferred pamphlets over other print formats and physicians to other health professionals. More discussion on these particular formats can be found below. In addition to preference for formats, the results of the loglinear analyses produced some interesting information about monitors and blunterners. For example, although different results were obtained for each format for the 29 topics, overall, more monitors wanted information about MS in various formats than did blunterners.

Theoretical Contributions of This Study

Theoretically, the results of this study contribute to Miller's theory of monitoring and blunting and Dervin's theory of sense making. In addition, the findings add to the body of knowledge on the information needs and seeking behaviours of people with MS recorded by Phillips (1986), Brooks and Matson (1982, 1987), Robinson (1983, 1987, 1988) and Stewart and Sullivan (1982).

Miller's theory of monitoring and blunting. The major contribution of this study to Miller's theory of monitoring and blunting concerns the information-seeking patterns of blunterners. The design of this study which allowed the general orientation to information of women to be examined in three different time frames of the disease, i.e., from diagnosis to seven years after diagnosis, permitted a more extended view of blunterners'

information needs and seeking patterns. What the results suggest is that, overall, blunters do want information about MS, but prefer to seek it after they have had the disease for a few years. This finding suggests that by seeking information later in the disease process, newly diagnosed blunters may be more motivated to "minimize the maximum danger to themselves" (Miller, Combs & Stoddart, 1989, p. 108), the danger in this case including both the diagnosis of and information about multiple sclerosis. Once the trauma of the diagnosis has abated and they have become somewhat acclimated to the disease, blunters seem to want information. On the other hand, monitors, faced with this same uncontrollable and unpredictable disease, prefer information earlier in the disease process. Monitors' immediate pattern of information seeking seems to support Miller's (1990) findings involving patients with hypertension who wanted information even in an uncontrollable situation. The pattern of information seeking of monitors in this study suggests that although the trauma of diagnosis may be the same for both blunters and monitors, the trauma would be worse for monitors if they were not able to obtain any information about the disease. Thus, despite the lack of control they are able to exert over the disease, monitors with MS want information immediately or within the first year after diagnosis.

The findings of this study also reveal a desire on the part of monitors for specific rather than general information, supporting the results of an earlier study by Auerbach, Martelli and Mercuri (1983). The results also indicate the importance of format in the delivery of information to monitors and blunters. Whereas monitors seem to prefer both human and print sources in all three phases of the disease, blunters indicated a preference only for print sources in the later phases of the disease.

Since the MBSS had not been used to measure general orientation to information of women with a chronic neurological disease, the findings of this study contribute to and validate Miller's theory that some people want information, while others turn away from it. Finally, in this sample of women with MS, the Miller Behavioral Style Scale proved

more useful for assessing general orientation to information than did the health-related measure, Krantz Health Opinion Survey-Information subscale.

Dervin's theory of sense making. Monitoring and blunting are also interesting from the perspective of Dervin's theory which postulates that people seek information when they have identified gaps in their knowledge and that "it is the gap situation which may precipitate" information-seeking behaviour (Dervin and Clark, 1987, p. 27). If Dervin's theory is applied to monitors and blunters, some interesting speculations are possible. For example, because they are continually seeking information, monitors may always be identifying situations and therefore, gaps in their knowledge about MS. They may not only be searching for information for the particular situation in which they find themselves at the present moment, but may also be anticipating situations, such as symptoms about which they have read or heard. Thus, they may be identifying future gaps in their knowledge concerning these situations, which have not, as yet, happened. This continuous seeking of information in a variety of formats is understandable, as the unpredictable and uncertain aspects of MS may prevent monitors from ever acknowledging or accepting the fact that their knowledge gaps may never be bridged. On the other hand, blunters may seek information only when they have identified a situation-specific gap in their knowledge. Their preference for information after having had MS for a few years seems to support this speculation. In other words, they may wait for a specific situation to occur before seeking information on that particular problem. Clearly, more research needs to be done in order to understand how monitors and blunters make sense of their situations.

Contributions to the body of knowledge about the information needs of people with MS. In other studies, the information needs of men and women have been reported in the aggregate. This study is unique in that it focuses only on women, whose information needs in three different time periods of the disease have been recorded. By investigating the general orientation to information of women with MS, this study

suggests that some women did not want information. This finding may explain why some of the participants in Phillips' (1986) study "specifically stated they did not [her emphasis] want information after receiving the diagnosis" (p. 58). Another reason people may not want information is that the content is not tailored to their need... In other words, if people with a low preference for information receive specific information, it may increase their anxiety levels and cause them to turn away from information. According to the results of this study, women with a low preference for information seem to prefer general information, while those with a high preference for information indicated a desire for more specific information. Another contribution to the body of knowledge about the information needs of women with MS concerns preferences for the various formats through which MS information can be delivered. The results suggest that information about various MS-related topics needs to be available in a wide variety of formats in order to satisfying the information needs of people with this disease.

Practical Contributions of This Study

From a practical perspective, the results of this study have several implications for people who provide information to patients with multiple sclerosis, including physicians and other health professionals, the MS Society and librarians. Clearly, women with MS want information about their disease, but they want it at different phases of the disease. They also want a wide range of topics of information in a variety of formats. Their desire for information appears to be dependent on their general orientation to information, as well as their age, level of education and the topic. If physicians, as primary information providers, know their patients' general orientation to information, they may gain a better understanding of the patients' information-seeking patterns and needs. Further, physicians can decrease the anxiety level of their patients by providing the proper content of information in an appropriate format at a time when the patients can handle the information. By interviewing patients to ascertain their general orientation

to information and then, gearing information to the specific needs of that person, physicians may help to alleviate potential communication difficulties between themselves and their patients with MS.

Public and hospital librarians, as well as the members of the MS Society and its local chapters, may also benefit from the results of this study, which suggest the need for people in both types of organizations to produce, collect and disseminate information on a broad range of topics in various formats and in varying degrees of specificity. That librarians were seldom mentioned as sources of information for the women in this study suggests that those who are located in areas with a high incidence of MS need to play a more proactive role in providing information to people with this disease. To facilitate this role, hospital and public librarians could liaise not only with each other, but also with the directors of the local MS chapters and the staff at the MS clinics in order to ensure that women (or people) with MS have access to all the information they need to help them cope with and adjust to the disease.

Comments on Some Popular and Unpopular Formats

Before proceeding to the limitations of this study, it is necessary to comment on the preference for some formats and sources of information, such as the popularity of pamphlets, popular magazine articles, physicians and spouses. As well, the low ranking of the MS Society and other MS people as sources of information for this sample of women with this disease are worthy of note.

Pamphlets. Similar to the results obtained by Phillips (1986), pamphlets were the most preferred format for information about multiple sclerosis. Familiarity with this format may have influenced the women's preference as a considerable amount of information published by the MS Society is in pamphlet form. Also, people are accustomed to seeing pamphlets containing health information in their pharmacies, supermarkets, doctors' or dentists' offices. Thus, familiarity with this format in general

and specifically as a vehicle for MS information may have influenced their choice of this format over other print ones. Regardless of the reason, pamphlets were undeniably a format of choice.

The popularity of pamphlets has several important implications for producers and distributors of information about this disease. As revealed in Part Two of this study, monitors want specific information, whereas blunters seem to prefer less specific, more general information. Thus, a generic pamphlet on the various topics of interest to women with MS may not be sufficient to satisfy the information needs of both monitors and blunters. Instead, a series of very general to very specific pamphlets may be needed in order to satisfy a greater range of information needs.

Since undertaking this project, the researcher has become more aware of the types of health information available in public places, such as pharmacies, supermarkets and libraries. There seems to be a dearth of information about multiple sclerosis in these places, notwithstanding the pamphlets on the MS fund raising events. Putting general information pamphlets on MS as well as general information on specific aspects of the disease in public places would serve two purposes. First, the neutral environment allows blunters and monitors to select material that is relevant to their information needs at that time. Also, monitors are free to take as much information on the various topics as they wish. Second, these general pamphlets can serve as an educational resource not only for the general public and people with MS, but also may provide relevant information to people who may be experiencing MS symptoms, but who have not yet been diagnosed. In other words, heightening the awareness of the disease in the public sector may reduce the problems involved in diagnosing this chronic disease.

If the general pamphlets are distributed through public channels, then the responsibility for distributing pamphlets containing more specific information may lie with the staff of MS clinics, physicians' offices and the MS Society and its chapters. These places are ideal locations for displaying specific information pamphlets on various

topics. Since many people with this disease visit MS clinics or their physicians at least once a year if not more, having the more specific pamphlets available may help satisfy the information needs of many people with MS. Health care professionals, especially physicians, should be made aware of the value people place on pamphlets and be proactive in disseminating MS information via this channel. Librarians also need to be aware of the vital role that format plays in satisfying information needs. Since the incidence of MS is high in Ontario and because some women indicated libraries as places to obtain MS information, librarians should be collecting literature on this disease not only in book format but also in the more popular formats, such as pamphlets and videos.

Popular magazine articles. The popularity of magazine articles seems to support the need for more public access to MS information. At first glance, magazine articles may not appear to be quality vehicles for carrying information about MS. However, they are a very valuable resource for several reasons. First, popular magazines are readable, inexpensive and very accessible. Second, since these magazines usually cover a wide variety of topics in each issue, both monitors and blunters can purchase them or read them in a library without fear of being labelled a victim of MS. In other words, the wide appeal of these magazines permits anonymity. Third, depending on focus of the magazine, a range of information from scientific to business to biographical is available to people with MS. For example, consumers of MS information can obtain scientific information from magazines such as Scientific American. Biographical accounts of how other women (or people) have coped with MS is available through magazines such as Redbook, Ladies Home Journal, or Sports Illustrated. These biographical sketches not only allow readers to identify with other MS people, including those with a high profile, but also to glean information on the successes or failures of various treatments or therapies. Accuracy of information was addressed in some of these magazines in the form of a separate box which included pertinent facts about MS, as well as the address of the National Multiple Sclerosis Society with encouragement to write for more

information. From business magazines, consumers can gain information on topics such as the testing and production of new pharmaceutical products. Therefore, given the wealth of information people can obtain about MS through popular magazines, their value as a vehicle for information about this disease should not be underestimated.

Physicians. Phillips (1986) found that neurologists were "the most frequently mentioned source of information" (p. 78). Although the women in this study did not specify neurologists *per se*, they did indicate physicians as their most preferred source for information. The uniqueness of the medical information needs of people with MS seems to be accentuated by the very characteristics of the disease, since so much is unknown and unpredictable. The physician is the only person who can speak to patient's medical queries with authority acquired from research, experience, or reading. The fact that doctors cannot answer most questions about MS with any degree of certainty or relieve the stress caused by the unpredictability of the disease does not seem to deter people because they assume that ultimately, it will be these doctors who will provide an effective treatment or cure.

Although Brooks and Matson (1987), Robinson (1988) and Stewart and Sullivan (1982) identified problems between physicians and people with MS, very few women in this study commented on interpersonal problems with their physicians. From the participants who wrote comments beside this question on the Format questionnaire, the major problem concerned communication: "a doctor with time to talk, who understands, who does more than dispense pills, who does not feel challenged by a patient's knowledge and questions." Since similar communication problems were identified in the literature mentioned above, it was not surprising to find at least some women in this study who were dissatisfied with their doctors.

Brooks and Matson (1987) stated that dissatisfaction with physicians stemmed from patients' desire for "life-encompassing direction which may go far beyond medical information" (p. 84). In this study, the results of Part One demonstrated that general

orientation to information was associated with preference for information from physicians with respect to various topics. This relationship was mediated to some extent by phase of the disease. For instance, monitors in the first two phases of the disease indicated physicians for each topic, while blunters in the same two phases seemed to be more discriminating. In the third phase of the disease, the pattern is reversed. These findings suggest that the frustration with physicians identified by Brooks and Matson (1987) may be a result of people's general orientation to information and may be more common among monitors in the first few years of the disease and blunters who have had the disease for many years. This frustration with physicians might be reduced if physicians know their patients' general orientation to information and understand why some people ask questions outside their domain of knowledge. By increasing their awareness of the variety of information resources available to people with this disease, physicians can become more proactive in reducing patients' frustration by assisting them in their quest for information.

Spouses. The ambiguity of the statement "I would like to talk to---about this topic" on the Format questionnaire makes it difficult to interpret the women's intent when they indicated spouses. For example, when the women responded with pastor for religious material or insurance agent for information on insurance, it is highly probable that they wanted to speak to those experts about that particular topic. However, when they responded "spouse", were the women indicating a desire to receive information from or give information to their partners? Although in Chapter 3, the husband was viewed as a source of information, the other interpretation of partner as receiver of information is equally viable.

The role of the spouse as information provider is a very plausible one, for spouses often attend MS classes with their wives (Staff member, Clinic A, personal communication, 1992; Power, 1985). As the partner of a woman involved in the pretest period stated, spouses may be just as interested in educating themselves as are their

wives, since MS affects all family members. Further, studies of information-seeking behaviour have shown that people "tend to seek out information which is most accessible" (Faibisoff & Ely, 1976, p. 9). As Primomo, Yates and Wood (1990) found in their study of social support of women with chronic illnesses, partners were "more likely to be confided in about the illness and to reciprocate" (p. 157). Thus, their accessibility, their level of education about MS or their ability to provide feedback on a daily basis may permit spouses to serve as information providers for women coping with this disease.

On the other hand, instead of seeing their spouses as resources of information, the women may have been indicating the need to educate their partners about the disease and how it affects both their roles within the relationship. Since family members are affected by MS and their coping behaviour is influenced by education (Power, 1985), it seems quite reasonable that women would want to educate their spouses about the disease. Although Power's study and books on living with chronic diseases, such as Register's (1987) and Strong's (1988), provide some insight into the effects of MS on families including spouses, more research needs to be done on the information needs of partners of people with MS.

MS Society and other people with MS. The results of this study concerning the MS Society and other people with the disease differed from the findings reported by Phillips (1986), who examined the frequency with which people with MS used different information sources. While the participants in her study ranked the MS Society and other people with MS (but not mutual support groups) high on the list of information providers, the women in this study did not indicate any of the three sources very often. That is, for some topics, no one indicated these resources, while for others, the number of respondents ranged from one to ten. While it is plausible to assume that the women in this study are not involved in support groups, do not find them particularly informative, or do not consider support groups or other people with MS as authoritative sources of

information, the paucity of "MS Society" responses is somewhat harder to explain. Through its newsletters, publications and fund raising events, the Society appears to have a high profile among people with MS. Although the Society has chapters in many Canadian cities that are ready to provide information, few women in this study seem to have thought of the MS Society as a source of information about their disease.

There may be a combination of reasons for this. First, many of the pamphlets published by the MS Society are, perhaps by necessity, generic and therefore, may appeal more to the newly diagnosed than those who have had the disease for any length of time. As in any medical condition, unique information needs cannot be met through generic publications. In fact, they may cause rather than alleviate frustration, especially for women looking for more detailed information. Second, the range of topics covered by MS Society publications is not extensive. Although the Society has a new computerized database of material on MS, many of the publications are clinically oriented and thus, may not appeal to a large number of lay people. Third, many of the respondents may not be aware of the extent of the services provided by the Society, especially if they do not belong to the MS Society or one of its chapters and therefore, do not receive any of their publications. Finally, many of the respondents may not want to be associated with the Society because they do not want to be labelled as having a chronic disease. More research needs to be done on the women's perception of the MS Society and its role in their lives.

Limitations of the Study

There are two main limitations of this study, one which affects the generalizability of the results and the other which arises from differentiation of concepts.

(a) Generalizability of results: Since not all patients with multiple sclerosis are referred to MS clinics, the generalizability of the results is naturally limited to clinic populations. As well, this study was restricted to women to control for possible effects of

gender-based information-seeking patterns and thus does not permit comparison with other study samples.

(b) Differentiation of concepts: Although no one in the pretesting phase of Part One of the study expressed difficulty in differentiating the main questions on the Interest and Amount questionnaires, some women in the study did not seem to understand the difference between the questions "How interested are you in this topic?" and "How much information do you want on this topic?" The women who did not appreciate the difference between these two questions answered only one or the other questionnaire, not both, thus leading to incomplete conclusions on interest in and amount of information wanted on the 29 topics. These two questionnaires could have been designed to minimize the possibility of misunderstandings. For example, the Interest and Amount questionnaires could have been printed on different coloured paper. Then, more women may have answered both questionnaires. In addition, since the order of the topics was identical on both questionnaires, many women circled the same number for both interest and amount. Although the numbers they circled may have reflected their true interest in and desire for information on a topic, their answers may have been different if the order of the topics had varied from one questionnaire to the other.

Suggestions for Future Research

The findings of this study suggest several issues for future research, particularly the relationship between uncertainty and information. More specifically, how does information affect the uncertainty experienced by people with MS? Does information relieve or increase uncertainty? Is information sought more during exacerbations or remissions?

Future research might also investigate physician-patient relationships in MS situations. Since communication problems have been discussed in the literature, even though they were not prominent in this study, some exploration of people's perceptions

of the role of doctors and their expectations of physicians as information providers may be of interest.

Since the MS Society was not indicated very often as an informational resource by the women in this study, research into people's perception of the MS Society, its role in their lives and their reaction to the Society's publications could provide valuable information to an organization dedicated to providing services and educational material to people stricken with this disease. Finally, a study of the information needs and seeking patterns of men with MS is also necessary, as this population has not been studied. A research project similar to this one would help to illustrate differences as well as similarities between male and female sufferers of this disease and their quest for information.

Value of the Study

The focus of this study makes it unique among research projects on people with MS for several reasons. First, the study concentrated only on women, providing a more in-depth profile of a group known to be at greater risk for MS and a comprehensive picture of their information needs at three different time periods of the disease. Second, the results also provide possible explanations as to why MS literature may increase the anxiety levels of people with the disease and why some people may not want information in the newly diagnosed period. Third, the study contributes to knowledge about methodology, as it provides further testing of the Miller Behavioral Style Scale and the Krantz Health Opinion Survey-Information subscale, which may help other researchers. Fourth, the results also have practical implications. Increasing awareness among providers of MS information of the need to assess general orientation to information (possibly through in-depth interviews) may ensure that any information delivered is tailored to the specific needs of the individual with MS. Finally, the value of this study lies in the fact that it not only provides a good basis for future research projects, but also

raises more questions about the role of information in helping (or not helping) women cope with the uncertainty of this unpredictable disease.

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APPENDIX A

PART ONE—QUESTIONNAIRE

- Miller Behavioral Style Scale
- Krantz Health Opinion Survey
- Interest Questionnaire
- Amount Questionnaire
- Format Questionnaire

[Miller Behavioral Style Scale]

MS-INFORMATION STUDY

Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check all of the statements that might apply to you.

- I would ask the dentist exactly what he was going to do.
- I would take a tranquilizer or have a drink before going.
- I would try to think about pleasant memories.
- I would want the dentist to tell me when I would feel pain.
- I would try to sleep.
- I would watch all the dentist's movements and listen for the sound of his drill.
- I would watch the flow of water from my mouth to see if it contained blood.
- I would do mental puzzles in my mind.

Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.

- I would sit by myself and have as many daydreams and fantasies as I could.
- I would stay alert and try to keep myself from falling asleep.
- I would exchange life stories with the other hostages.
- If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.
- I would watch every movement of my captors and keep an eye on their weapons.
- I would try to sleep as much as possible.
- I would think about how nice it's going to be when I get home.
- I would make sure I knew where every possible exit was.

Vividly image that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days. Check all of the statements that might apply to you.

— I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.

— I would review the list of duties for my present job and try to figure out if I had fulfilled them all.

— I would go to the movies to take my mind off things.

— I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.

— I would push all thoughts of being laid off out of my mind.

— I would tell my spouse that I'd rather not discuss my chances of being laid off.

— I would try to think which employees in my department the supervisor might have thought had done the worst job.

— I would continue doing my work as if nothing special was happening.

Vividly imagine that you are on an airplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check all of the statements that might apply to you.

— I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.

— I would make small talk with the passenger beside me.

— I would watch the end of the movie, even if I had seen it before.

— I would call for the stewardess and ask her exactly what the problem was.

— I would order a drink or tranquilizer from the stewardess.

— I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.

— I would talk to the passenger beside me about what might be wrong.

— I would settle down and read a book or magazine or write a letter.

[Krantz Health Opinion Survey]

MS-INFORMATION STUDY

The following questions ask for your opinions about different kinds of health care. For each statement below, decide whether you agree or disagree and circle the answer which best fits your opinion. Each person is different, so there are not "right" or "wrong" answers. Even if you find you don't completely agree or disagree with a statement, choose the one answer that comes closest to what you believe. Your answers are confidential and will be used for research purposes only.

For each question, circle only one answer that comes CLOSEST to what you believe:

I usually don't ask the doctor or nurse many questions about what they're doing during a medical exam.

AGREE

DISAGREE

Except for serious illness, it's generally better to take care of your own health than to seek professional help.

AGREE

DISAGREE

I'd rather have doctors and nurses make the decisions about what's best than for them to give me a whole lot of choices.

AGREE

DISAGREE

Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health.

AGREE

DISAGREE

It is better to rely on the judgements of doctors (who are experts) than to rely on "common sense" in taking care of your own body.

AGREE

DISAGREE

Clinics and hospitals are good places to go for help since it's best for medical experts to take responsibility for health-care.

AGREE

DISAGREE

Learning how to cure some of your illness without contacting a physician is a good idea.

AGREE

DISAGREE

I usually ask the doctor or nurse lots of questions about the procedures during a medical exam.	AGREE	DISAGREE
It's almost always better to seek professional help than to try to treat yourself.	AGREE	DISAGREE
It is better to trust the doctor or nurses in charge of a medical procedure than to question what they are doing.	AGREE	DISAGREE
Learning how to cure some of your illness without contacting a physician may create more harm than good.	AGREE	DISAGREE
Recovery is usually quicker under the care of a doctor or nurse than when patients take care of <u>themselves</u>.	AGREE	DISAGREE
If it costs the same, I'd rather have a doctor or nurse give me treatments than to do the same treatments myself.	AGREE	DISAGREE
It is better to rely less on physicians and more on your own common sense when it comes to caring for your body.	AGREE	DISAGREE
I usually wait for the doctor or nurse to tell me about the results of a medical exam rather than asking them immediately.	AGREE	DISAGREE
I'd rather be given many choices about what's best for my health than to have the doctor make the decisions for me.	AGREE	DISAGREE

MS-INFORMATION STUDY

In this section, you will find a list of topics believed to be of interest to people with MS. Circle the number that **BEST** describes your interest in the topic.

How interested are you in this topic?

	Not Interested				Extremely Interested
1. General information on MS	1	2	3	4	5
2. How to deal with a "hidden" disability (a disability not obvious to others)	1	2	3	4	5
3. Education and support for family members	1	2	3	4	5
4. Insurance (health, life, disability, drug- how to get and keep it)	1	2	3	4	5
5. Career choices and goals	1	2	3	4	5
6. Nutritional literature (special diets, vitamins, healthy eating)	1	2	3	4	5
7. Pain	1	2	3	4	5
8. Uncertainty (about the course of MS, treatments)	1	2	3	4	5
9. Employer relations or discrimination (what to tell and when, legal implications)	1	2	3	4	5
10. Sexual problems associated with MS	1	2	3	4	5
11. Fatigue	1	2	3	4	5
12. Relations with physicians and other health professionals	1	2	3	4	5
13. Mutual support groups for women with MS	1	2	3	4	5
14. Memory problems or forgetfulness	1	2	3	4	5
15. Independent living aids, such as canes, home aids, scooters	1	2	3	4	5
16. Pregnancy and/or contraception	1	2	3	4	5

	Not Interested				Extremely Interested
17. Emotional behaviour in MS	1	2	3	4	5
18. Biographies or autobiographies of other women with MS	1	2	3	4	5
19. Exercise, fitness and yoga (benefits and drawbacks)	1	2	3	4	5
20. Religious and spiritual material	1	2	3	4	5
21. Hereditary or genetic aspects of MS	1	2	3	4	5
22. Bowel and bladder disturbances (what happens, how to deal with these problems)	1	2	3	4	5
23. Friendships (telling friends, being abandoned by friends, maintaining friends)	1	2	3	4	5
24. MS Society (what it can do for me, what is the role of the MS Society)	1	2	3	4	5
25. Muscle spasticity/weakness (what to do for these problems, who can help me, how can I help myself)	1	2	3	4	5
26. Effects of stress, alcohol or smoking on MS	1	2	3	4	5
27. Understanding the caregiver role	1	2	3	4	5
28. Government agencies (who they are, how they can help)	1	2	3	4	5
29. Effects of overheating (sunbathing, hot baths)	1	2	3	4	5

MS-INFORMATION STUDY

In this section, you will find a list of topics believed to be of interest to people with MS. Circle the number that **BEST** describes the amount of information you want on each topic.

How much information do you want on this topic?

	Nothing at all				Everything available
1. General information on MS	1	2	3	4	5
2. How to deal with a "hidden" disability (a disability not obvious to others)	1	2	3	4	5
3. Education and support for family members	1	2	3	4	5
4. Insurance (health, life, disability, drug- how to get and keep it)	1	2	3	4	5
5. Career choices and goals	1	2	3	4	5
6. Nutritional literature (special diets, vitamins, healthy eating)	1	2	3	4	5
7. Pain	1	2	3	4	5
8. Uncertainty (about the course of MS, treatments)	1	2	3	4	5
9. Employer relations or discrimination (what to tell and when, legal implications)	1	2	3	4	5
10. Sexual problems associated with MS	1	2	3	4	5
11. Fatigue	1	2	3	4	5
12. Relations with physicians and other health professionals	1	2	3	4	5
13. Mutual support groups for women with MS	1	2	3	4	5
14. Memory problems or forgetfulness	1	2	3	4	5
15. Independent living aids, such as canes, home aids, scooters	1	2	3	4	5
16. Pregnancy and/or contraception	1	2	3	4	5

	Nothing at all				Everything available
17. Emotional behaviour in MS	1	2	3	4	5
18. Biographies or autobiographies of other women with MS	1	2	3	4	5
19. Exercise, fitness and yoga (benefits and drawbacks)	1	2	3	4	5
20. Religious and spiritual material	1	2	3	4	5
21. Hereditary or genetic aspects of MS	1	2	3	4	5
22. Bowel and bladder disturbances (what happens, how to deal with these problems)	1	2	3	4	5
23. Friendships (telling friends, being abandoned by friends, maintaining friends)	1	2	3	4	5
24. MS Society (what it can do for me, what is the role of the MS Society)	1	2	3	4	5
25. Muscle spasticity/weakness (what to do for these problems, who can help me, how can I help myself)	1	2	3	4	5
26. Effects of stress, alcohol or smoking on MS	1	2	3	4	5
27. Understanding the caregiver role	1	2	3	4	5
28. Government agencies (who they are, how they can help)	1	2	3	4	5
29. Effects of overheating (sunbathing, hot baths)	1	2	3	4	5

MS-INFORMATION STUDY

In this section, the emphasis is on **FORMAT** of information. In other words, you are given a topic and then asked if you would like to talk to people, read some material, listen to a tape or view a video.

INSTRUCTIONS FOR COMPLETING THIS SECTION:

1. For each question, decide whether you want information on this topic or not.
2. If **NO**, skip to next topic.
3. a. If **YES**, first decide if you would like to talk to a person (or to some people) about this topic, and indicate that person's relationship to you. **DO NOT ANSWER WITH PERSON'S NAME**, such as Dr. Jones or Ms. Taylor. Instead, respond by writing the person's relationship to you, such as doctor, friend with MS, social worker, pastor, etc.
 - b. Next, indicate whether you want printed material, a cassette or a video on this topic by placing an "X" in the appropriate box or boxes. Choose as many formats as you wish.

EXAMPLE:

The following is an example of how you might answer this section :

General information on MS

I would like to talk to my doctor, spouse, social worker, a friend with MS AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

TOPICS:

1. General information on MS

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

2. How to deal with a "hidden" disability (a disability not obvious to others)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

3. Education and support for family members

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

4. Insurance (health, life, disability, drug—how to get and keep it)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

5. Career choices and goals

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

6. Nutritional literature (special diets, vitamins, healthy eating)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

7. Pain

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

8. Uncertainty (about the course of MS, treatments)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats--Please specify: _____

9. Employer relations or discrimination (what to tell and when, legal implications)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats--Please specify: _____

10. Sexual problems associated with MS

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

11. Fatigue

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

12. Relations with physicians and other health professionals

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

13. Mutual support groups for women with MS

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

14. Memory problems or forgetfulness

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

15. Independent living aids, such as canes, home aids, scooters

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

16. Pregnancy and/or contraception

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

17. Emotional behaviour in MS

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

18. Biographies or autobiographies of other women with MS

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

19. Exercise, fitness and yoga (benefits and drawbacks)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

20. Religious and spiritual material

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

21. Hereditary or genetic aspects of MS

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

22. Bowel and bladder disturbances (what happens, how to deal with these problems)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

23. Friendships (telling friends, being abandoned by friends, maintaining friends)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

24. MS Society (what it can do for me, what is the role of the MS Society)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

25. Muscle spasticity/weakness (what to do for these problems, who can help me, how can I help myself)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

26. Effects of stress, alcohol or smoking on MS

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

27. Understanding the caregiver role

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

28. Government agencies (who they are, how they can help)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

29. Effects of overheating (sunbathing, hot baths)

I would like to talk to _____ about this topic AND I would like to receive information in the following formats: (Choose as many formats as you wish)

- Books
- Pamphlets
- Popular magazine articles
- Medical articles
- Audiocassettes
- Videos
- Other formats—Please specify: _____

Age:

under 19	[]
20-39	[]
40-59	[]
60 and over	[]

Education:

What was the highest grade you completed in school?

Elementary	1 2 3 4 5 6 7 8
Secondary school	9 10 11 12 13
Community college	1 2 3 4
University	1 2 3 4
Post-graduate work	1+

Degree obtained:

Are there other topics of interest to you that have not been included here? If so, please list them:

Note: If you would like more information on any of these topics, please contact me and I shall be happy to send you additional material.

Lynda M. Baker
 PhD Candidate
 School of Library and Information Science
 Elbom College
 University of Western Ontario
 London, Ontario • N6G 1H1
 (519) 679-2111 ext. 8516

APPENDIX B

PART TWO—QUESTIONNAIRE

- Miller Behavioral Style Scale
- Pamphlets: Fatigue, General
Fatigue, Specific
Treatment of Acute Attacks, General
Treatment of Acute Attacks, Specific
- Questionnaire

[Miller Behavioral Style Scale]

MS-INFORMATION STUDY

Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check all of the statements that might apply to you.

- I would ask the dentist exactly what he was going to do.
- I would take a tranquilizer or have a drink before going.
- I would try to think about pleasant memories.
- I would want the dentist to tell me when I would feel pain.
- I would try to sleep.
- I would watch all the dentist's movements and listen for the sound of his drill.
- I would watch the flow of water from my mouth to see if it contained blood.
- I would do mental puzzles in my mind.

Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.

- I would sit by myself and have as many daydreams and fantasies as I could.
- I would stay alert and try to keep myself from falling asleep.
- I would exchange life stories with the other hostages.
- If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.
- I would watch every movement of my captors and keep an eye on their weapons.
- I would try to sleep as much as possible.
- I would think about how nice it's going to be when I get home.
- I would make sure I knew where every possible exit was.

Vividly image that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days. Check all of the statements that might apply to you.

— I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.

— I would review the list of duties for my present job and try to figure out if I had fulfilled them all.

— I would go to the movies to take my mind off things.

— I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.

— I would push all thoughts of being laid off out of my mind.

— I would tell my spouse that I'd rather not discuss my chances of being laid off.

— I would try to think which employees in my department the supervisor might have thought had done the worst job.

— I would continue doing my work as if nothing special was happening.

Vividly imagine that you are on an airplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check all of the statements that might apply to you.

— I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.

— I would make small talk with the passenger beside me.

— I would watch the end of the movie, even if I had seen it before.

— I would call for the stewardess and ask her exactly what the problem was.

— I would order a drink or tranquilizer from the stewardess.

— I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.

— I would talk to the passenger beside me about what might be wrong.

— I would settle down and read a book or magazine or write a letter

[Fatigue, General]

FATIGUE

Fatigue is one of the most common complaints of people with multiple sclerosis (MS). The fatigue is often described as excessive when it is compared with the amount of activity preceding it or with the individual's degree of disability. People often describe this fatigue as feeling "wasted". Although many people with MS report fatigue or a feeling of overwhelming tiredness, the exact cause is not understood. This is not surprising since there are many aspects of MS that, to date, are neither known nor understood. However, some physiological and psychological causes have been identified.

Physical changes in the central nervous system as a result of multiple sclerosis make people tire easily and at a faster rate. This is not unusual. Fatigue can also be caused by other factors, including those that contribute to tiredness in people who do not have MS. However, the fatigue experienced by people with MS is greater and occurs more frequently. In addition, psychological factors may contribute to the feeling of fatigue or tiredness. Since fatigue can vary from one day to another, people with MS may require rest periods when others do not. Interestingly, people, such as the individual's family, friends and co-workers, often may not understand why the person with MS gets so tired and why she requires more periods of rest and relaxation. It may be necessary to explain quite often to these people that fatigue is a known symptom of multiple sclerosis and that many MS people experience it.

The treatment for fatigue in MS is varied and can be of a physiological or psychological nature, or even a combination of both. Some forms of therapy can include taking commonsense precautions against getting overtired or overheated. Within each person's limitations, individuals with MS should keep physically fit, as active as possible and should attempt to maintain normal work and social relationships. In other words, the person with MS should recognize her own limitations and work within these parameters. This may mean more deliberate planning of daily activities in order to make the most use of high energy levels. This also necessitates planning scattered rest periods throughout the day when energy levels are low. In addition to these precautions, it is helpful for the person with multiple sclerosis to accept the fact that fatigue is an integral part of the disease. Just recognizing this fact may actually help the person with MS, her family, friends and co-workers to deal more realistically with this symptom.

Some research studies have been done examining the effects of an anti-viral drug on fatigue. The evidence is not conclusive. There is some indication that the drug works in some cases, but does not work in others. People with multiple sclerosis who are bothered by fatigue may want to discuss the possibility of taking this drug with their physician.

[Fatigue, Specific]

FATIGUE

Fatigue is one of the most common complaints of people with multiple sclerosis (MS). The fatigue is often described as excessive when it is compared with the amount of activity preceding it or with the individual's degree of disability. Although the number of people reporting fatigue ranges from 40% to 90%, the exact cause is not understood. Some physiological and psychological causes have been identified.

Physiologically, fatigue is related to the loss of the myelin sheath surrounding the nerve fibres. The sheath is responsible for the conduction of nerve impulses and when destroyed, the nerve fibres have to work harder to get the impulses past the demyelinated area. The increased work load for the nerve fibres makes them tire easily. Also, without the sheath, the fibres are more sensitive to changes in body temperature. Increased body temperature and thus, fatigue, can occur after too much physical activity. Fatigue can also be caused by exposure to heat, such as a hot bath or sunbathing. Similarly, infections can contribute to feelings of fatigue because infections are often accompanied by fevers. Another source of fatigue is muscle strain, that is, the strong muscles tire from compensating for the weaker ones. Fatigue may also have a psychological basis. The feeling of tiredness is very real for the person with MS; however, since it is invisible to family and friends, it is often misunderstood. In fact, they may consider the person with MS to be lazy or trying to escape work. Although not actually causing it, other factors contributing to fatigue include feelings of depression, anxiety or a sense of hopelessness that often accompany MS.

Treatment for fatigue can be physiological, psychological or a combination of both, and can include such commonsense things as getting 8 hours of sleep, eating a balanced diet, quitting smoking, and avoiding hot baths or sunbathing. More specifically, since the body temperature varies throughout the day and is higher in the afternoon (from 3 p.m. to 6 p.m.), daily plans should include rest periods, especially in late afternoon. Keeping fit within one's limitations may also help. Exercise programs tailored by a physical therapist to an individual's routine, interests and ability may help reduce fatigue; an occupational therapist can devise some energy saving methods for accomplishing daily chores. Some people may consider self-help groups as a type of therapy, because talking to others with MS and sharing similar concerns may help to relieve feelings of depression and loneliness. Finally, understanding that fatigue is an integral part of MS may help patients, their families and friends deal more realistically with this symptom.

Clinical research studies on the effects of an anti-viral drug, Amantadine or Symmetrel, on fatigue seem to show that this drug may reduce fatigue in some patients, but not all. In addition, the drug was found to have no effect on disability.

[Treatment, General]

TREATMENT FOR ACUTE ATTACKS

The cause of multiple sclerosis (MS) remains a mystery and no cure exists. The course of the disease in any individual case cannot be predicted; however, different patterns of MS have been identified. In some cases, people experience only two or three acute attacks (exacerbations) and then remain free of symptoms or attacks the rest of their lives. However, in other cases, people experience a number of exacerbations, followed by varying degrees of recovery. Exacerbations may involve the appearance of new or old symptoms, lasting at least a day. When the person with MS reports new symptoms, it is important for the physician to determine why these new symptoms have occurred. The symptoms may not have any relationship to MS, but may result from some other problem.

Depending on the symptoms, different types of treatment may be prescribed. The kind of treatment recommended will depend on how the person's body has handled previous attacks. Mild attacks that do not impede a person's ability to function, that is, attacks that create no major day-to-day difficulties for the person with MS, often do not require treatment. Moderate attacks that cause some disability or create minor problems in day-to-day functioning can be treated on an outpatient basis with drugs. Severe attacks that cause a lot of problems and disabilities may require, under some conditions, hospitalization as well as different kinds of drug treatment. Although these drugs do not alter the course of the disease, they have been shown to decrease some of the problems people with acute attacks experience. Some drugs are given by mouth, while others are given intravenously or intramuscularly. The length of treatment depends on the particular drug prescribed. With most of the drugs, the therapy regime starts with a high dose that is decreased steadily over a certain time period. In other words, it is necessary for the physician to taper the dosage from high to low before these drugs can be discontinued. Some positive side effects of these drugs have been reported by patients, and noted by physicians. However, drug researchers, physicians and patients have reported that there are also adverse or negative side effects to these drugs which may affect both the patient's physical appearance, physiological status and emotional state. Some of these side effects are minor, others are serious.

The course of drug therapy for each patient differs as the treatment depends on the severity of the attack and the personal preference of the physician. For example, in severe attacks, some physicians prefer to use one drug while others use another. The drug that the physician chooses to use depends both on the physician's past experience with that drug and on the individual patient's history, that is, how that particular patient responded to and tolerated this drug treatment in the past.

[Treatment, Specific]

TREATMENT FOR ACUTE ATTACKS

The cause of multiple sclerosis (MS), a chronic disease affecting the myelin sheath that covers the brain and spinal cord, remains a mystery and no cure exists. The course of the disease cannot be predicted. However, the majority of people with multiple sclerosis fall into the relapsing/remitting or relapsing/progressive categories, characterized by short periods of acute attacks (exacerbations) followed by complete, partial or no recovery (remissions). Exacerbations are defined as the appearance of new or worsening of old symptoms lasting at least 24 hours. When new symptoms occur, it is important for the physician to determine whether they result from new or old injuries to the myelin sheath, or if they are the result of some other illness. If the symptoms are due to some other illness, they are treated specifically.

Treatment for new or extended injuries to the myelin sheath are based not only on the severity of these new symptoms, but also on how the person's body has handled previous attacks. For example, mild attacks that do not create problems for a person on a day-to-day basis often do not require treatment. Moderate attacks that cause some functional problems may be treated on an outpatient basis with a drug called prednisone. Severe attacks that cause a lot of problems or disabilities may require that the person be hospitalized and treated with drugs, such as ACTH or Solu-Medrol. Although these drugs do not alter the course of the disease, they are known to decrease the severity and the duration of acute attacks. Prednisone is taken by mouth usually once a day or on alternate days for about 4 weeks, the dosage decreasing per week. ACTH and Solu-Medrol can be given intravenously (into the vein) or intramuscularly (into the muscle). Treatment with ACTH may take approximately one month because it is necessary to taper the dosage from high to low before discontinuing the drug; treatment with Solu-Medrol may last for approximately five to nine days, starting with a high dose that is decreased steadily over this time period. These drugs have side effects. Patients have identified some positive side effects, including a sense of well-being, increased energy and motivation, and a decrease in spasticity. However, the negative or adverse side effects are generalized puffiness, weight gain, general infections, acne, and stomach problems.

The course of therapy for each patient differs as treatment depends on the severity of the attack and the personal preference of the physician. For example, in severe attacks, some physicians prefer to treat with ACTH, while others use Solu-Medrol. The physician's drug preference and the length of therapy are guided by results of drug studies reported in the medical literature, on the doctor's past experience with the drugs and on the patient's history of response to and tolerance of the treatment.

MS-INFORMATION STUDY

After you have read the enclosed pamphlet, please fill out this questionnaire by inserting an "X" in the boxes or by answering in your own words in the space provided.

1. How long ago did you receive a confirmed diagnosis of multiple sclerosis from the physician?

_____ Years _____ Months

2. How much did you know about this topic before you read this pamphlet?

Please explain: _____

3. Did you have any questions on this topic before you read this pamphlet?

YES [] NO []

If NO, please skip to question 5.

If YES, please explain: _____

4. How did the information in this pamphlet help you to answer your questions?

Please explain: _____

5. How relevant was this pamphlet to you? Please check the appropriate answer.

Not relevant []
 Slightly relevant []
 Relevant []
 Very relevant []
 Extremely relevant []

6. How would you describe the amount of information contained in the pamphlet? Please check the appropriate answer.

No information

Not enough information

Enough information

Too much information

Excessive amount of information

7. How would you describe the contents of this pamphlet? Please check the appropriate answer.

Too specific

Very specific

Neutral

Very general

Too general

8. Would you like more information on this topic?

YES NO

If YES, what more would you like to know? _____

9. Would you recommend this pamphlet be given to others who have had MS as long as you have?

YES NO

Please explain why you feel this way: _____

COMMENTS:

AGE:

under 19 | |
20-39 | |
40-59 | |
60 and over | |

Education:

What was the highest grade you completed in school?

Elementary 1 2 3 4 5 6 7 8

Secondary School 9 10 11 12 13

Community college 1 2 3 4

University 1 2 3 4

Post-graduate work 1+

Degree obtained:

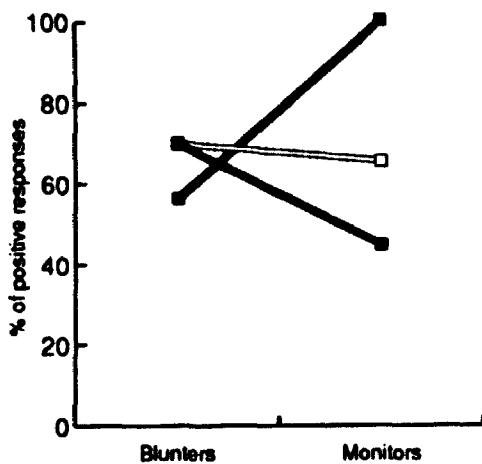
NOTE: If you would like more information on this topic, please contact me and I shall be happy to send you additional literature.

Thank you.

Lynda M. Baker
Doctoral Candidate
School of Library and Information Science
Elbom College
University of Western Ontario
London, Ontario N6G 1H1
(519) 679-2111 ext. 8516

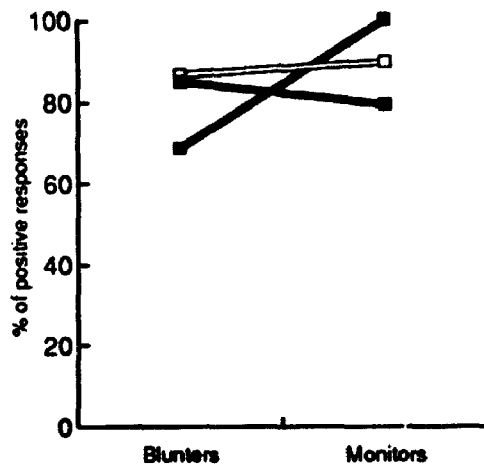
APPENDIX C

**PART ONE-SELECTED LOGLINEAR ANALYSIS FIGURES
[Each Format (for each topic) x MType x Length of time with MS]**



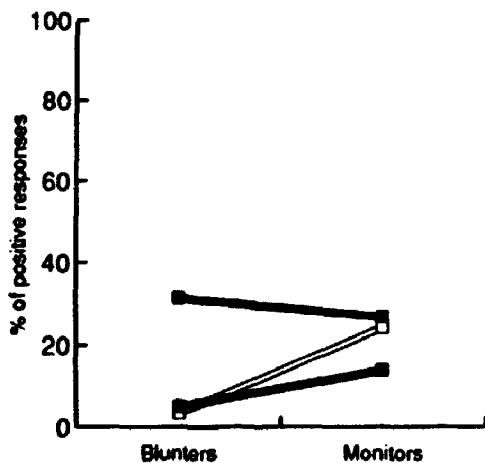
$G^2(2, n = 139) = 14.40, p = .001$
 $X^2(2, n = 139) = 11.63, p = .003$

Figure A1: Books



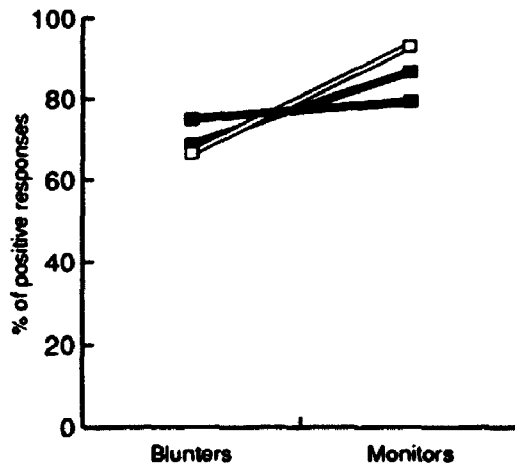
$G^2(2, n = 139) = 6.81, p = .033$
 $X^2(2, n = 139) = 5.07, p = .079$

Figure A2: Medical Articles



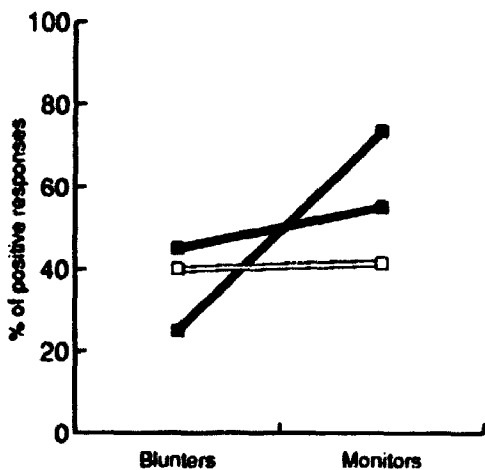
$G^2(2, n = 139) = 6.54, p = .038$
 $X^2(2, n = 139) = 7.31, p = .026$

Figure A3: Spouses



$G^2(1, n = 139) = 5.60, p = .018$
 $X^2(1, n = 139) = 5.52, p = .019$

Figure A4: Pamphlets

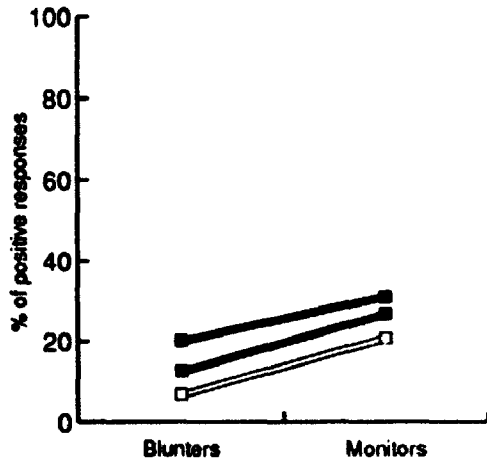


$G^2(1, n = 139) = 5.36, p = .021$
 $X^2(1, n = 139) = 5.24, p = .022$

Figure A5: Popular magazine articles

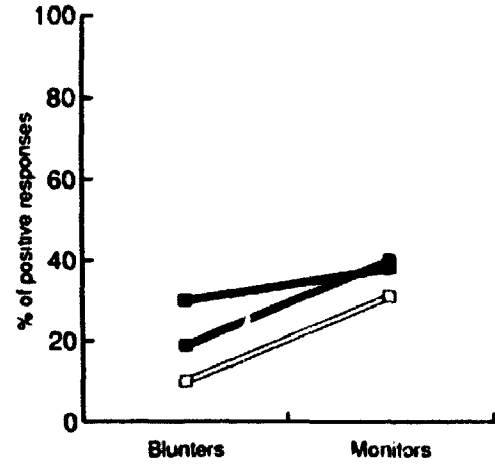
Fatigue

Phase 1 ● Phase 2 ◻ Phase 3 ●



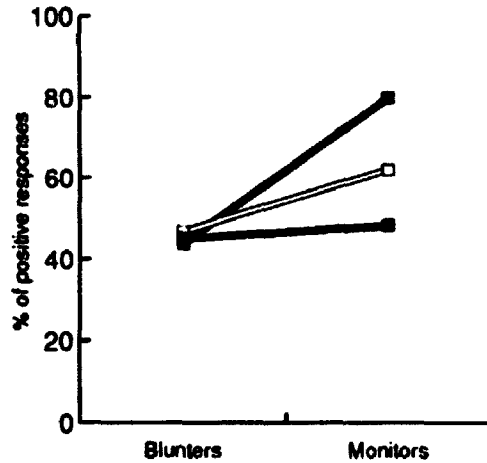
$G^2(1, N = 139) = 3.99, p = .046$
 $X^2(1, N = 139) = 3.92, p = .048$

Figure A6: Audiocassettes



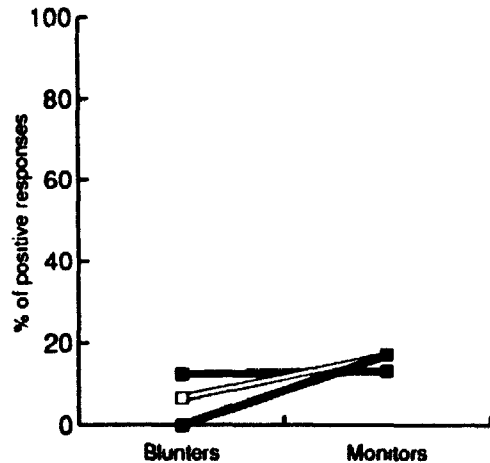
$G^2(1, N = 139) = 5.23, p = .022$
 $X^2(1, N = 139) = 5.13, p = .024$

Figure A7: Videos



$G^2(1, N = 139) = 4.65, p = .031$
 $X^2(1, N = 139) = 4.56, p = .033$

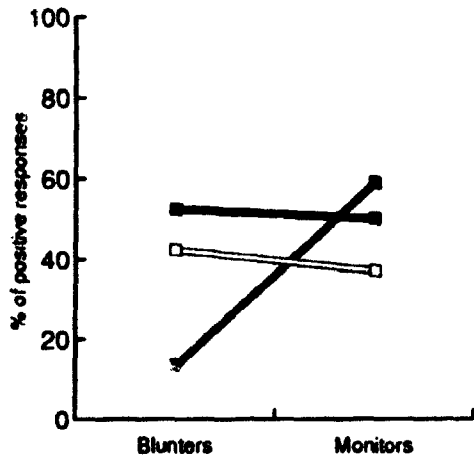
Figure A8: Physicians



$G^2(1, N = 139) = 4.94, p = .026$
 $X^2(1, N = 139) = 4.13, p = .042$

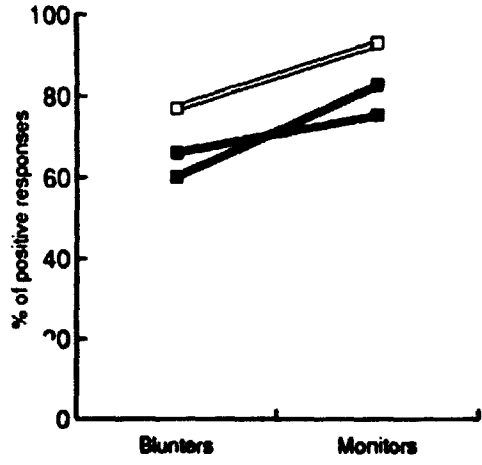
Figure A9: Family

Fatigue
 Phase 1 ● Phase 2 □ Phase 3 ●



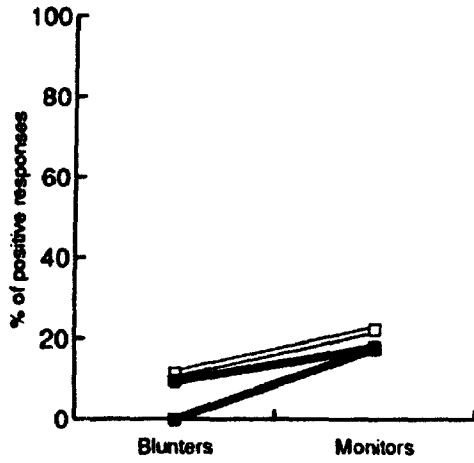
$G^2 (2, N = 134) = 6.84, p = .033$
 $X^2 (2, N = 134) = 6.43, p = .044$

Figure B1: Popular magazine articles



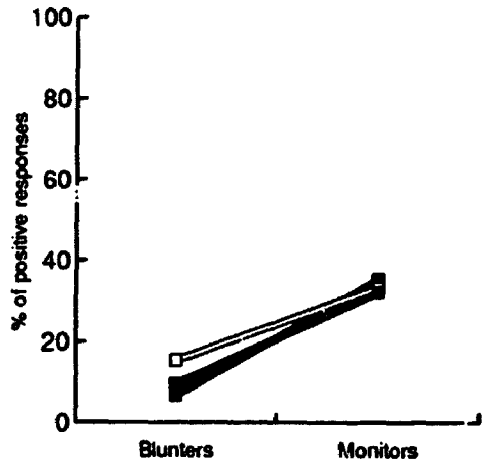
$G^2 (1, N = 134) = 4.74, p = .029$
 $X^2 (1, N = 134) = 4.66, p = .031$

Figure B2: Pamphlets



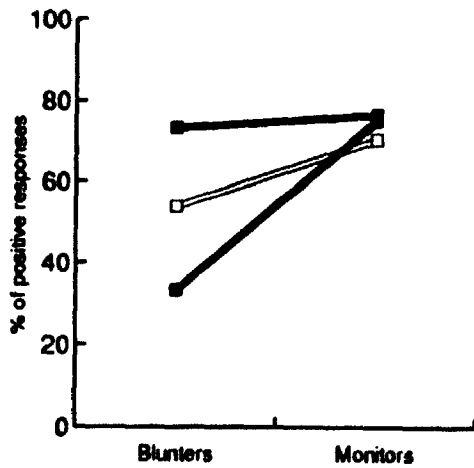
$G^2 (1, N = 134) = 5.78, p = .016$
 $X^2 (1, N = 134) = 4.61, p = .032$

Figure B3: Audiocassettes



$G^2 (1, N = 134) = 10.31, p = .001$
 $X^2 (1, N = 134) = 9.63, p = .002$

Figure B4: Videos

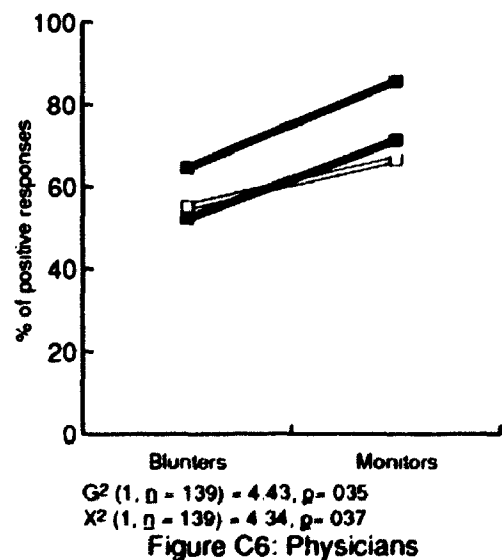
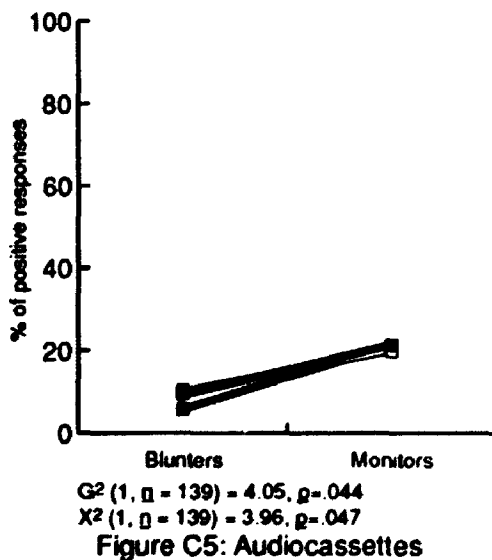
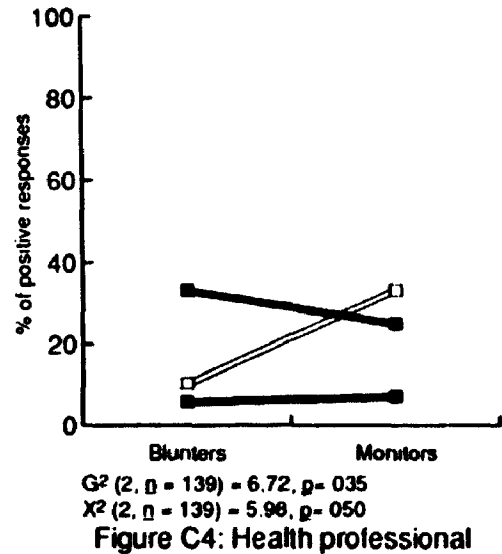
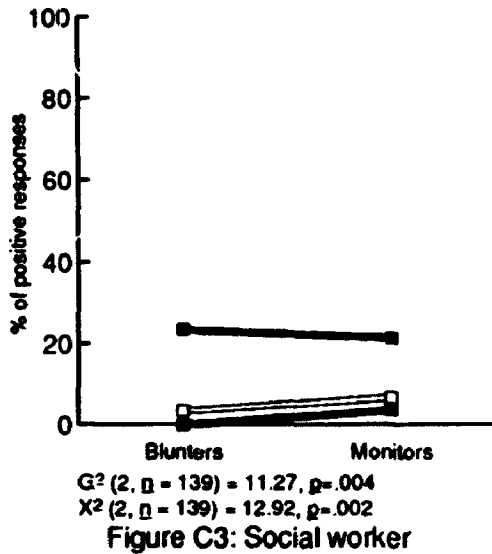
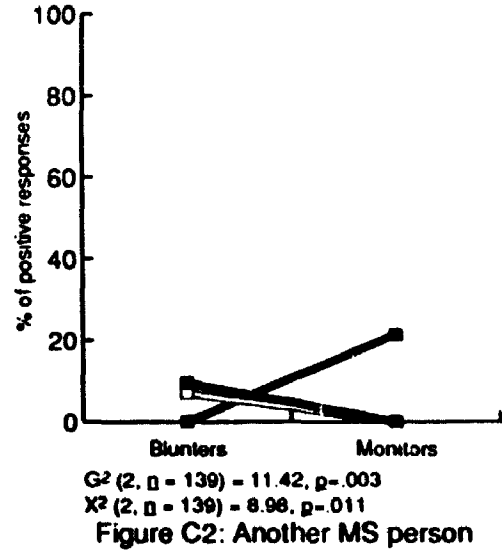
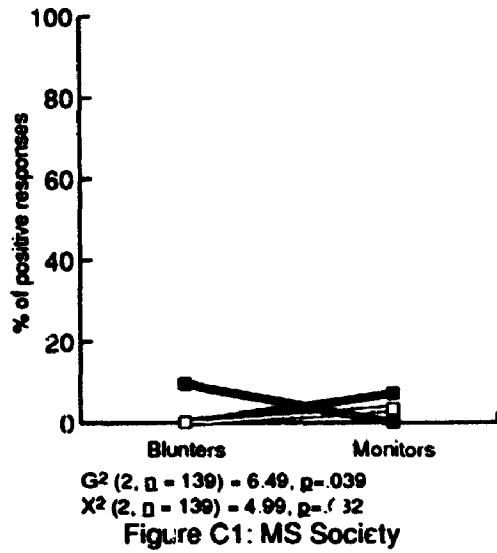


$G^2 (1, N = 134) = 5.08, p = .024$
 $X^2 (1, N = 134) = 5.31, p = .021$

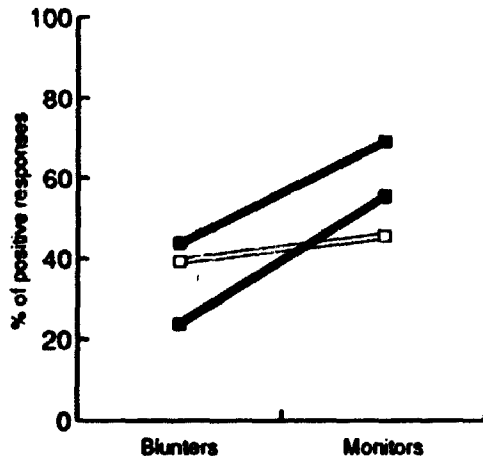
Figure B5: Physicians

Hereditary or Genetic Aspects of MS

Phase 1 ● Phase 2 □ Phase 3 ■

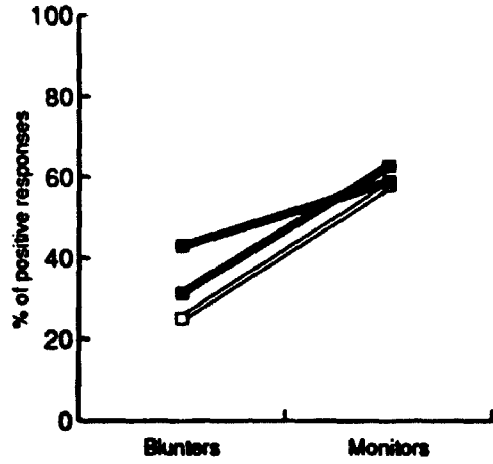


Muscle Spasticity or Weakness
 Phase 1 ● Phase 2 □ Phase 3 ●



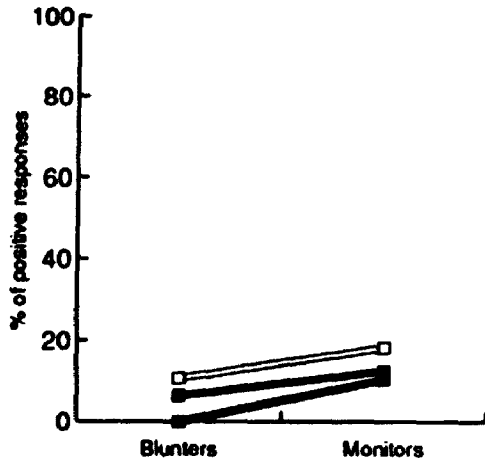
$G^2(1, n = 143) = 6.04, p = .014$
 $X^2(1, n = 143) = 5.96, p = .015$

Figure D1: Popular magazine articles



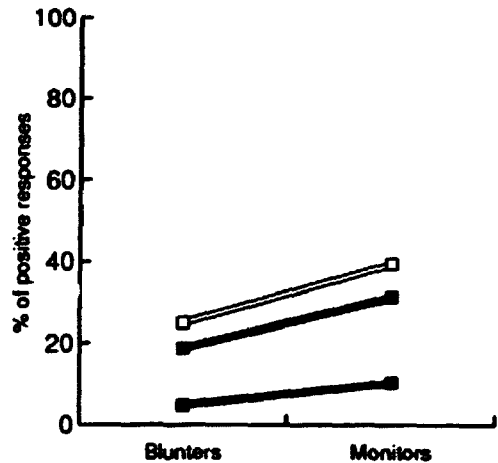
$G^2(1, n = 143) = 9.64, p = .002$
 $X^2(1, n = 143) = 9.54, p = .002$

Figure D2: Videos



$G^2(1, n = 143) = 4.01, p = .045$
 $X^2(1, n = 143) = 3.19, p = .074$

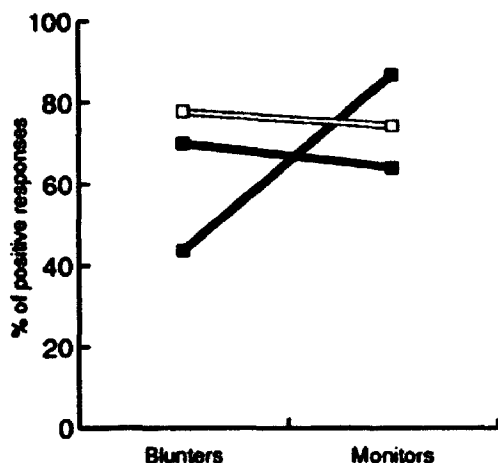
Figure D3: Family



$G^2(2, n = 143) = 10.64, p = .005$
 $X^2(2, n = 143) = 9.48, p = .009$

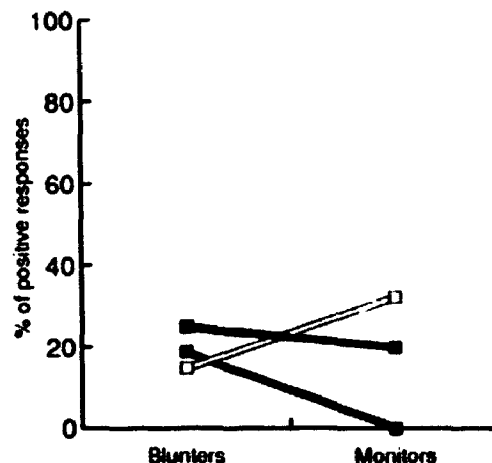
Figure D4: Spouses

General Information on MS
 Phase 1 ● Phase 2 □ Phase 3 ■



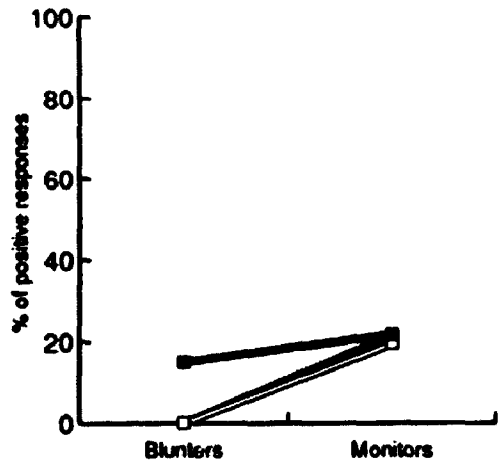
$G^2 (2, n = 134) = 6.23, p = .044$
 $X^2 (2, n = 134) = 5.90, p = .052$

Figure E1: Medical articles



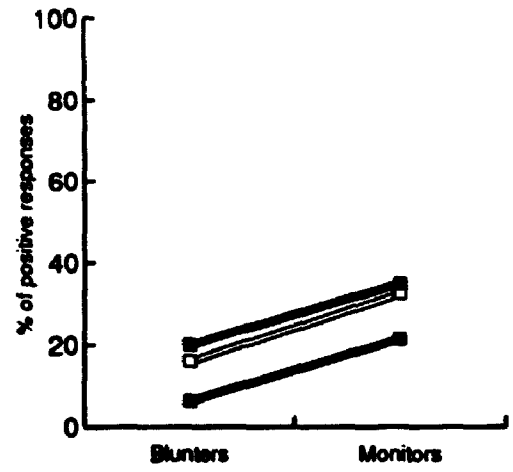
$G^2 (2, n = 134) = 6.85, p = .033$
 $X^2 (2, n = 134) = 5.63, p = .066$

Figure E2: Health professionals



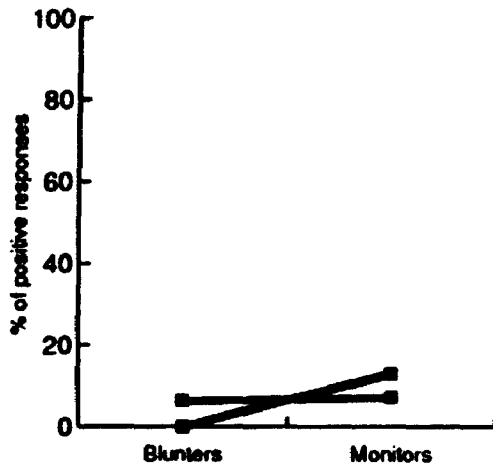
$G^2(1, n = 129) = 11.60, p = .001$
 $X^2(1, n = 129) = 8.91, p = .003$

Figure F1: Audiocassettes



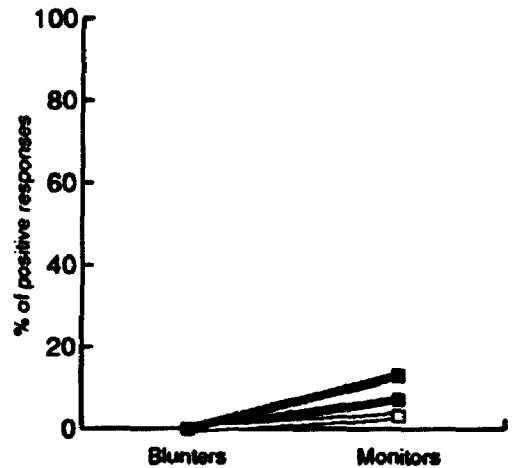
$G^2(1, n = 129) = 4.35, p = .037$
 $X^2(1, n = 129) = 4.35, p = .037$

Figure F2: Videos



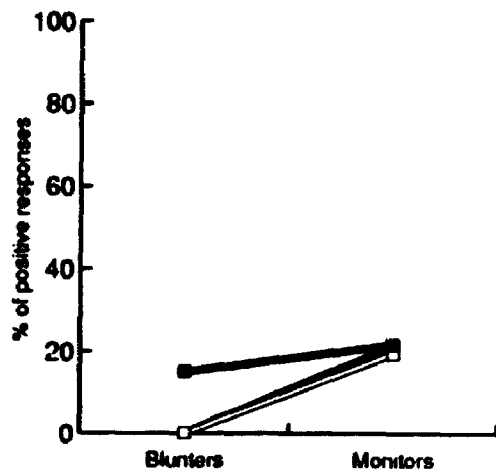
$G^2(1, n = 129) = 5.91, p = .015$
 $X^2(1, n = 129) = 5.89, p = .015$

Figure F3: Spouses



$G^2(1, n = 129) = 5.63, p = .018$
 $X^2(1, n = 129) = 4.47, p = .035$

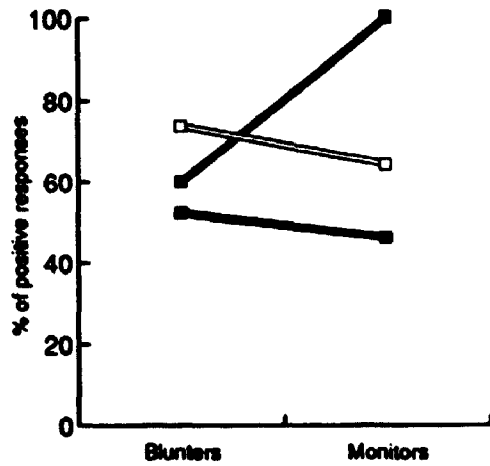
Figure F4: Friends



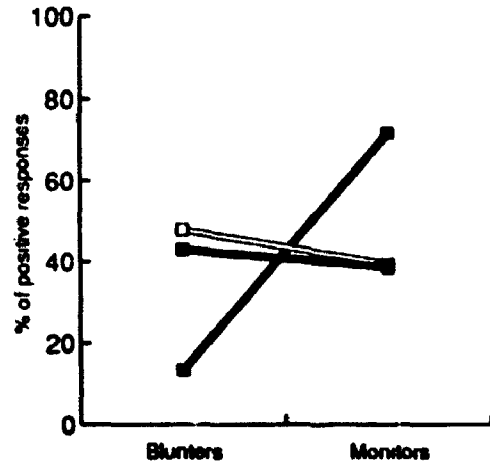
$G^2(2, n = 129) = 6.01, p = .050$
 $X^2(2, n = 129) = 4.95, p = .084$

Figure F5: Audiocassettes

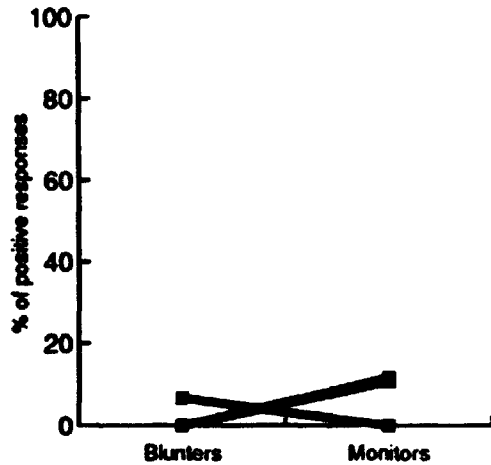
Effects of Overheating
 Phase 1 \blacksquare Phase 2 \square Phase 3 \bullet



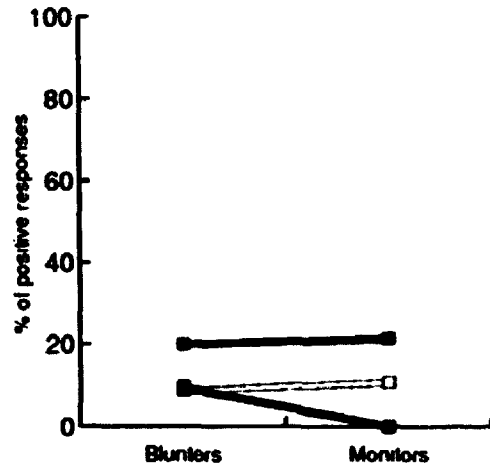
$G^2 (2, n = 127) = 9.97, p = .007$
 $X^2 (2, n = 127) = 7.68, p = .021$
Figure G1: Books



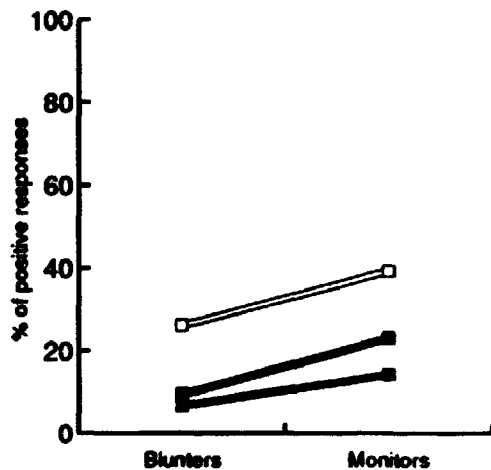
$G^2 (2, n = 127) = 10.38, p = .006$
 $X^2 (2, n = 127) = 9.71, p = .008$
Figure G2: Popular Magazine Articles



$G^2 (2, n = 127) = 5.46, p = .065$
 $X^2 (2, n = 127) = 5.98, p = .050$
Figure G3: Spouses

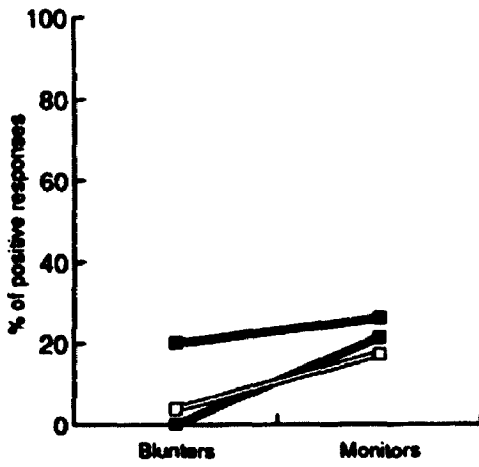


$G^2 (2, n = 127) = 6.92, p = .031$
 $X^2 (2, n = 127) = 6.11, p = .047$
Figure G4: Social Workers



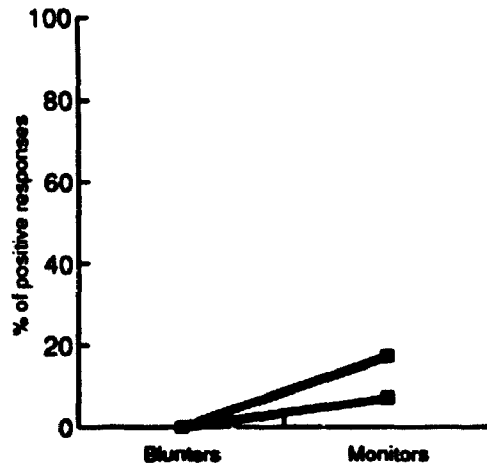
$G^2 (2, n = 127) = 6.77, p = .034$
 $X^2 (2, n = 127) = 6.82, p = .033$
Figure G5: Health Professionals

Nutritional Literature
 Phase 1 ● Phase 2 ◻ Phase 3 ●



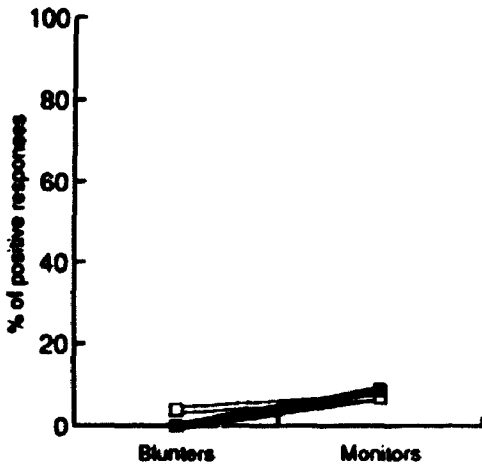
$G^2(1, n = 126) = 7.06, p = .008$
 $X^2(1, n = 126) = 5.73, p = .017$

Figure H1: Audiocassettes



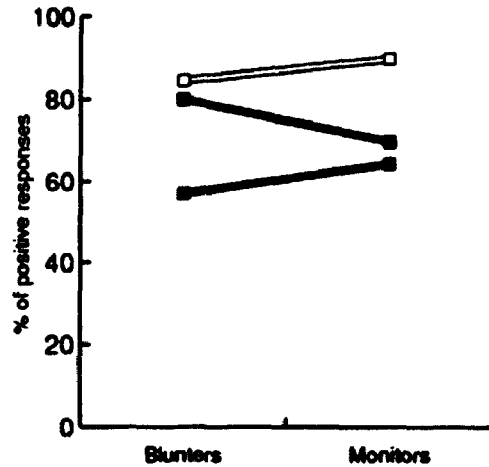
$G^2(1, n = 126) = 9.75, p = .002$
 $X^2(1, n = 126) = 15.72, p = .000$

Figure H2: Spouses



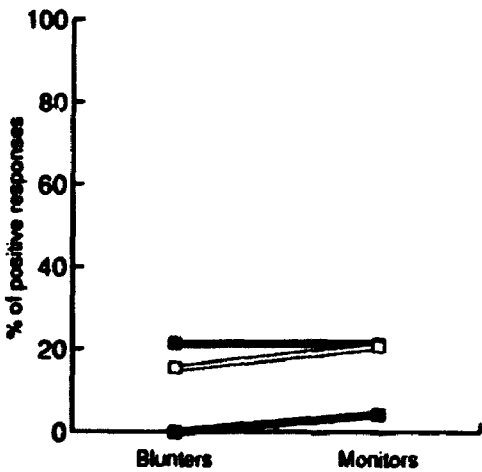
$G^2(1, n = 126) = 3.94, p = .047$
 $X^2(1, n = 126) = 3.04, p = .081$

Figure H3: Family



$G^2(2, n = 126) = 7.48, p = .024$
 $X^2(2, n = 126) = 7.56, p = .023$

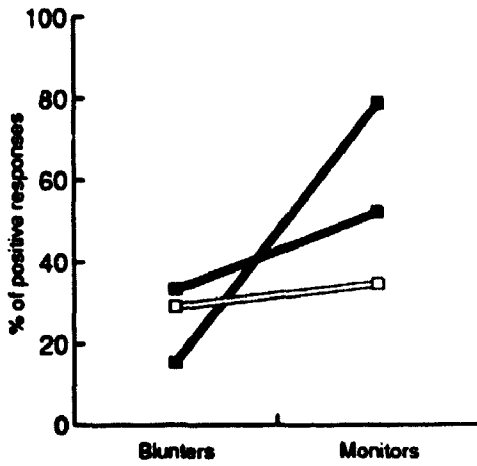
Figure H4: Pamphlets



$G^2(2, n = 126) = 10.01, p = .007$
 $X^2(2, n = 126) = 7.31, p = .026$

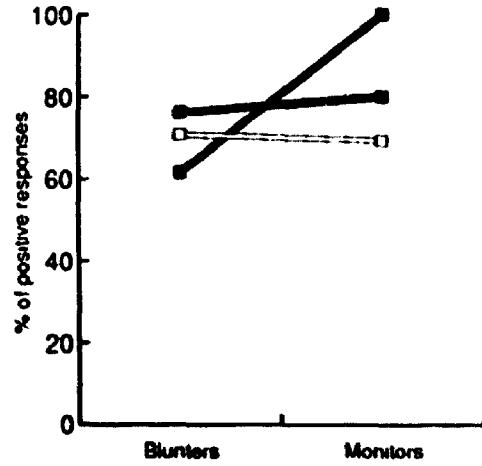
Figure H5: Social workers

Effects of Stress, Smoking or Alcohol
 Phase 1 ● Phase 2 □ Phase 3 ○



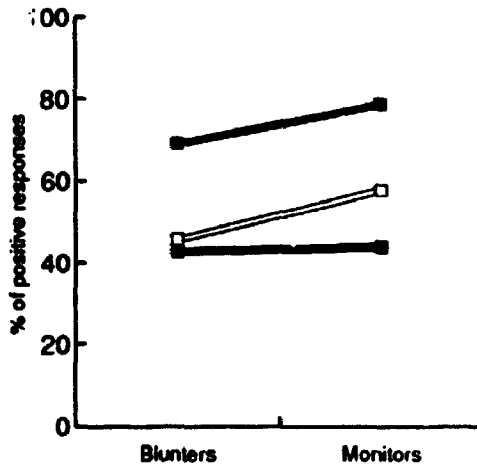
$G^2(2, n = 123) = 6.44, p = .040$
 $X^2(2, n = 123) = 6.00, p = .050$

Figure 11: Popular magazine articles



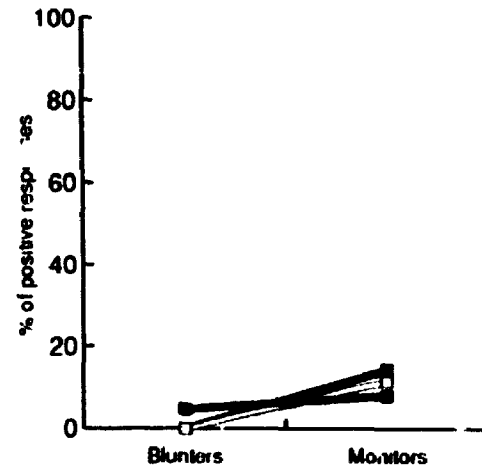
$G^2(2, n = 123) = 7.23, p = .027$
 $X^2(2, n = 123) = 5.41, p = .067$

Figure 12: Medical articles



$G^2(2, n = 123) = 6.74, p = .034$
 $X^2(2, n = 123) = 6.50, p = .039$

Figure 13: Physicians

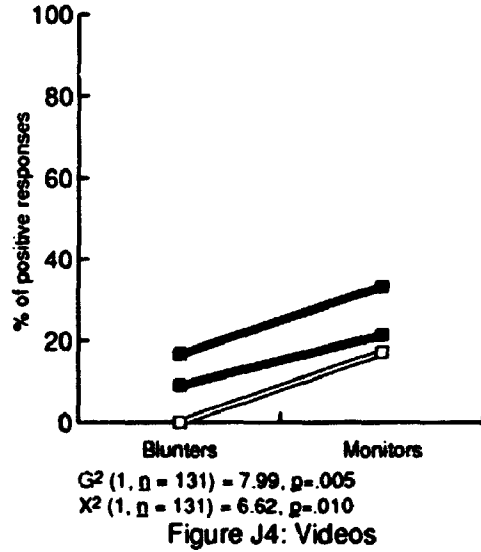
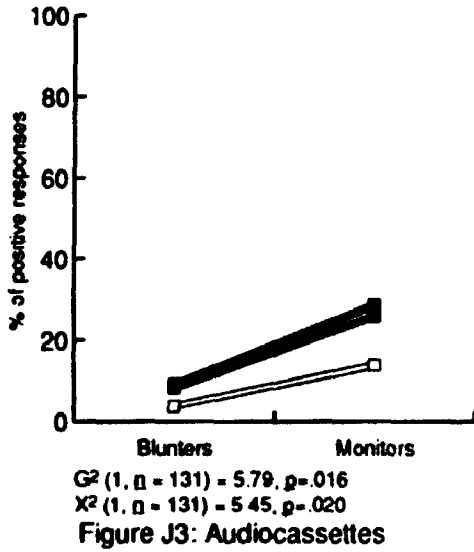
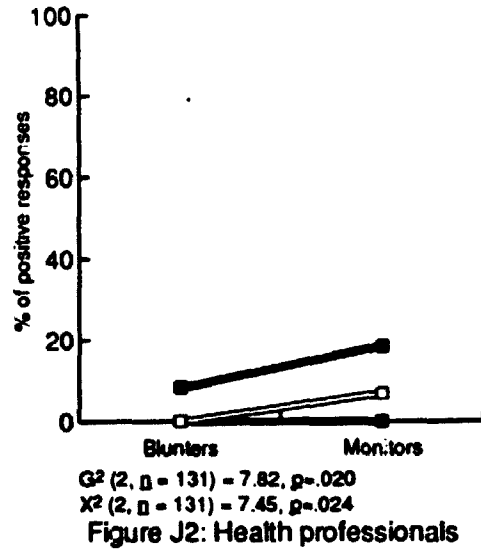
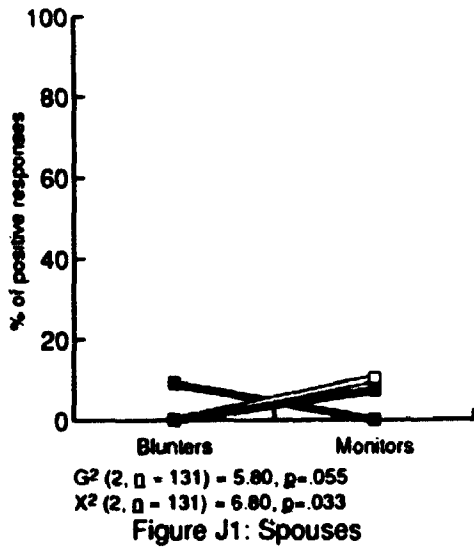


$G^2(1, n = 123) = 6.24, p = .012$
 $X^2(1, n = 123) = 4.67, p = .031$

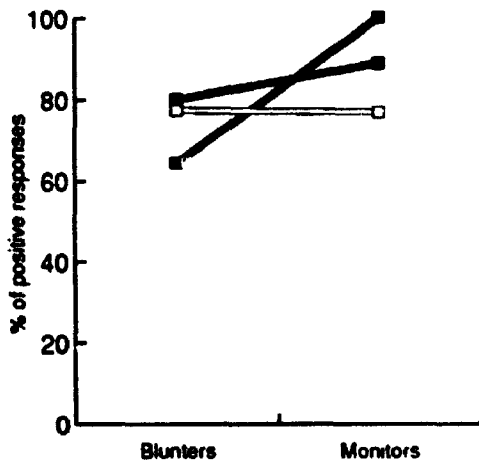
Figure 14: Friends

Memory Problems or Forgetfulness

Phase 1 ● Phase 2 □ Phase 3 ◆

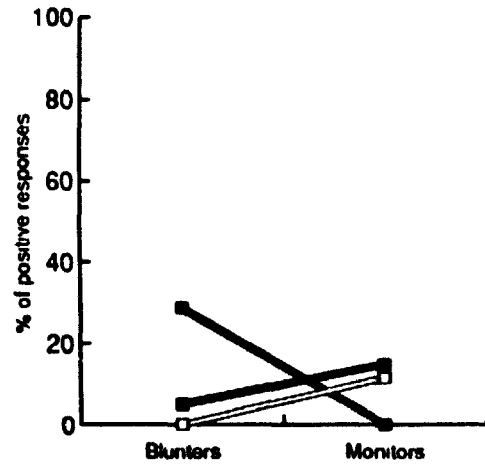


Bowel and Bladder Problems
 Phase 1 ● Phase 2 □ Phase 3 ■



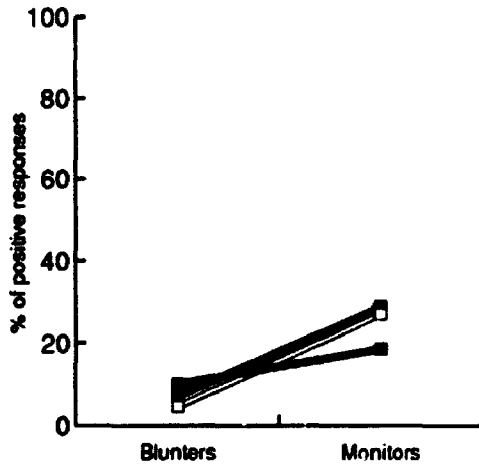
$G^2(2, n = 123) = 6.10, p = .047$
 $X^2(2, n = 123) = 4.52, p = .105$

Figure K1: Medical articles



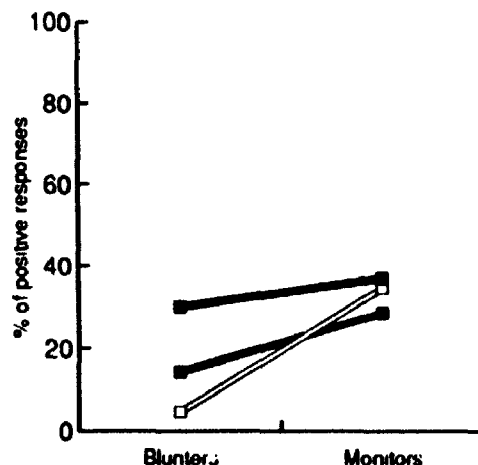
$G^2(2, n = 123) = 11.23, p = .004$
 $X^2(2, n = 123) = 8.55, p = .014$

Figure K2: Spouses



$G^2(1, n = 123) = 6.87, p = .009$
 $X^2(1, n = 123) = 6.43, p = .011$

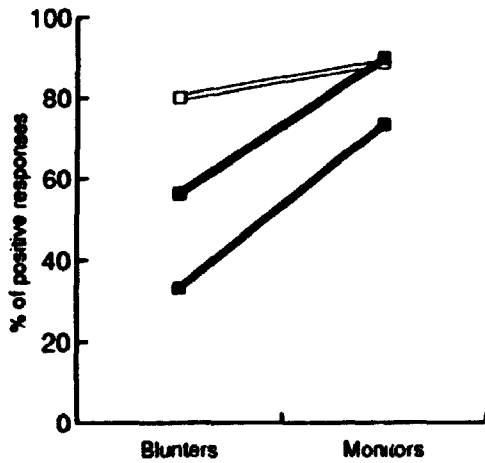
Figure K3: Audiocassettes



$G^2(1, n = 123) = 5.97, p = .015$
 $X^2(1, n = 123) = 5.72, p = .017$

Figure K4: Videos

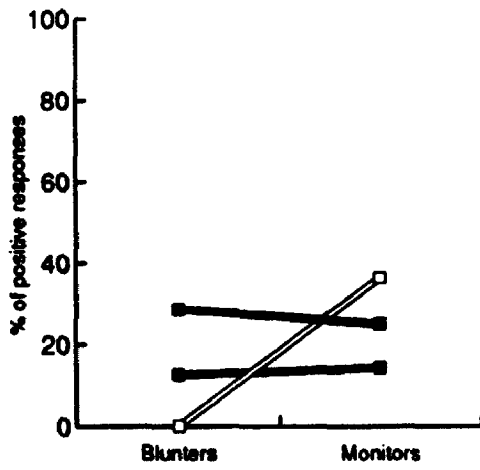
Pain
 Phase 1 ● Phase 2 □ Phase 3 ●



$G^2(2, n = 105) = 6.62, p = .037$
 $X^2(2, n = 105) = 7.06, p = .029$

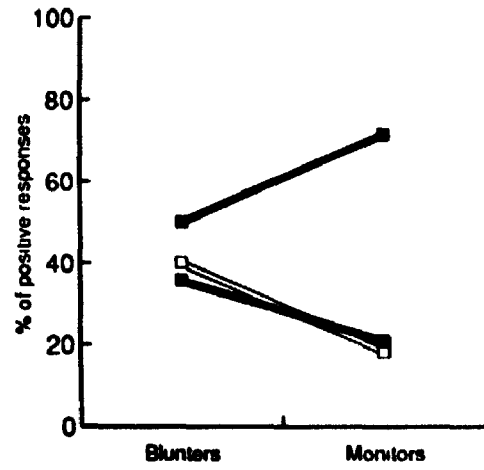
Figure L1: Pamphlets

Sexual Problems Associated with MS
Phase 1 \blacksquare Phase 2 \square Phase 3 \bullet



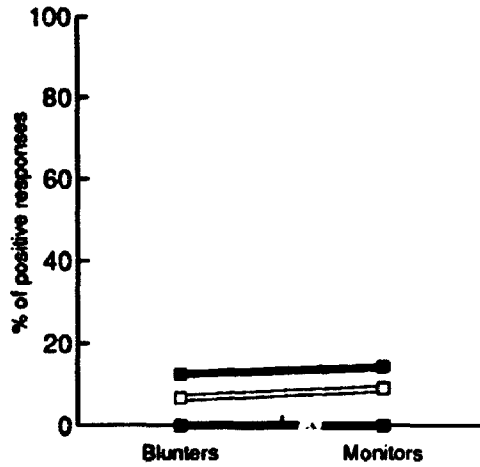
$G^2(2, n = 97) = 7.36, p = .025$
 $X^2(2, n = 97) = 5.60, p = .061$

Figure M1: Health professionals



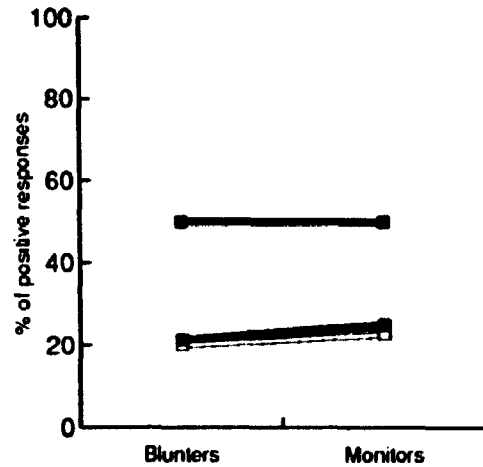
$G^2(2, n = 97) = 7.09, p = .029$
 $X^2(2, n = 97) = 7.98, p = .018$

Figure M2: Books



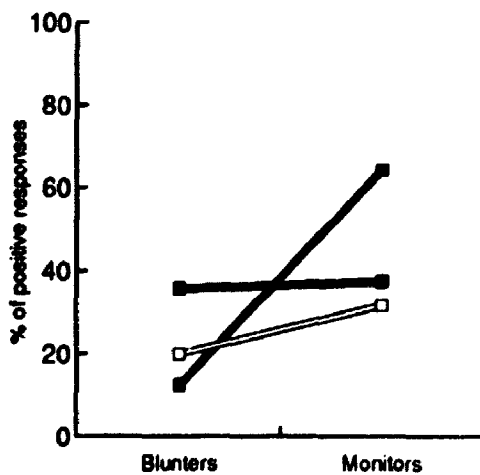
$G^2(2, n = 97) = 6.11, p = .047$
 $X^2(2, n = 97) = 4.79, p = .091$

Figure M3: MS Society



$G^2(2, n = 97) = 5.56, p = .061$
 $X^2(2, n = 97) = 6.13, p = .047$

Figure M4: Social workers



$G^2(1, n = 97) = 4.68, p = .031$
 $X^2(1, n = 97) = 4.40, p = .036$

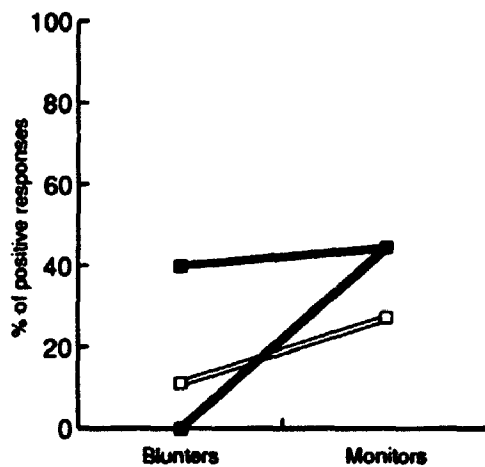
Figure M5: Popular magazine articles

Independent Living Aids
 Phase 1 ● Phase 2 ◻ Phase 3 ●



$G^2(2, N = 48) = 7.48, p = .024$
 $X^2(2, N = 48) = 7.44, p = .024$

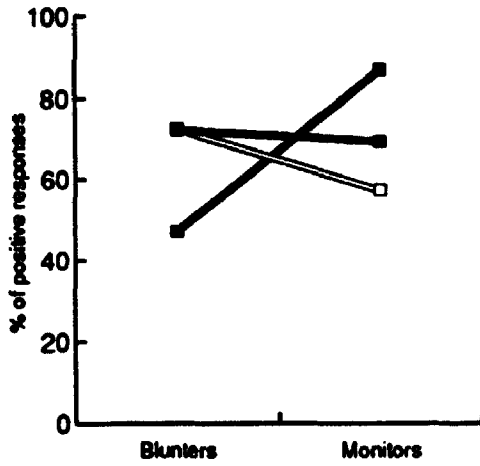
Figure N1: Spouses



$G^2(1, N = 48) = 4.08, p = .043$
 $X^2(1, N = 48) = 3.23, p = .072$

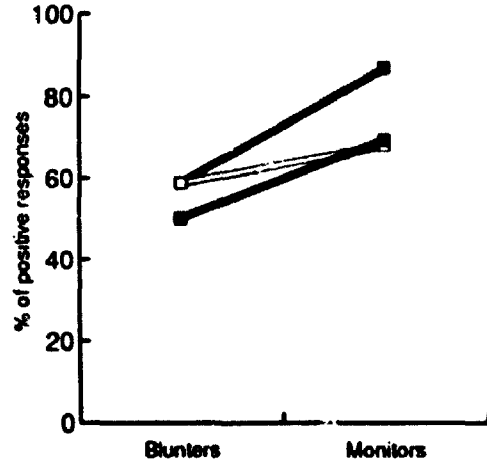
Figure N2: Videos

Pregnancy and/or Contraception
 Phase 1 ● Phase 2 □ Phase 3 ●



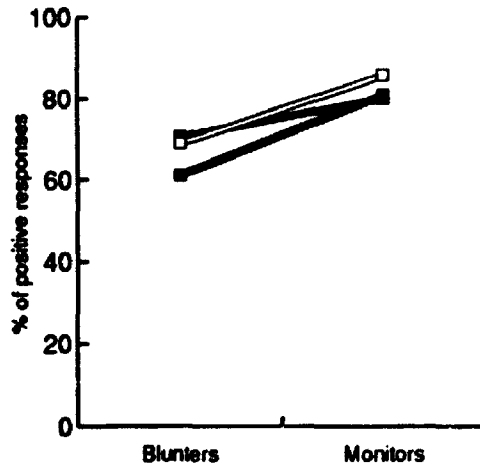
$G^2 (2, n = 133) = 7.35, p = .025$
 $X^2 (2, n = 133) = 7.00, p = .030$

Figure O1: Medical Articles



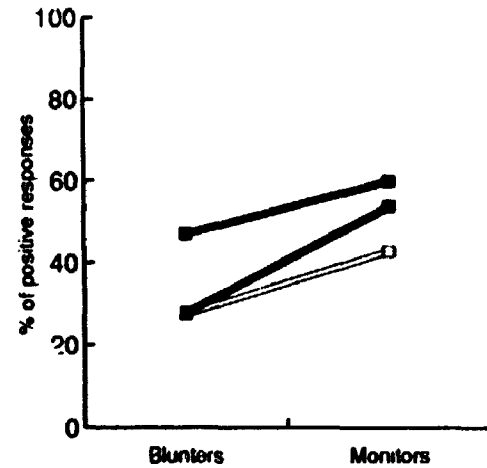
$G^2 (1, n = 133) = 5.22, p = .022$
 $X^2 (1, n = 133) = 5.09, p = .024$

Figure O2: Books



$G^2 (1, n = 133) = 3.91, p = .048$
 $X^2 (1, n = 133) = 3.90, p = .048$

Figure O3: Pamphlets

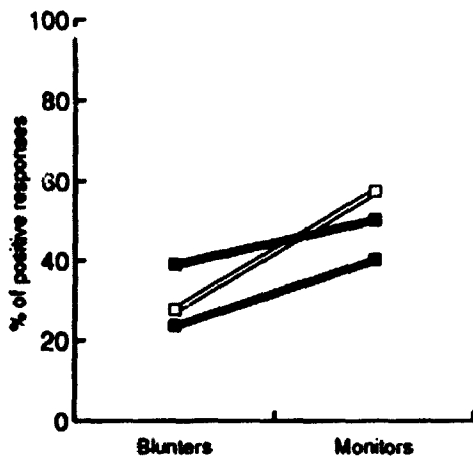


$G^2 (1, n = 133) = 4.32, p = .038$
 $X^2 (1, n = 133) = 4.29, p = .038$

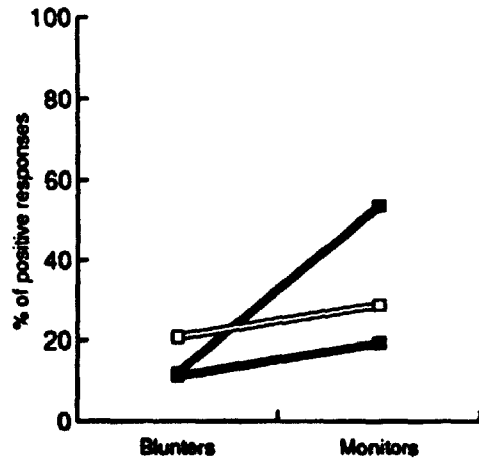
Figure O4: Popular Magazine Articles

Hidden Disabilities

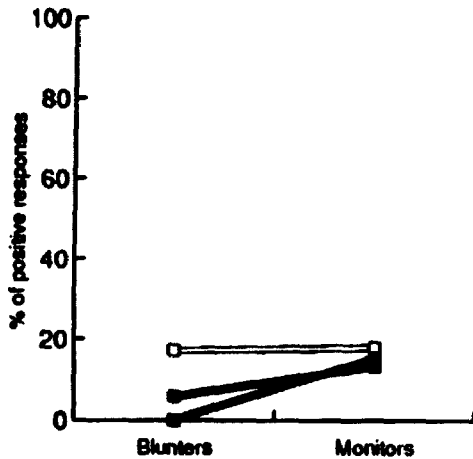
Phase 1 ● Phase 2 ◻ Phase 3 ◼



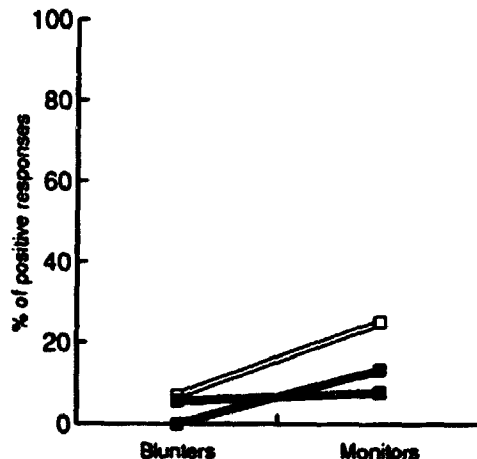
$G^2(1, n = 133) = 4.79, p = .029$
 $\chi^2(1, n = 133) = 4.80, p = .028$
Figure O5: Videos



$G^2(1, n = 133) = 5.61, p = .018$
 $\chi^2(1, n = 133) = 5.44, p = .020$
Figure O6: Physicians

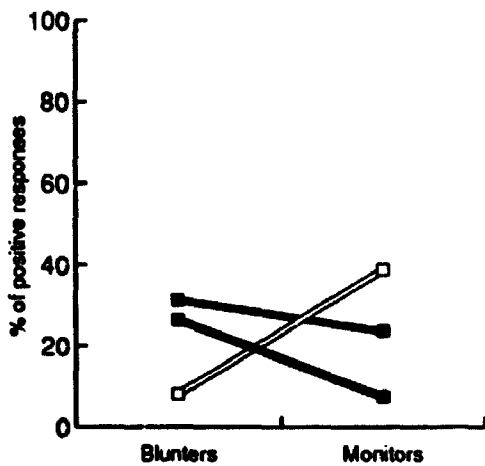


$G^2(1, n = 133) = 3.89, p = .049$
 $\chi^2(1, n = 133) = 3.06, p = .080$
Figure O7: Family

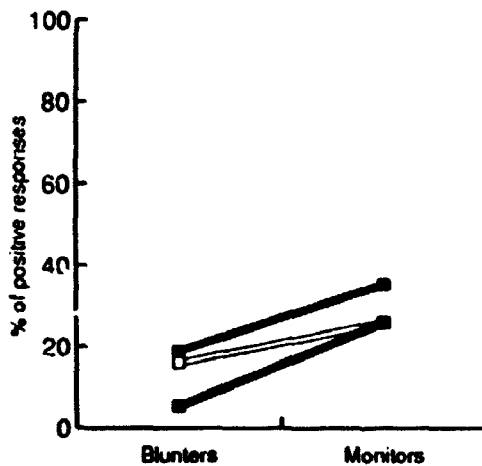


$G^2(1, n = 133) = 4.73, p = .030$
 $\chi^2(1, n = 133) = 4.02, p = .045$
Figure O8: Friends

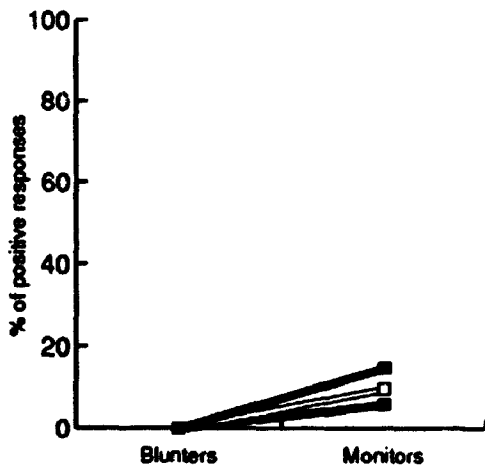
Hidden Disabilities
 Phase 1 ● Phase 2 □ Phase 3 ■



$G^2(2, n = 135) = 10.56, p = .005$
 $X^2(2, n = 135) = 10.20, p = .006$
Figure P1: Social Workers

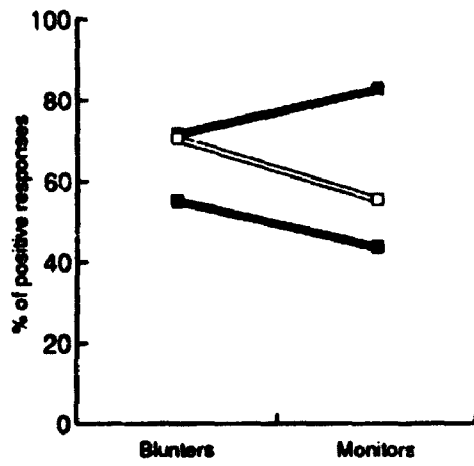


$G^2(1, n = 135) = 5.38, p = .020$
 $X^2(1, n = 135) = 5.05, p = .025$
Figure P2: Audiocassettes



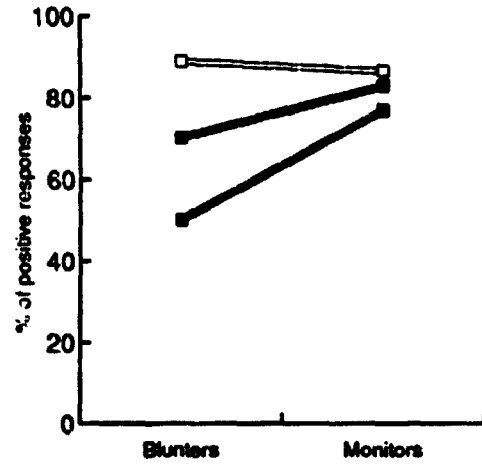
$G^2(1, n = 135) = 7.83, p = .005$
 $X^2(1, n = 135) = 7.92, p = .005$
Figure P3: Family

Uncertainty
 Phase 1 ● Phase 2 ◻ Phase 3 ●



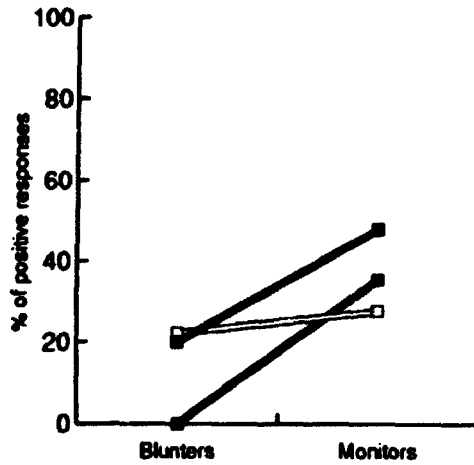
$G^2(2, n = 130) = 6.12, p = .047$
 $X^2(2, n = 130) = 5.99, p = .050$

Figure Q1: Books



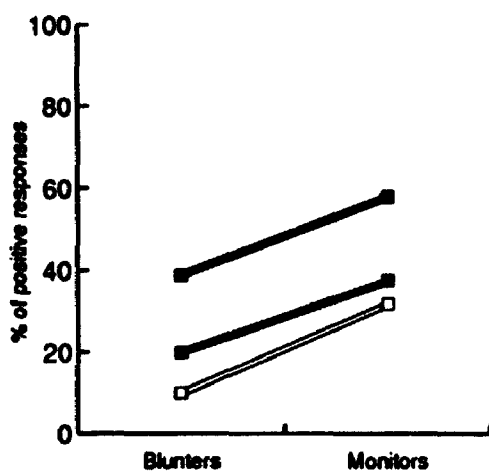
$G^2(2, n = 130) = 6.12, p = .047$
 $X^2(2, n = 130) = 6.32, p = .043$

Figure Q2: Pamphlets



$G^2(1, n = 130) = 11.12, p = .001$
 $X^2(1, n = 130) = 8.99, p = .003$

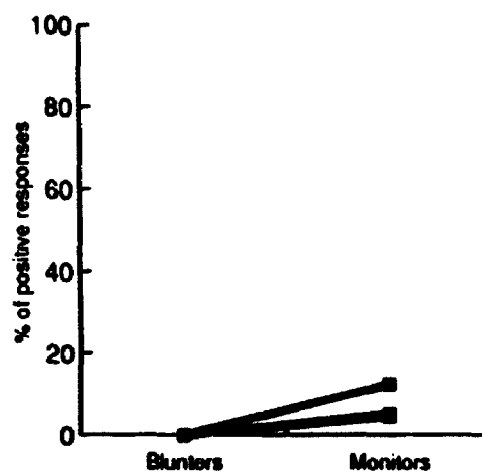
Figure Q3: Videos



$G^2(2, n = 105) = 7.59, p = .022$

$X^2(2, n = 105) = 7.56, p = .023$

Figure R1: Videos



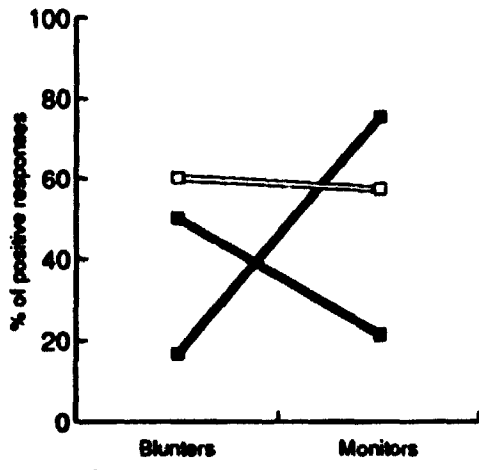
$G^2(1, n = 105) = 4.57, p = .033$

$X^2(1, n = 105) = 3.29, p = .070$

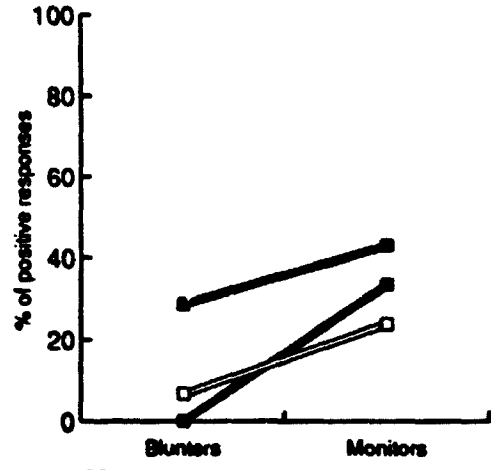
Figure R2: MS Society

Biographies or Autobiographies

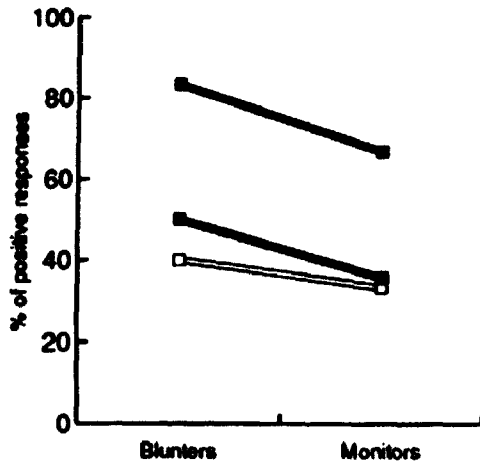
Phase 1 ● Phase 2 □ Phase 3 ●



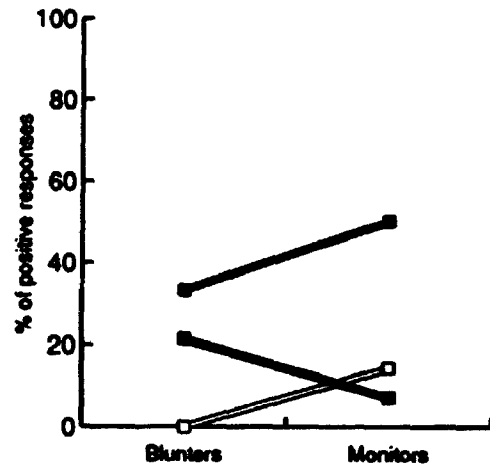
$G^2 (2, n = 82) = 8.40, p = .015$
 $X^2 (2, n = 82) = 8.03, p = .018$
Figure S1: Medical articles



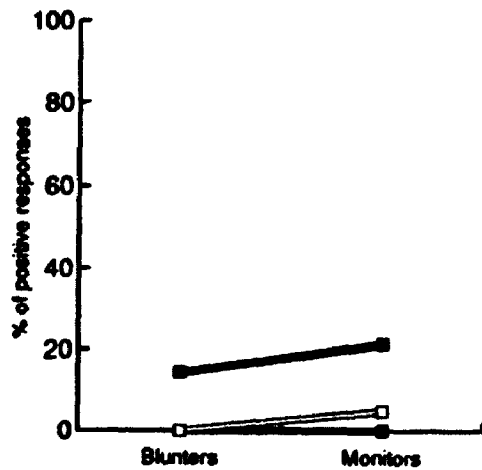
$G^2 (1, n = 82) = 6.37, p = .012$
 $X^2 (1, n = 82) = 5.01, p = .025$
Figure S2: Videos



$G^2 (2, n = 82) = 7.03, p = .030$
 $X^2 (2, n = 82) = 6.77, p = .034$
Figure S3: Books

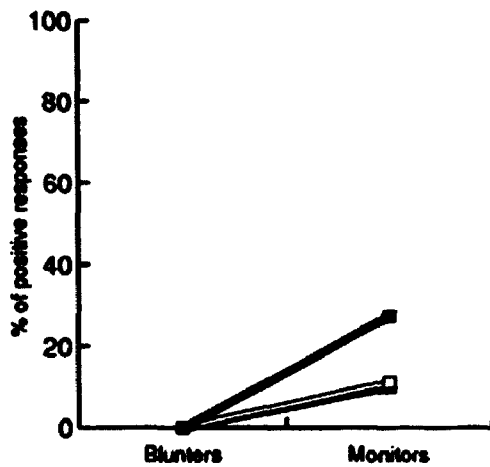


$G^2 (2, n = 82) = 9.61, p = .008$
 $X^2 (2, n = 82) = 13.57, p = .001$
Figure S4: Physicians



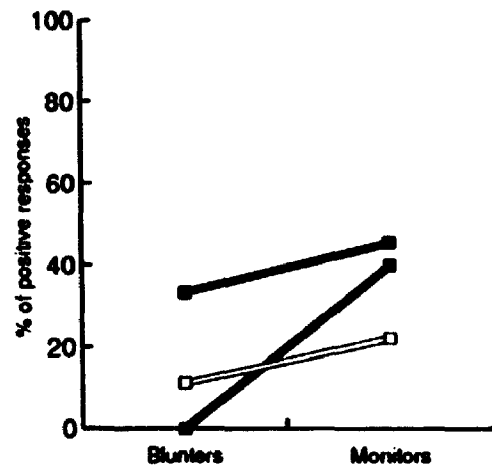
$G^2 (2, n = 82) = 8.03, p = .018$
 $X^2 (2, n = 82) = 7.55, p = .023$
Figure S5: Friends

Understanding the Caregiver Role
 Phase 1 ● Phase 2 ◻ Phase 3 ●



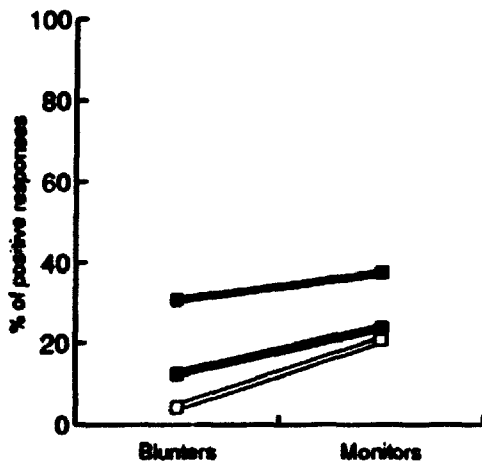
$G^2(1, n = 50) = 4.52, p = .033$
 $X^2(1, n = 50) = 3.26, p = .072$

Figure T1: Spouses



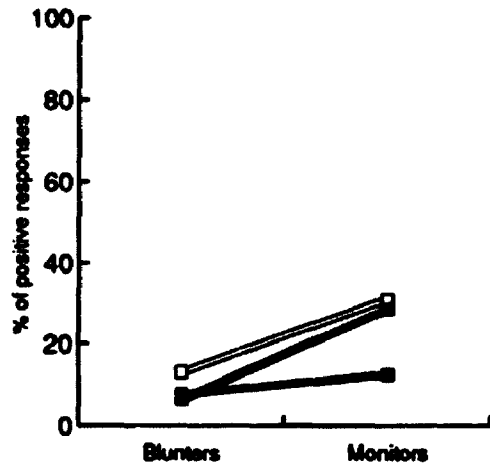
$G^2(1, n = 50) = 3.86, p = .049$
 $X^2(1, n = 50) = 3.09, p = .079$

Figure T2: Popular magazine articles



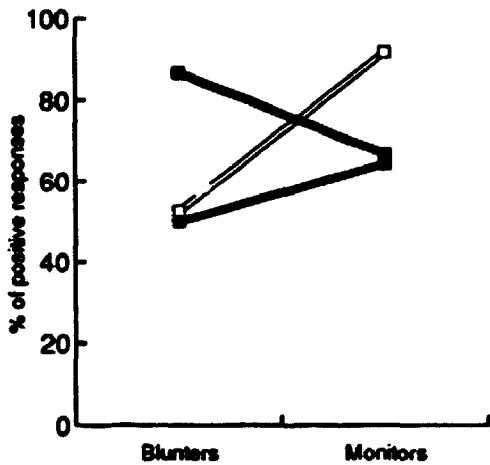
$G^2(2, N = 118) = 6.18, p = .045$
 $X^2(2, N = 118) = 6.44, p = .040$

Figure U1: Audiocassettes



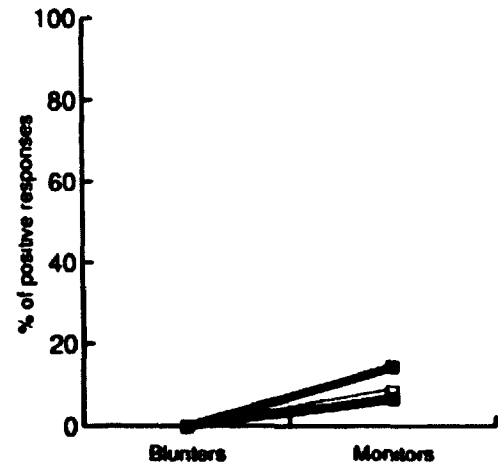
$G^2(1, N = 118) = 3.76, p = .052$
 $X^2(1, N = 118) = 3.85, p = .050$

Figure U2: Family



$G^2(2, n = 95) = 8.53, p = .014$
 $X^2(2, n = 95) = 8.40, p = .015$

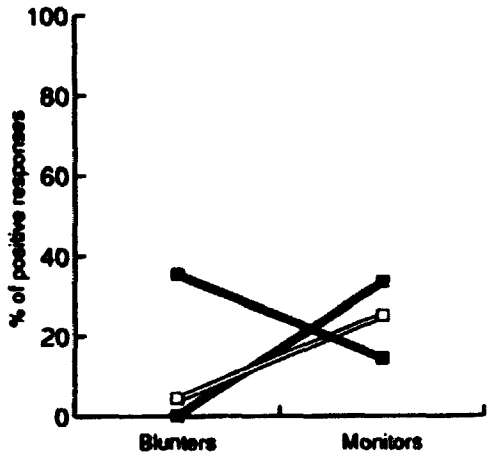
Figure V1: Pamphlets



$G^2(1, n = 95) = 5.52, p = .019$
 $X^2(1, n = 95) = 4.07, p = .044$

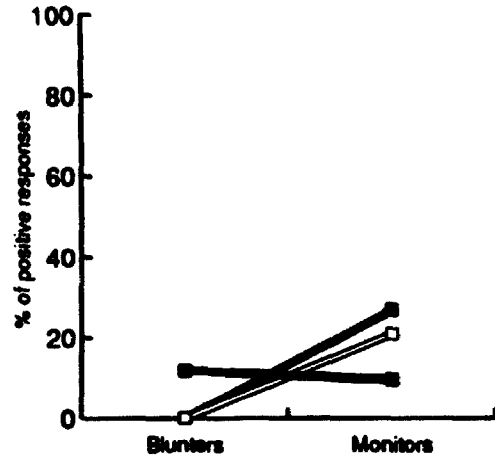
Figure V2: Family

Relations with Physicians
Phase 1 \bullet Phase 2 \square Phase 3 \blacksquare



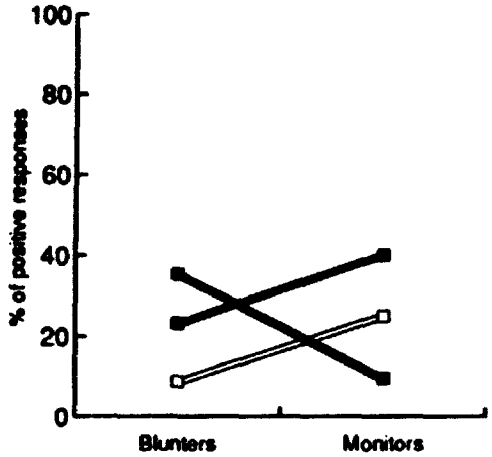
$G^2 (2, n = 113) = 11.96, p = .003$
 $X^2 (2, n = 113) = 10.61, p = .005$

Figure W1: Videos



$G^2 (2, n = 113) = 6.43, p = .040$
 $X^2 (2, n = 113) = 6.39, p = .041$

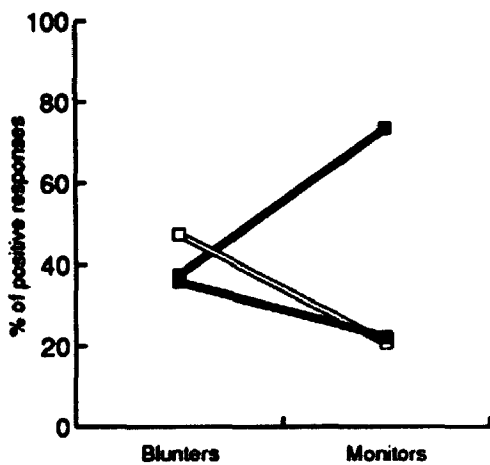
Figure W2: Physicians



$G^2 (2, n = 113) = 6.97, p = .031$
 $X^2 (2, n = 113) = 6.84, p = .033$

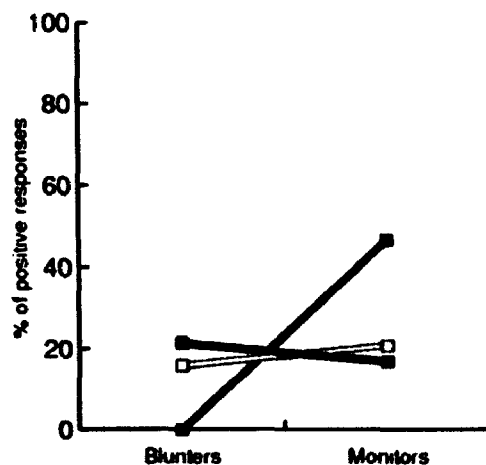
Figure W3: MS Society

Multiple Sclerosis Society
 Phase 1 ● Phase 2 ◻ Phase 3 ◉



$G^2 (2, n = 98) = 6.15, p = .046$
 $X^2 (2, n = 98) = 6.28, p = .043$

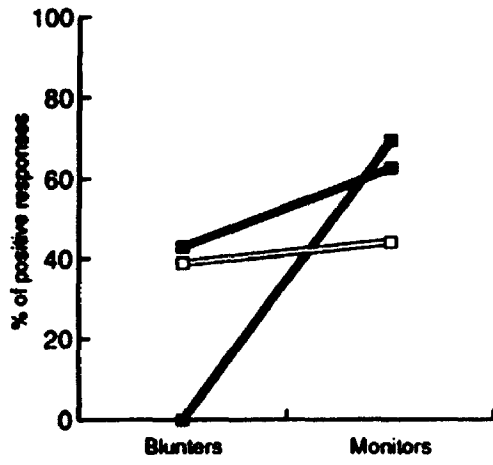
Figure X1: Books



$G^2 (2, n = 98) = 6.06, p = .045$
 $X^2 (2, n = 98) = 4.52, p = .105$

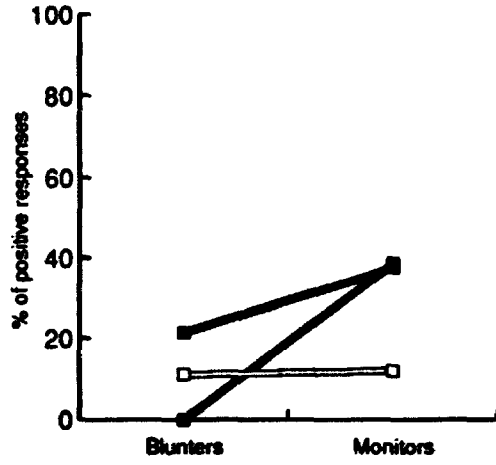
Figure X2: Videos

Mutual Support Groups
 Phase 1 ● Phase 2 □ Phase 3 ●



$G^2(2, n = 94) = 8.57, p = .014$
 $X^2(2, n = 94) = 6.41, p = .040$

Figure Y1: Popular magazine articles

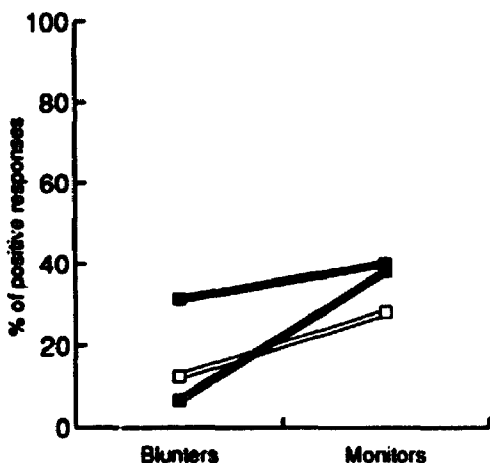


$G^2(1, n = 94) = 4.97, p = .026$
 $X^2(1, n = 94) = 3.90, p = .048$

Figure Y2: Videos

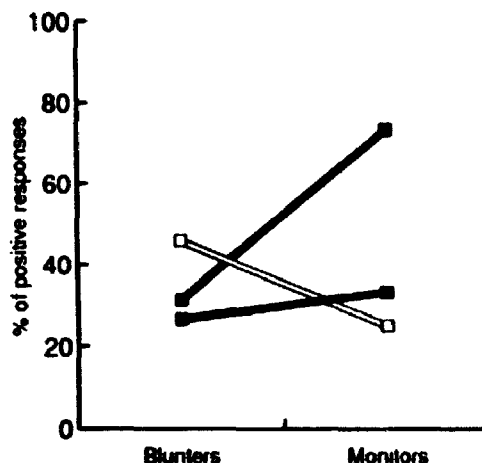
Friendships

Phase 1 ● Phase 2 □ Phase 3 ■



$G^2(1, n = 123) = 6.25, p = .012$
 $\chi^2(1, n = 123) = 5.87, p = .015$

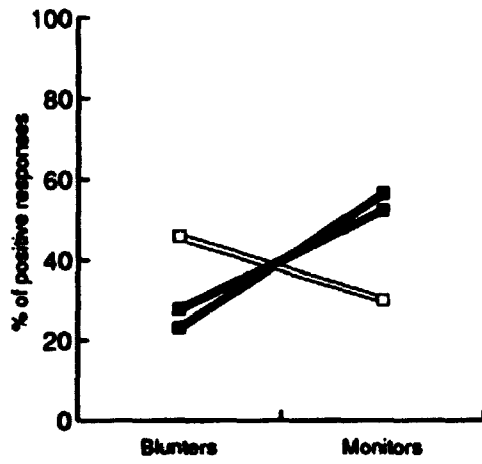
Figure Z1: Videos



$G^2(2, n = 123) = 8.36, p = .015$
 $\chi^2(2, n = 123) = 8.22, p = .016$

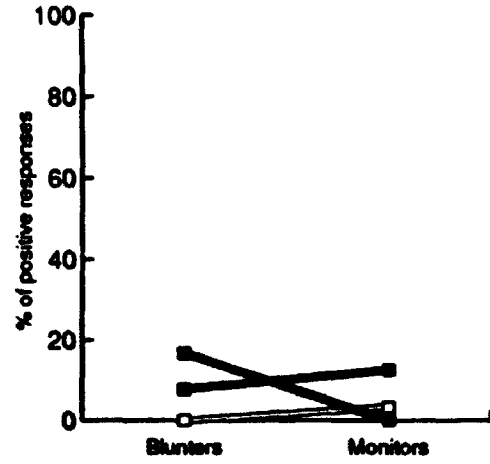
Figure Z2: Popular magazine articles

Insurance
 Phase 1 ◀ Phase 2 ▶ Phase 3 ▶



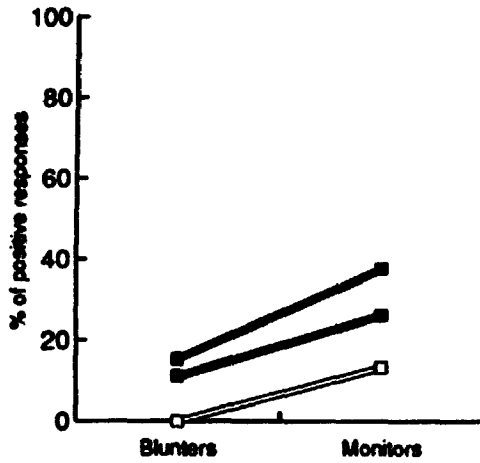
$G^2(2, N = 124) = 6.29, p = .043$
 $X^2(2, N = 124) = 6.26, p = .044$

Figure AA1: Popular magazine articles



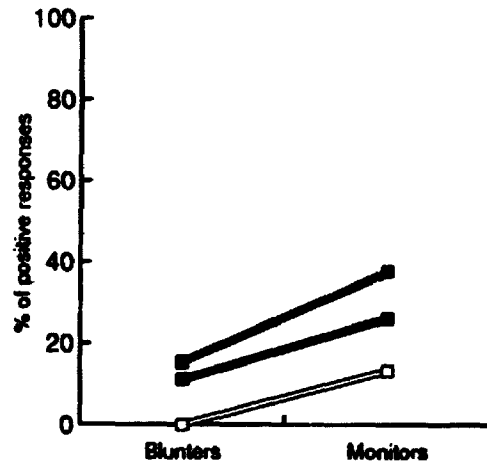
$G^2(2, N = 124) = 6.12, p = .047$
 $X^2(2, N = 124) = 4.66, p = .087$

Figure AA2: MS Society



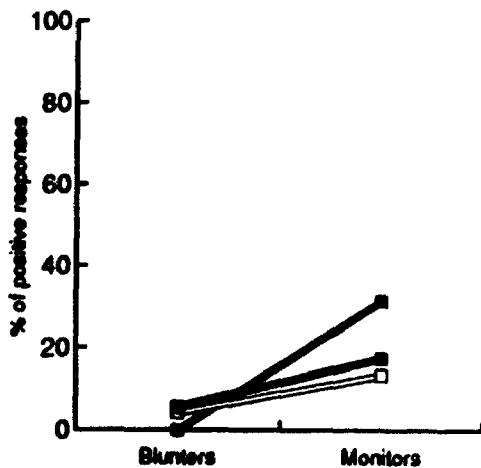
$G^2(2, N = 124) = 7.93, p = .019$
 $X^2(2, N = 124) = 6.77, p = .034$

Figure AA3: Physicians



$G^2(1, N = 124) = 8.27, p = .004$
 $X^2(1, N = 124) = 6.66, p = .010$

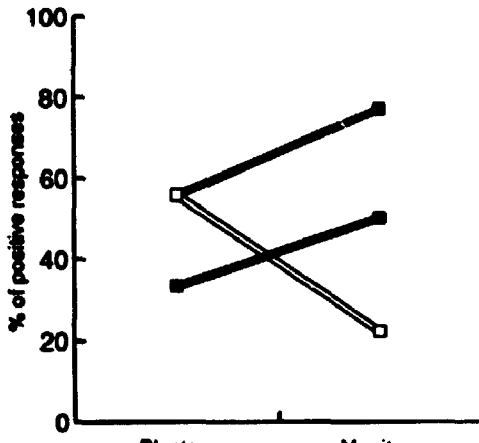
Figure AA4: Physicians



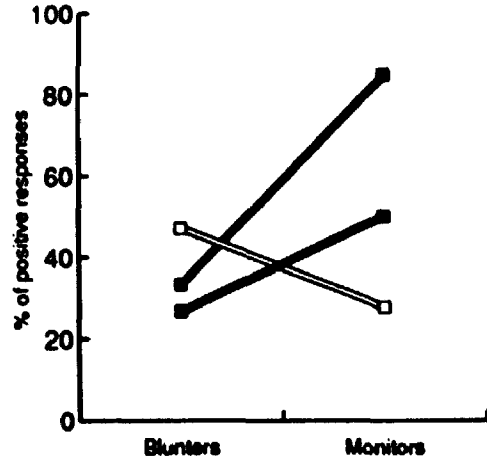
$G^2(1, N = 124) = 8.90, p = .003$
 $X^2(1, N = 124) = 7.23, p = .007$

Figure AA5: Audiocassettes

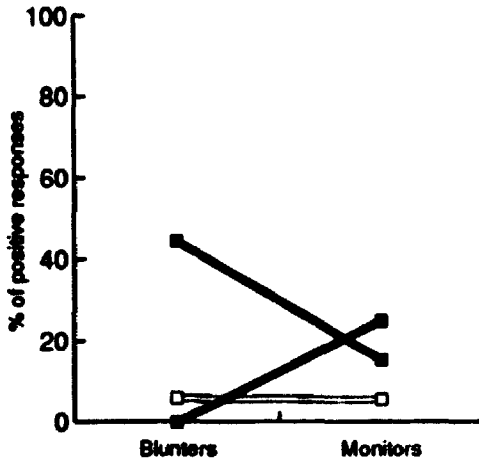
Government Agencies
 Phase 1 (■) Phase 2 (●) Phase 3 (□)



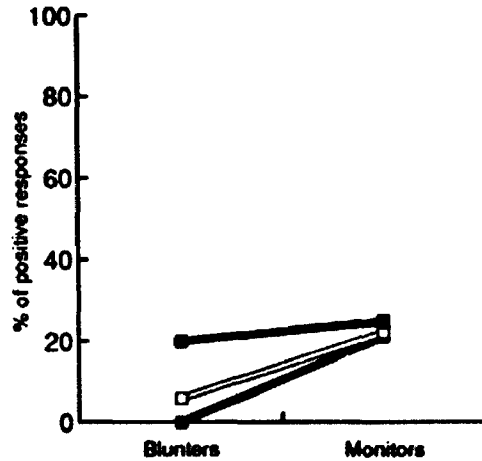
$G^2 (2, n = 80) = 6.40, p = .041$
 $X^2 (2, n = 80) = 6.36, p = .042$
Figure BB1: Books



$G^2 (2, n = 80) = 7.71, p = .021$
 $X^2 (2, n = 80) = 7.56, p = .023$
Figure BB2: Popular magazine articles



$G^2 (2, n = 80) = 6.81, p = .033$
 $X^2 (2, n = 80) = 6.48, p = .039$
Figure BB3: Spouses



$G^2 (1, n = 80) = 4.68, p = .031$
 $X^2 (1, n = 80) = 3.87, p = .049$
Figure BB4: Audiocassettes

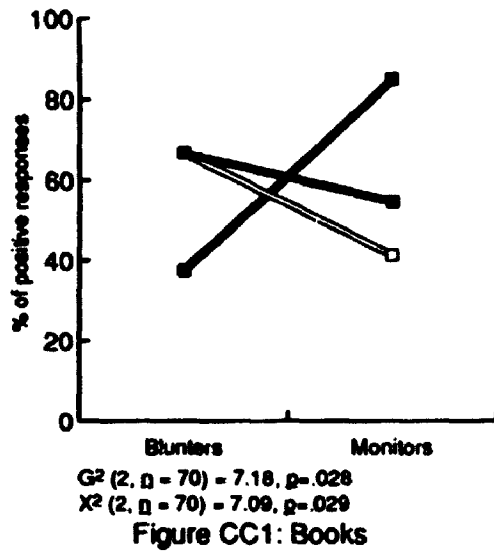


Figure CC1: Books

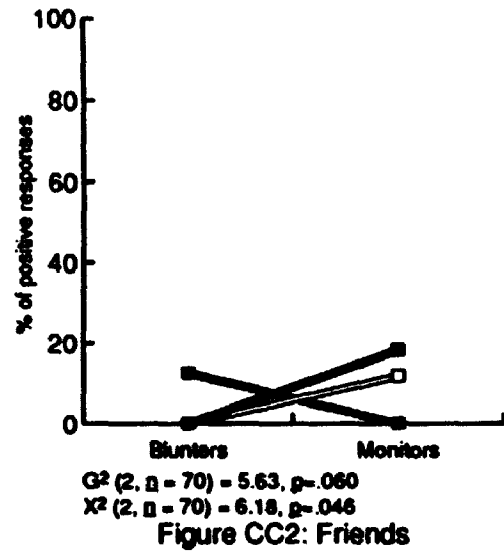


Figure CC2: Friends

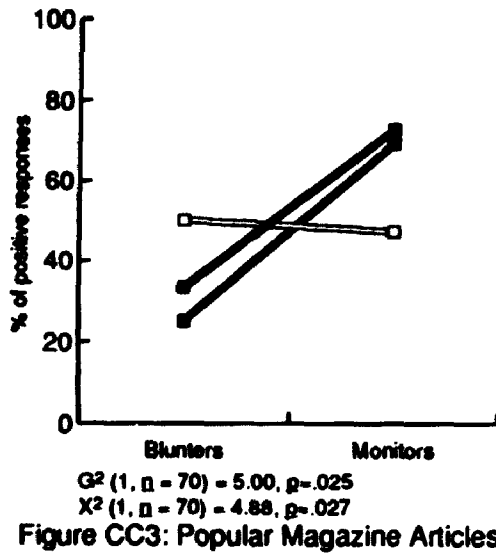


Figure CC3: Popular Magazine Articles

Career Choices and Goals
 Phase 1 ● Phase 2 □ Phase 3 ■

APPENDIX D

LETTERS

PART ONE OF STUDY

- Letter to Medical Director, Clinic A
- Letter from Staff Member, Clinic A, to Participants
- Letter from Researcher to Participants

PART TWO OF STUDY

- Letter to Medical Director, Clinic B
- Samples of Pamphlets Sent to Director, Clinic B
- Letter from Staff Member, Clinic B, to Participants
- Letter from Researcher to Participants

Letter to Medical Director, Clinic A

April 1992

Dear Dr-----:

I am a doctoral student in the School of Library and Information Science and a former registered nurse. The focus of my research project concerns the information needs and information-seeking patterns of women with multiple sclerosis.

This is an interesting disease to study because of the uncertainty factor, since studies have shown that people need and use information to reduce uncertainty and to help them cope with and adjust to the disease. What has not been addressed is the nature and amount of information these people want and need, when they want it, and how effective they find the available information to be.

In order to get a comprehensive picture of their information needs over the course of the disease, I would like to include participants who have been diagnosed within six months, two years, and five to seven years. I am writing to ask your permission to access the patient files at the MS Clinic, so that I may select a representative sample for each time period. Having worked as a registered nurse for fifteen years, I am very aware of the ethical and confidentiality issues surrounding patients and their charts. Therefore, confidentiality will be guaranteed.

My study consists of sending out a questionnaire that will take approximately one hour to complete. If you would like to see a copy of it, I will be glad to send one to you. I have discussed this project with [staff member]. I hope to receive your permission to access the patients' records in order to carry out this research study. Thank you for your attention to this request.

Yours truly,

Lynda M. Baker
PhD Candidate

Letter from Staff Member, Clinic A, to Participants

April 1992

Dear _____:

The MS Clinic has been approached by Lynda Baker, a former registered nurse and currently a doctoral student in the School of Library and Information Science, who is interested in studying information-related issues for women with MS. After discussing the project with her, we have agreed to assist Ms Baker in selecting women from our clinic records and introducing her to you.

Her study, which involves completing a short questionnaire, will take about one hour of your time. You do not need to complete it all at once if you find it too lengthy. Confidentiality is guaranteed.

Please read the accompanying letter from Ms Baker for further information about her study. Thank you.

Yours truly,

Letter from Researcher to Participants

April 1992

Dear

**INVESTIGATOR: Lynda M. Baker
TITLE: MS-Information Study
LOCATION: London, Ontario**

The purpose of this research project is to examine the level of interest in specific topics relevant to women with MS throughout the course of the disease. As part of the study, you are being asked to fill out the enclosed questionnaire, which should take approximately one hour to complete.

You are not obliged to answer any question that makes you feel uncomfortable. Further, you are free to withdraw from the study at any time. If you should decide not to complete the questionnaire, please draw a line through the first page and return the questionnaire in the stamped addressed envelope that is provided. This will help me keep my records straight and I will not send you any follow-up notices.

If you decide to continue in the study, I would ask that you complete the questionnaire. If you are physically unable to fill out the forms, then a family member can record your responses. Please return the completed questionnaire in the stamped addressed envelope provided.

In order to ensure anonymity, the questionnaires have been coded only by number. The returned questionnaires will be kept in my office, which is locked, and the answers you provide will be seen only by me. When the results of this study are published, neither your name nor the name of the institution (Clinic A) will be identified in any manner. Upon completion of the study, the list containing the names of the participants will be destroyed.

If you have any questions or are interested in receiving more information on any of the topics or about the project, please contact me. My address and phone numbers (work and home) are listed below.

Yours truly,

**Lynda M. Baker, PhD Candidate
School of Library and Information Science
Elbom College
University of Western Ontario
London, Ontario N6G 1H1
Phone: (519) 679-2111 ext. 8516 (work)
(519) 432-8658 (home)**

Letter to Medical Director, Clinic B

April 1992

Dear Dr----:

I am a doctoral student in the School of Library and Information Science and a former registered nurse. I met you at the EFPO workshop in May 1991, when we were in the same group session. My purpose in writing to you is to ask for your permission to include women from the MS Clinic in my research project, which concerns the information needs and information-seeking patterns of women with multiple sclerosis.

Although there is a considerable amount of literature available to people with the disease, no studies have addressed the effectiveness of the information provided in this literature from the MS person's perspective. My study involves measuring women's stated preference for information and their reaction to and satisfaction with general or specific information on topics of concern to people with MS, namely fatigue or treatment of acute exacerbations.

In order to get a comprehensive picture of this group's information needs in the first two to three years post-diagnosis, I would like to include only those women who have been diagnosed since April 1989. I would like your permission to see the patient files at the MS Clinic, so that I may select a representative sample of these recently diagnosed women. Having worked as a registered nurse for fifteen years, I am very aware of the ethical and confidentiality issues surrounding patients and their charts. I propose to ensure confidentiality by keeping the list of names in my locked office and destroying it upon completion of the project. In addition, the results will be reported only in the aggregate.

Once a suitable sample has been gathered, I will be mailing out a package consisting of two short questionnaires and a short pamphlet containing either general or specific information on fatigue or treatment of acute exacerbations. The surveys will take approximately 45 minutes to one hour to complete. For your information, I have attached the complete package of materials to be sent out.

I have discussed this project with [staff members], who are very interested in the results and have offered to assist in the selection of subjects. They have also reviewed the survey materials. I hope to receive your permission to access the patients' records in order to carry out this research study.

Thank you for your attention to this request.

Yours truly,

Lynda M. Baker
PhD Candidate

FATIGUE (General)

Fatigue is one of the most common complaints of people with multiple sclerosis (MS). The fatigue is often described as excessive when it is compared with the amount of activity preceding it or with the individual's degree of disability. People often describe this fatigue as feeling "wasted". Although many people with MS report fatigue or a feeling of overwhelming tiredness, the exact cause is not understood. This is not surprising since there are many aspects of MS that, to date, are neither known nor understood. However, some physiological and psychological causes have been identified.

Physical changes in the central nervous system as a result of multiple sclerosis make people tire easily and at a faster rate. This is not unusual. Fatigue can also be caused by other factors, including those that contribute to tiredness in people who do not have MS. However, the fatigue experienced by people with MS is greater and occurs more frequently. In addition, psychological factors may contribute to the feeling of fatigue or tiredness. Since fatigue can vary from one day to another, people with MS may require rest periods when others do not. Interestingly, people, such as the individual's family, friends and co-workers, often may not understand why the person with MS gets so tired and why she requires more periods of rest and relaxation. It may be necessary to explain quite often to these people that fatigue is a known symptom of multiple sclerosis and that many MS people experience it.

The treatment for fatigue in MS is varied and can be of a physiological or psychological nature, or even a combination of both. Some forms of therapy can include taking commonsense precautions against getting overtired or overheated. Within each person's limitations, individuals with MS should keep physically fit, as active as possible and should attempt to maintain normal work and social relationships. In other words, the person with MS should recognize her own limitations and work within these parameters. This may mean more deliberate planning of daily activities in order to make the most use of high energy levels. This also necessitates planning scattered rest periods throughout the day when energy levels are low. In addition to these precautions, it is helpful for the person with multiple sclerosis to accept the fact that fatigue is an integral part of the disease. Just recognizing this fact may actually help the person with MS, her family, friends and co-workers to deal more realistically with this symptom.

Some research studies have been done examining the effects of an anti-viral drug on fatigue. The evidence is not conclusive. There is some indication that the drug works in some cases, but does not work in others. People with multiple sclerosis who are bothered by fatigue may want to discuss the possibility of taking this drug with their physician.

Information for this pamphlet was adapted from the following sources:

Burnfield, A. (1988). Coping with fatigue in MS takes understanding and planning (rev. ed.). Toronto: Multiple Sclerosis Society of Canada.

Canadian MS Research Group. (1987). A randomized controlled trial of amantadine in fatigue associated with multiple sclerosis. Canadian Journal of Neurological Sciences, 14, 273-278.

Herndon, R. M. , & Rudick, R. (1982). Fatigue. Toronto: Multiple Sclerosis Society of Canada.

Murray, T. J. (1985). Amantadine therapy for fatigue in multiple sclerosis. Canadian Journal of Neurological Sciences, 12, 251-254.

Scheinberg, L. C., & Smith, C. R. (1987). Signs and symptoms of multiple sclerosis. In L. C. Scheinberg & N. J. Holland (Eds.), Multiple sclerosis: A guide for patients and their families (2nd ed.) (pp. 43-51). New York: Raven Press.

FATIGUE (Specific)

Fatigue is one of the most common complaints of people with multiple sclerosis (MS). The fatigue is often described as excessive when it is compared with the amount of activity preceding it or with the individual's degree of disability. Although the number of people reporting fatigue ranges from 40% to 90%, the exact cause is not understood. Some physiological and psychological causes have been identified.

Physiologically, fatigue is related to the loss of the myelin sheath surrounding the nerve fibres. The sheath is responsible for the conduction of nerve impulses and when destroyed, the nerve fibres have to work harder to get the impulses past the demyelinated area. The increased work load for the nerve fibres makes them tire easily. Also, without the sheath, the fibres are more sensitive to changes in body temperature. Increased body temperature and thus, fatigue, can occur after too much physical activity. Fatigue can also be caused by exposure to heat, such as a hot bath or sunbathing. Similarly, infections can contribute to feelings of fatigue because infections are often accompanied by fevers. Another source of fatigue is muscle strain, that is, the strong muscles tire from compensating for the weaker ones. Fatigue may also have a psychological basis. The feeling of tiredness is very real for the person with MS; however, since it is invisible to family and friends, it is often misunderstood. In fact, they may consider the person with MS to be lazy or trying to escape work. Although not actually causing it, other factors contributing to fatigue include feelings of depression, anxiety or a sense of hopelessness that often accompany MS.

Treatment for fatigue can be physiological, psychological or a combination of both, and can include such commonsense things as getting 8 hours of sleep, eating a balanced diet, quitting smoking, and avoiding hot baths or sunbathing. More specifically, since the body temperature varies throughout the day and is higher in the afternoon (from 3 p.m. to 6 p.m.), daily plans should include rest periods, especially in late afternoon. Keeping fit within one's limitations may also help. Exercise programs tailored by a physical therapist to an individual's routine, interests and ability may help reduce fatigue; an occupational therapist can devise some energy saving methods for accomplishing daily chores. Some people may consider self-help groups as a type of therapy, because talking to others with MS and sharing similar concerns may help to relieve feelings of depression and loneliness. Finally, understanding that fatigue is an integral part of MS may help patients, their families and friends deal more realistically with this symptom.

Clinical research studies on the effects of an anti-viral drug, Amantadine or Symmetrel, on fatigue seem to show that this drug may reduce fatigue in some patients, but not all. In addition, the drug was found to have no effect on disability.

Information for this pamphlet was adapted from the following sources:

Burnfield, A. (1988). Coping with fatigue in MS takes understanding and planning (rev. ed.). Toronto: Multiple Sclerosis Society of Canada.

Canadian MS Research Group. (1987). A randomized controlled trial of amantadine in fatigue associated with multiple sclerosis. Canadian Journal of Neurological Sciences, 14, 273-278.

Herndon, R. M., & Rudick, R. (1982). Fatigue. Toronto: Multiple Sclerosis Society of Canada.

Matthews, W. B. (1991). Treatment. In W. B. Matthews, A. Compston, I. V. Allen & C. N. Martyn (Eds.), McAlpine's Multiple Sclerosis (2nd ed.) (pp. 251-298). Edinburgh: Churchill Livingstone.

Murray, T. J. (1985). Amantadine therapy for fatigue in multiple sclerosis. Canadian Journal of Neurological Sciences, 12, 251-254.

TREATMENT FOR ACUTE ATTACKS (General)

The cause of multiple sclerosis (MS) remains a mystery and no cure exists. The course of the disease in any individual case cannot be predicted; however, different patterns of MS have been identified. In some cases, people experience only two or three acute attacks (exacerbations) and then remain free of symptoms or attacks the rest of their lives. However, in other cases, people experience a number of exacerbations, followed by varying degrees of recovery. Exacerbations may involve the appearance of new or old symptoms, lasting at least a day. When the person with MS reports new symptoms, it is important for the physician to determine why these new symptoms have occurred. The symptoms may not have any relationship to MS, but may result from some other problem.

Depending on the symptoms, different types of treatment may be prescribed. The kind of treatment recommended will depend on how the person's body has handled previous attacks. Mild attacks that do not impede a person's ability to function, that is, attacks that create no major day-to-day difficulties for the person with MS, often do not require treatment. Moderate attacks that cause some disability or create minor problems in day-to-day functioning can be treated on an outpatient basis with drugs. Severe attacks that cause a lot of problems and disabilities may require, under some conditions, hospitalization as well as different kinds of drug treatment. Although these drugs do not alter the course of the disease, they have been shown to decrease some of the problems people with acute attacks experience. Some drugs are given by mouth, while others are given intravenously or intramuscularly. The length of treatment depends on the particular drug prescribed. With most of the drugs, the therapy regime starts with a high dose that is decreased steadily over a certain time period. In other words, it is necessary for the physician to taper the dosage from high to low before these drugs can be discontinued. Some positive side effects of these drugs have been reported by patients, and noted by physicians. However, drug researchers, physicians and patients have reported that there are also adverse or negative side effects to these drugs which may affect both the patient's physical appearance, physiological status and emotional state. Some of these side effects are minor, others are serious.

The course of drug therapy for each patient differs as the treatment depends on the severity of the attack and the personal preference of the physician. For example, in severe attacks, some physicians prefer to use one drug while others use another. The drug that the physician chooses to use depends both on the physician's past experience with that drug and on the individual patient's history, that is, how that particular patient responded to and tolerated this drug treatment in the past.

Information for this pamphlet was adapted from the following sources:

Multiple Sclerosis Society of Canada. (1988). Multiple sclerosis: Its effects on you and those you love. Toronto: Multiple Sclerosis Society of Canada.

Multiple Sclerosis Society of Canada. (1987). What everyone should know about multiple sclerosis. Toronto: Multiple Sclerosis Society of Canada.

Scheinberg, L. C., & Smith, C. R. (1987). Signs and symptoms of multiple sclerosis. In L. C. Scheinberg & N. J. Holland (Eds.), Multiple sclerosis: A guide for patients and their families (2nd ed.) (pp. 43-51). New York: Raven Press.

TREATMENT FOR ACUTE ATTACKS (Specific)

The cause of multiple sclerosis (MS), a chronic disease affecting the myelin sheath that covers the brain and spinal cord, remains a mystery and no cure exists. The course of the disease cannot be predicted. However, the majority of people with multiple sclerosis fall into the relapsing/remitting or relapsing/progressive categories, characterized by short periods of acute attacks (exacerbations) followed by complete, partial or no recovery (remissions). Exacerbations are defined as the appearance of new or worsening of old symptoms lasting at least 24 hours. When new symptoms occur, it is important for the physician to determine whether they result from new or old injuries to the myelin sheath, or if they are the result of some other illness. If the symptoms are due to some other illness, they are treated specifically.

Treatment for new or extended injuries to the myelin sheath are based not only on the severity of these new symptoms, but also on how the person's body has handled previous attacks. For example, mild attacks that do not create problems for a person on a day-to-day basis often do not require treatment. Moderate attacks that cause some functional problems may be treated on an outpatient basis with a drug called prednisone. Severe attacks that cause a lot of problems or disabilities may require that the person be hospitalized and treated with drugs, such as ACTH or Solu-Medrol. Although these drugs do not alter the course of the disease, they are known to decrease the severity and the duration of acute attacks. Prednisone is taken by mouth usually once a day or on alternate days for about 4 weeks, the dosage decreasing per week. ACTH and Solu-Medrol can be given intravenously (into the vein) or intramuscularly (into the muscle). Treatment with ACTH may take approximately one month because it is necessary to taper the dosage from high to low before discontinuing the drug; treatment with Solu-Medrol may last for approximately five to nine days, starting with a high dose that is decreased steadily over this time period. These drugs have side effects. Patients have identified some positive side effects, including a sense of well-being, increased energy and motivation, and a decrease in spasticity. However, the negative or adverse side effects are generalized puffiness, weight gain, general infections, acne, and stomach problems.

The course of therapy for each patient differs as treatment depends on the severity of the attack and the personal preference of the physician. For example, in severe attacks, some physicians prefer to treat with ACTH, while others use Solu-Medrol. The physician's drug preference and the length of therapy are guided by results of drug studies reported in the medical literature, on the doctor's past experience with the drugs and on the patient's history of response to and tolerance of the treatment.

Information for this pamphlet was adapted from the following sources:

Lopez-Bresnahan, N. V., & Hauser, S. L. (1991). Multiple sclerosis. In R. E. Rakel (Ed.), Conn's current therapy 1991 (pp. 852-857). Philadelphia: W. B. Saunders.

Matthews, W. B. (1991). Treatment. In W. B. Matthews, A. Compston, I. V. Allen & C. N. Martyn (Eds.), McAlpine's Multiple Sclerosis (2nd ed.) (pp. 257-260). Edinburgh: Churchill Livingstone.

Scheinberg, L. C., & Smith, C. R. (1987). Signs and symptoms of multiple sclerosis. In L. C. Scheinberg & N. J. Holland (Eds.), Multiple sclerosis: A guide for patients and their families (2nd ed.) (pp. 53-66). New York: Raven Press.

Troiano, R., Cook, S. D., & Dowling, P. C. (1990). Corticosteroid therapy in acute multiple sclerosis. In S. D. Cook (Ed.), Handbook of multiple sclerosis (pp. 351-369). New York: Marcel Dekker.

Letter from Staff Member, Clinic B, to Participants

July 1992

Dear

The MS Clinic has been approached by Lynda Baker, a former registered nurse and currently a doctoral student in the school of Library and Information Science, who is interested in studying information-related issues for women with MS. After discussing the project with her, we have agreed to assist Ms Baker in selecting women from our clinic records and introducing her to you.

Her study involves completing two short questionnaires and reading a pamphlet, which will take about 45 minutes to one hour of your time. You do not need to complete it all at once if you find it too lengthy. Confidentiality is guaranteed.

Please read the accompanying letter from Ms Baker for further information about her study. Thank you.

Yours truly,

Letter from Researcher to Participants

July 1992

Dear

INVESTIGATOR: Lynda M. Baker
TITLE: MS-Information Study
LOCATION: London, Ontario

The purpose of this research project is to learn more about the information that is of interest to women who have been recently diagnosed with MS. Enclosed are two short questionnaires and a pamphlet. If you choose to participate in the study, it will take approximately 45 minutes to one hour of your time to read the pamphlet and complete the surveys.

Please note that if you fill out the questionnaires, you need not answer any question that makes you feel uncomfortable and you are free to withdraw from the study at any time. If you should decide not to complete the questionnaire, please draw a line through the first page and return the questionnaire in the stamped addressed envelope that is provided. This will help me keep my records straight and I will not send you any follow-up notices.

If you decide to participate in the study, I would like you to complete the first questionnaire, read the pamphlet and then answer the questions on the second questionnaire. If you are physically unable to fill out the forms, then a friend or family member can record your responses. Please return the completed forms in the stamped addressed envelope provided. You may keep the pamphlet.

Your responses to the questionnaires will remain anonymous and will be reported only in a summarized form along with the responses of the other women who participate. In other words, your answers to the questions will not be used in any way that could identify you.

If you have any questions or are interested in receiving more information on the topic or about the project, please contact me. My address and phone numbers (work and home) are listed below.

Yours truly,

Lynda M. Baker, PhD Candidate
School of Library and Information Science
Elbom College
University of Western Ontario
London, Ontario N6G 1H1
Phone: (519) 679-2111 ext. 8516 (work)
(519) 432-8658 (home)