

# **PUBLIC AWARENESS ABOUT DEPRESSION: THE EFFECTIVENESS OF A PATIENT GUIDELINE**

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## **ABSTRACT**

**OBJECTIVE:** To evaluate the effectiveness of a patient guideline for educating the public in the recognition and treatment of depression.

**METHOD:** Volunteer lay public as subjects were interviewed about their prior knowledge and beliefs about depression through the use of a semi-structured questionnaire. They were asked to “think aloud” while evaluating two clinical case scenarios, both with and without the use of a patient guideline. All data were audio taped, transcribed and analyzed for subjects’ thought processes and accuracy of responses, with and without the guideline. Relationship between prior beliefs and problem interpretation for depression was also assessed.

**RESULTS:** The results showed that: (1) the subjects with no prior history of depression identified fewer symptoms of depression listed in the patient guideline than subjects with a history of depression; (2) without the help of the patient guideline, a) only 50% and 38% of the subjects provided an accurate diagnosis of depression for the simple and complex problems respectively, b) the subjects entertained many hypotheses unrelated to depression; (3) with the help of the patient guideline, a) 92% and 83% of the subjects provided an accurate diagnosis of depression for the simple and complex problems respectively b) the subjects identified more symptoms and related them to the diagnosis of depression for the simple problem; and (c) the subjects recognized more symptoms and their relationship to the diagnosis of depression, and increased the linkages between concepts for the complex problem.

**CONCLUSIONS:** Lay people have a limited knowledge of the nature and treatment of depression, and were unable to recognize symptoms of depression without the help of the patient guideline. The patient guideline helps lay people by assisting in knowledge reorganization and focusing their reasoning on the direct relationships between the symptoms of depression and its diagnosis. Depression guidelines for the lay public increase peoples’ recognition of symptoms and are an effective educational tool.

**KEYWORDS:** Patient guidelines, depression, prior knowledge, evaluation studies, cognitive science

## INTRODUCTION

Clinical practice guidelines are generally thought of as an educational tool for the physician to aid in the execution of effective treatment. These guidelines help physicians by

providing the latest information on relevant clinical findings and medical procedures.

Increasingly there is a need for patients to understand their role in their own treatment [1] and due to the importance of this role, guidelines have also been developed for the patient. These patient guidelines are sources of information designed to educate the public in the hope that the individual patient will be better able to participate in his or her own treatment plan. The current study aims to evaluate one such patient guideline, designed by the American College of Physicians (ACP) [2], used in the recognition and treatment of depression.

### **PATIENT EDUCATION IN THE TREATMENT OF DEPRESSION**

It is estimated that, overall, depression will be one of the most serious causes of ill health in the general public; it currently affects at least one sixth of the population [3]. Furthermore, the National Comorbidity Survey (NCS) found that major depression is the most common disorder, with a lifetime prevalence rate of 17.3 percent and a 12 month prevalence rate of 10.3 percent [4]. Despite such a high prevalence, many people with depression suffer without being diagnosed or properly treated. For example, only a small percentage of people receive adequate dosages of antidepressant medication, both in primary care and in the mental health sector [4]. The seriousness of this lack of treatment can be seen in several theories of suicidal behaviors that are based on the empirical link between suicide and depression, and highlights the potentially fatal consequences of depression [5]. Furthermore, it has been recommended that robust interventions and periodic monitoring for suicidal ideation and hopelessness are crucial for the reduction of long-term suicide risk [6]. Thus, the improvement in the recognition and treatment of depression has important implications, including the reduction of suicidal behaviors.

The underrecognition and undertreatment of depression has been attributed to three factors: (1) the health care provider, (2) the patient, and (3) the health care system [4, 7].

Generally, the primary care physician is inadequately trained in the diagnosis and management of depression, which creates a gap between knowledge about the correct diagnosis and treatment of depression and the actual treatment that is being received by patients [7]. Also, the primary care physician often does not view depression as a “real illness,” or does not have the time available to treat depression effectively. Patients for their part do not seek treatment, because either they do not recognize that they are depressed or the illness deprives them of the drive to seek help, in addition to trying to cope with the social stigma attached to the illness. Furthermore, patients with depression are often non-compliant when taking antidepressant therapies. This fact has been attributed to a lack of knowledge about the nature of depression, the efficacy of pretreatment education, the nature of treatments and their side effects, and negative attitudes and beliefs about medication on the part of patients and their families and treating physicians [8].

The health care system also contributes to the problem by not recognizing the chronic and recurrent nature of depression. As a result, insurance plans may not allow for frequent monitoring, more than one treatment approach, or the use of the latest medications [9]. Due to these difficulties, patients suffering from depression are often dissuaded from seeking treatment. Thus, it can be hypothesized that educating the lay public about depression may lead to an improvement in their early recognition of the symptoms of depression and in their propensity to seek help for treatment, which is precisely the goal of patient and physician guidelines: to educate and improve the quality of care. In addition, improving patients’ understanding of the signs and symptoms of depression is also likely to facilitate better communication with their physicians, since they will have some shared knowledge.

Patient education has been shown to be effective in a wide range of treatments, such as in improving the social functioning and quality of life of schizophrenic patients [10] and in reducing distress in cancer patients [11]. Similarly, educational programs on depression have

resulted in a significant decrease in inpatient care, morbidity, mortality, and costs due to depressive illness [12]. Providing patients with educational materials, such as informational booklets and videos, significantly increased medication adherence and improved clinical outcomes in the primary care setting [13]. The patient guideline used in the present study was based on a clinical guideline written for primary care givers [14], who generally lack the skill and prior knowledge of depression to effectively engage in psychologically oriented interventions. This is particularly important since many depressed individuals may seek treatment from their primary care giver rather than seeking help from psychologists or psychiatrists. Furthermore, clinically depressed individuals often arrive with physical symptoms of an ill-defined nature that may or may not be related to depression. Thus, these guidelines may also provide physicians with the tools necessary to address depression in practice.

However, before an education plan can be implemented, information needs to be collected concerning what people currently know about depression, what they should know, and how this information can be transmitted to the public effectively. Guidelines intended for the physician and for the patient may be an effective way of providing this much needed communication and education.

### **GUIDELINE COMPLEXITY AND LAY INTERPRETATION**

Guidelines may be considered difficult to understand and use. Semantically they can be very complex, and are often composed of elaborate collections of prescribed procedures with logical gaps or contradictions that can lead to ambiguity [15]. Thus, when reading a text such as a patient guideline there is an underlying assumption that the reader has a certain amount of prior knowledge, where this prior knowledge is used to make inferences that are required to understand the text [16]. However, difficulties in comprehension may arise when the reader is

unable to make these inferences due to a lack of required knowledge, such as when interpreting pharmaceutical labels [17]. Therefore, in order for patient guidelines to be designed and used effectively, the prior knowledgebase of the intended users of the guideline must be considered. Research examining prior knowledge and its influence on behavior has established that lay people are influenced by their prior knowledge of health and illness when interacting health care materials [17, 18].

In order to understand how the reader's knowledge may interact with a text, such as a patient guideline, it is important to consider how these texts are produced. The process of representing verbal information in text form begins with the thoughts and ideas that need to be expressed externally, in some physical medium [15]. However, the relationship between these internal ideas and their external representation as a text is not a simple one-to-one mapping. Typically, the resulting text simplifies the intended meaning, as the writer's prior knowledge cannot be fully expressed, given that many internal ideas are never verbalized. For instance, high-level inferences, assumptions, and presuppositions are often left out of the text. Guidelines are generally written by a team of experts in the medical area covered by each particular guideline, where they approach the task, as writers, with a more highly organized knowledge base than the intended users [16]. Writers often unintentionally expect the reader to have a similar knowledge base, and be able to make the high-level inferences required to fully comprehend the guideline. Given that patient guidelines are intended to be read by lay people (i.e., non-experts), errors or frustrations may result if the reader is not able to make the appropriate inferences.

Comprehension of a text may be regarded as a construction process, whereby the reader attempts to build the writer's representation of the information that has been communicated via the text [19]. The implication of this is that reading or interpreting a text, such as a patient

guideline, requires the availability of prior knowledge and beliefs that contextualize the way these texts are to be interpreted. Prior knowledge in the form of assumptions and presuppositions provide a common ground to such interpretation. However, a shared understanding or knowledge of scientific principles will not always produce similar understanding of material, due to differing life experiences. Thus, the reader's interpretation of a text must match the intended meaning put forth by the writer in order for optimal comprehension of the text. Guidelines that are dynamically generated and adaptable to the specific expertise level of the reader may be most effective in producing optimal comprehension [19].

### **STUDY PURPOSE**

The purpose of this study is to evaluate the effectiveness of a patient guideline for educating the public in the recognition and treatment of depression [2]. In doing so, we aim to describe the following: (1) lay people's prior knowledge and beliefs about depression, (2) their interpretation of clinical scenarios of depression, with and without the help of the patient guideline, and (3) their opinions of the patient guideline in educating the public about depression. By investigating lay people as they interact with and apply a patient guideline, we may gain a better understanding of the way their interpretations of guidelines are matched to the intentions of the guidelines themselves. Such insight may allow for the better matching of knowledge between the writers and readers of guidelines, ultimately improving the comprehensibility and usability of patient guidelines.

### **METHOD**

## **SUBJECTS**

Twenty-four subjects (12 males, 12 females) from the McGill University community in Montreal were recruited on a volunteer basis by the investigators to participate in this study. The subjects interviewed were laypeople belonging to multi-ethnic/cultural groups (71% North American/ European, 25% Asian Canadian, 4% African Canadian). The subjects ranged in age, with 67% of subjects aged 20-40 years, 29% over 40 years, and 4% under 20 years of age. The subjects' education level varied as well: college diploma (25%), undergraduate degree (33%), Master's degree (29%), and Ph.D. (13%). During the course of data collection, five (21%) of the subjects were identified themselves as having been diagnosed with and/or treated for clinical depression. The composition of this subgroup of subjects was similar in makeup to the other subjects, in terms of gender, ethnicity and educational level.

## **MATERIALS AND PROCEDURE**

This study used a semi-structured think-aloud interview design based on previous research related to patient reasoning about diabetes [20]. Specifically, the semi-structured interview was used to assess the reasoning, knowledge, and beliefs about depression of lay people in the evaluation of a patient problem related to depression, both with and without the use of a guideline for the recognition and treatment of depression [2]. This interview format was chosen to allow for the elaboration of the subjects' reasoning related to the topics of interest in a more open-ended format than what would be possible with the use of closed-ended questionnaires.

Since depression presents itself clinically in many different forms, the two case scenarios of depression used in the interview were adapted from real clinical cases. These scenarios were



used to determine lay people's ability to identify different presentations of depression and the effect of the patient guideline in aiding people to recognize symptoms of depression. The first scenario was adapted from a case report that was used for teaching purposes in the Department of Psychiatry at McGill University in Montreal, Canada, and the second scenario was adapted from a clinical casebook on mental disorders[21]. Both scenarios were developed with the assistance of a clinical psychiatrist. Specifically, the first scenario involved a woman who feels sad and worthless, her children and husband have left her, and she is considering early retirement. This scenario was chosen to be relatively less complex for the subjects to assess than the second scenario because it contained more typical symptoms of depression, and provided a plausible explanation for her symptoms. The first case scenario was described as follows:

A 52 year-old woman is feeling blue. She has recently lost weight and is having episodes of insomnia and wakening up early in the morning. Her appetite is poor. She owns her own business but recently her interest in her work has been diminishing and she is considering early retirement. She is worried that, if she retires, she will not be able to support herself. Her adult daughter has recently left home after completion of graduate school and has taken a job in a distant city. Her older son is married and has a prestigious business assignment in Europe. She is estranged from the children's father and they have lived apart for the past four years, he with a younger woman who had been his secretary. She has expressed feelings of worthlessness to her daughter.

The second scenario was chosen to be relatively more complex than the first scenario, where less typical symptoms of depression were included and there were no explanations given for any possible causes of these symptoms. In this scenario, the problem is manifested in more physical symptoms, and the emotional symptoms of the patient are in the form of irritability rather than sadness, as given below:

Mr. Smith, 23 years old, is having difficulty thinking, concentrating, and remembering things. He is also unable to sleep. These problems began several months ago when he first started to have trouble sleeping. He used to play baseball and follow games on television and in the newspaper, but is no longer interested. Although he has tolerated these problems for while, he came to the clinic when he started having headaches. He feels tired all the time, and finds himself eating frequently when he has trouble sleeping.

He has been irritable and gets angry easily. He has gained 15 pounds within the last 3 months.

Prior to the interview the subjects were only told that they would be asked questions focusing on health and illness, without specifically referring to depression. All subjects were interviewed individually, where the interview took, on average, 25 minutes to complete. During the interviews, subjects were asked to “think aloud” as they walked through the questions. They were requested to provide as complete answers as possible and were encouraged to ask questions if necessary. All of the subjects’ responses during the interviews were audiotaped. The procedure consisted of five steps:

- 1) The prior health beliefs of the subjects were assessed with questions or probes focusing on illness and health-related concepts. The subjects were asked about their thoughts on what it meant to be healthy, what they did to be healthy, and information about their sources of health information. The subjects were also asked how they felt when they are sick, and the effects of illness on their daily lives.
- 2) Following these questions, the subjects read through the first case scenario and were asked to provide an explanation for what they thought were the potential causes of the symptoms and to make suggestions for treatment. The purpose was to assess the subjects’ spontaneous problem-solving skills. After the subjects had given their responses, the procedure was repeated for the second scenario.
- 3) Following the scenarios, the next set of questions focused on the subjects’ knowledge of depression. Specifically, they were asked about the symptoms of depression and the perceived effects depression would have on their daily lives. The purpose of these questions was to assess the subject's underlying knowledge and attitudes about depression.

- 4) Subjects were then asked to read the ACP patient guideline, "Feeling Blue? Tired all the time? Your internist can help"[2]. After reading the guideline, evaluative questions were asked concerning reactions to the guideline, how helpful the subject felt the guideline was and how helpful they felt it would be for others in terms of educating the public about depression.
- 5) The two scenarios were then reread and the subjects were asked to revise their evaluation, having read the patient guideline. The purpose of this section was to assess the subjects' guideline-primed problem-solving and whether the guideline influenced their interpretations of the problem.

### **ANALYSES**

The think-aloud responses from all interviews were transcribed verbatim and each response was coded for content. The coding scheme was developed such that the specific concepts in the subjects' responses were first coded for frequency in order to determine the overall accuracy of the subjects. This allowed for a structured approach to the initial coding of the transcripts, where lists of concepts that were used by the subjects in their responses to each question were generated. A number of more specific concepts were then collapsed by grouping related concepts into broader conceptual categories, where the data were reported as the sum frequency of specific concepts provided by the subjects belonging to each broad concept category. For example, in the first section of the interview a conceptual category called "absence of illness symptoms" was derived from comments made by the subjects which included concepts such as "not tired," "not feeling sore," "don't sneeze," "not sick," "no headaches," and "no scratchy throat" in response to the question "what is being healthy?" The frequency of responses

belonging to the “absence of illness” conceptual category was then determined by adding the frequencies of occurrence for each of the specific concepts belonging to that category (i.e. “not tired,” “not feeling sore,” “don’t sneeze,” “not sick,” “no headaches,” and “no scratchy throat”). During the analysis, the broader main categories were sometimes used, and other times it was more appropriate to use the more detailed sub-categories. For example, the broader categories of symptoms of depression were used to indicate whether the subjects differed in their conceptualization of depression, while the specific symptoms they listed were used to assess the accuracy of their knowledge. During spontaneous and primed problem-solving, the concepts were coded in terms of diagnosis and recommended treatment, both before and after reading the patient guideline, in order to determine the accuracy of their responses.

Further analysis of the subjects’ think-aloud responses generated while processing the case scenarios was performed using formal methods of discourse and protocol analysis, based on previous research involving guideline-assisted reasoning [15, 19]. Specifically, the responses were segmented into concepts. This segmentation process identified both the concepts and the relations among concepts in the subjects’ reasoning. Semantic networks were then constructed, where concepts and their relations are developed into graphical structures that represent the steps in their reasoning. As a result, these semantic networks make it possible to visualize the relational structure of the subjects’ responses in their totality. Each representation consists of a set of nodes and a set of links connecting the nodes. An individual node may represent clinical findings, hypotheses, or steps in a procedure, while links represent the directed connections between nodes. Therefore, the nodes define the content of the subjects’ responses, and the links define the structure of their responses. Semantic networks such as these convey two types of information: conceptual information (i.e. the concepts used to solve a problem) and structural information (i.e. how the concepts are related to each other) about how the subjects constructed

their diagnoses when initially reasoning through the scenarios (spontaneous problem-solving) and how they updated their explanations of the patient problems after the guideline was introduced (primed problem-solving). Readers are referred to our previous research for a more detailed explanation of the development and analysis of semantic networks [15].

## **RESULTS AND DISCUSSION**

### **CONCEPTUALIZATION OF HEALTH AND ILLNESS**

Figure 1 presents the percentage of subjects who identified concepts associated with the main conceptual categories for being healthy. The results show that 88% of the subjects said that feeling well physically, including having energy and being physically active and productive, meant that they were healthy. In addition, for 67% of the subjects being healthy included an absence of illness or symptoms such as soreness, tiredness, and headaches. Other concepts related to being healthy included being able to carry out normal daily activities (50% of the participants), not being inhibited by your body (42%), feeling positive psychologically (42%) and not needing to see a physician (8%). Similarly, when asked what they did to maintain their health, 67% of the subjects identified eating properly or avoiding eating poorly, and 54% identified regular exercise as something they did to stay healthy.

Figure 2 presents the percentage of subjects who identified concepts associated with major categories for being sick. Specifically, sickness was defined by 87% of the subjects as a reduction of daily activities, 54% referred to concepts associated with feeling negative physically, and 50% referred to the presence of illness symptoms. Other concepts that were related to being sick referred to feeling negative psychologically (33%), being cognitively impaired (29%), and negative behavioral consequences (17%). According to the fourth edition of

the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), symptoms of depression include lack of energy, and diminished interest in daily activities, both of which were cited by the majority of the subjects as evidence of illness[22]. The upper portion of Table 1 gives a representative response common to most subjects that illustrates the way lay people conceptualize health and sickness.

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When the subjects were asked what they did when feeling sick, 46% said they visited health care professionals, while half of the subjects said that they sought advice from friends or family. Although the subjects considered friends and family as a good source of treatment

information when ill, 83% indicated that they get their general health-related information from health-care professionals and 79% claimed to get this information from books, magazines, or newspapers. Only 33% said that they get general health-related information from other laypeople. The majority of the subjects indicated that they are accustomed to learning about general health issues from their physicians rather than lay sources.

### **PRIOR KNOWLEDGE AND BELIEFS ABOUT DEPRESSION**

To assess subjects' knowledge about depression, they were asked to list the symptoms of depression and indicate how depression affects the daily lives of those who are depressed.

Figure 3 presents the percentage of subjects who identified symptoms associated with the major symptom categories for depression. When asked to list the symptoms of depression, 96% of subjects mentioned symptoms that were psychological in nature. These psychological symptoms of depression included a loss of interest in things the patient used to enjoy, difficulties concentrating, and low self-esteem. In addition, 54% of the subjects cited emotional symptoms of depression, such as sadness and feelings of worthlessness. Similarly, 54% of the subjects referred to health problems, such as trouble sleeping and lowered immune functioning. Representative responses taken from the whole sample of subjects that illustrate the way lay people conceptualize depression are given in the lower portion of Table 1.

When the subjects' prior beliefs were compared to the diagnostic criteria of the patient guideline and the DSM-IV, the results showed that every symptom was cited by at least one subject, except for significant weight loss/gain, which was only listed in the DSM-IV. The DSM-IV qualifies the diagnosis by indicating the number of symptoms and the time period over which a patient must have the symptoms before being diagnosed with depression. Neither the patient guideline, nor any of the subjects provided any such qualifiers. Nonetheless, the accuracy of the

lay peoples' knowledge about depression was quite high. Only three of the symptoms (mood swings, easily gets sick, and neglects personal hygiene) that were listed by the subjects were not in the diagnostic criteria of either the patient guideline or the DSM-IV. However, these symptoms may be related to the results of depressive episodes. Although no subjects listed "suicidal thoughts" as a symptom of depression, four subjects (17%) raised concerns about suicide at some point during the interview. Specifically, they acknowledged the potential risk of suicide among people suffering from depression.

Despite the seemingly high level of knowledge of depression and its symptoms, the results showed that subjects with no prior history of depression only identified an average of three of the eleven symptoms of depression listed in the patient guideline. In comparison, those with a past diagnosis of depression identified an average of five of the symptoms listed in the guideline. This indicates that lay people base their diagnosis on only a few well-known symptoms of depression and are not aware of other related symptoms.

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Figure 4 presents the percentage of subjects and the categories of effects of depression that they identified. There were no significant differences within these categories between the males and females. When asked to list the effects of depression, 96% of the subjects listed



behavioral effects, which included an alteration in the ability to carry out daily activities and changes in eating habits. In addition, 42% identified psychological consequences of depression such as having severe negative social effects on their life style and having low self-esteem.

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When asked about their reaction to someone they knew who was depressed, surprisingly, only 46% of the subjects tested said that they would recommend seeking professional help from a doctor and 21% said that they would recommend seeking help from a mental health care worker, even if they considered the effects of depression to be severe. Rather than seeking treatment, they recommended being sympathetic and helpful to this person (21%), diverting their minds from depressed thoughts (21%), and keeping them busy (17%). There appears to be a lack of understanding about depression and its severity, which can be seen in the recommended treatment modalities. From lay peoples' responses, it was clear that most of them thought that depression was self-induced. These results suggest that there is an inability to recognize depression as a clinical problem and to understand the impact of not providing adequate professional help.

### **SPONTANEOUS PROBLEM-SOLVING**

#### *Simple Problem (Scenario 1)*

During spontaneous problem-solving for the simple problem scenario, only half of the subjects diagnosed the problem as a case of depression, although 79% mentioned the existence of emotional problems. Additional diagnoses that were considered included stress (33%), low

self-esteem (21%), and situational factors (17%). Furthermore, less than half of the subjects (42%) recommended that the patient should consult a physician or counselor, while the majority of subjects (71%) said that she should actively engage in activities to change her life and encourage a more positive attitude. Please note that these are not mutually exclusive response categories. Table 2 gives a representative example of the thoughts and suggestions given by the subjects, who reasoned and thought aloud while solving the problem. Many of the subjects attributed causality to the external factors that were given in the scenario, where overall, the subjects did not recommend that the woman seek professional help. Of the 50% of subjects who recognized depression as a factor, 66% of these (33% of total) recommended professional treatment, while the remaining subjects focused on external solutions such as keeping busy by going out with friends and join clubs

### *Complex Problem (Scenario 2)*

During spontaneous problem-solving for the complex problem scenario, 38% of the subjects diagnosed the problem as a case of depression. Other diagnoses that were given included physical problems (50%), mental problems (39%), and stress (11%). Most subjects (75%) recommended that the patient seek professional treatment, while 54% also suggested the patient talk to friends, diversify his activities, or try to take a greater interest in life. In this complex situation, the subjects were more willing to consider physical or mental illness as a cause for the symptoms. Fewer external factors influencing patient condition were available in this scenario as compared to the simple scenario, making the former task more difficult. When these factors were not available, the subjects provided their own explanations for the condition. These explanations showed that lay people do not have an accurate causal understanding of depression and its consequences.

### **PRIMED PROBLEM-SOLVING**

A comparison of the diagnostic hypotheses that were generated during spontaneous and primed problem-solving is presented in Table 3. Please note that these diagnoses are not mutually exclusive and they reflect the subjects' responses while reasoning through the problems. During spontaneous problem-solving, the main diagnostic hypotheses generated by the subjects were loneliness/feeling of isolation, low self-esteem, and depression for the simple problem, and depression and mental/psychological illness for the complex problem. As indicated by Figure 5, the subjects entertained many more hypotheses unrelated to depression when making their final diagnosis during spontaneous problem-solving than during primed problem-solving for both scenarios. The results indicate that the guideline assisted the subjects in screening out irrelevant diagnostic hypotheses, focusing on more accurate ones.

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### *Simple Problem (Scenario 1)*

After reading the patient guideline, 92% of subjects made a diagnosis of depression for the simple problem and 79% recommended that the patient seek professional help. A paired-samples t-test showed that the accuracy of the subjects' responses was significantly higher after reading the guideline [ $t = 4.053$ ,  $df = 23$ ,  $p < 0.01$ ]. These results suggest that the guideline was effective in increasing the subjects' recognition of depression in the simple problem. This is also evident from the response given in the lower section of Table 2 by a subject who diagnosed the woman as menopausal during spontaneous problem-solving and then reassessed the scenario by diagnosing the woman in the scenario as depressed and recommending that she seek treatment from a physician. However, many of the subjects still focused on the external factors given in the problem description, where 63% of the subjects also recommended talking to friends, going out and meeting new people, thinking positively, and looking for a change in lifestyle. The biological aspect of the illness is not recognized.

Figure 6 presents the semantic networks generated from the think aloud protocols from a female subject when reevaluating the scenario after reading the guideline. The figure shows that the subject focused on symptoms directly related to depression and she correctly diagnosed the woman in the scenario as being depressed. In addition, the subject recommended seeking treatment for depression and considering the use of herbal and antidepressant medications, as suggested by the guideline. This was a common pattern of response among the subjects. Specifically, during guideline-primed problem-solving, the subjects focused on the direct relationships between the symptoms that were given in the case and the diagnosis of depression. Here they already were primed with the hypothesis of depression and the subjects looked for symptoms in the case to match the hypothesis. In this scenario these symptoms were easy to find. In contrast, Figure 7 presents the network generated from the same subject's scenario protocol

prior to reading the guideline. The figure shows that the subject did not focus on the underlying problem of depression and was not able to identify any of the symptoms as being related to depression. Instead she focused on the external factors associated with the problem, such as the woman's estrangement from her husband and the decisions she must make about retirement. Although she recommended seeking professional help, this was specifically in response to the difficulty she had in sleeping. There appears to be a direct relationship between seeking professional help and signs of physical problems. With anything other than obvious physical symptoms, people have to be guided and they do not appear to automatically think about getting professional help.

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### *Complex Problem (Scenario 2)*

After reading the patient guideline, 83% of the subjects made a diagnosis of depression in the complex scenario and 96% recommended that the male in the scenario seek professional help. A paired-samples t-test indicated that the accuracy of the subjects' responses was significantly

higher after reading the guideline [ $t = 3.412$ ,  $df = 23$ ,  $p < 0.01$ ]. The recognition of symptoms of depression after reading the guideline suggests that the guideline was effective in making the participants aware of this connection.

Figure 8 presents the semantic networks generated from the think-aloud protocols from a male subject when reevaluating the complex scenario after reading the guideline. Most notably, he identified more of the symptoms associated with depression in the scenario and recognized its severity. Also, his knowledge became highly structured, where concepts were accurately connected to each other, and related to the symptoms, diagnosis and treatment of depression. This suggests that the guideline influenced the structure of knowledge and how it was used during problem-solving. In contrast, Figure 9 presents the network generated from the same male subjects' protocols prior to reading the guideline. Although he did eventually make the diagnosis of depression, he limited his diagnosis to a casual episode of depression and did not link any of the symptoms directly to clinical depression, with the exception of "difficulty sleeping." The figure shows that his knowledge was not structured, with little connection between concepts, and lacked a focused approach to diagnosis and treatment based on the symptoms given in the problem.

The guideline was used differently in the simple and complex problem situations. In the complex case, the guideline served to both increase the focus of the subjects' diagnoses, in terms of recognizing symptoms in the scenario and their relationship to the diagnosis of depression, and to restructure the way concepts were organized and linked together. This pattern is different from the simple scenario, where it was easy to identify the symptoms, once primed with the hypothesis. In the complex scenario, the subjects had to work harder at reorganizing information to connect specific symptoms to the hypothesis of depression.

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### *Clinically Depressed Subjects' Problem-Solving*

The results for the subjects who identified themselves as clinically depressed were evaluated relative to the other subjects. Before reading the guideline, 60% of the clinically depressed subjects (CD) recognized depression in the simple scenario, compared to 47% of all other subjects. Sixty percent of these subjects recognized depression in the complex scenario, compared to 32% of all other subjects. In addition, 80% of the CD subjects recommended seeking treatment in both the simple and complex scenarios, while 74% of all other subjects recommended treatment in the simple scenario and only 32% in the complex scenario. The participants with personal experiences of depression were more accurate in diagnosing depression and recommending treatment in both problem situations than all other subjects during spontaneous problem-solving. Furthermore, the differences in accuracy between the CD subjects and all other subjects were reduced considerably after they read the guideline and reevaluated the scenarios, due to the improved accuracy of the non-depressed subjects.

The relationship between symptoms of depression and its diagnosis is illustrated Figure 10. It presents a semantic network generated from the protocol of one of the CD subjects before and after reading the guideline. Most notably, there was no new information generated by the subject after reading the guideline, as seen by the lack of gray boxes in the figure. This is due to

the high accuracy of the original response prior to reading the guideline. In this case, the subject generated a very focused explanation of the scenario by accurately identifying the symptoms and diagnosing depression and recommending treatment consistent with the guideline. Furthermore, the structure of the subject's reasoning followed the precise order outlined in the guideline, where almost all of the concepts that were generated by the subject matched those in the guideline. Thus, the subject's knowledge structure did not change after reading the guideline, but it confirmed the earlier response. This suggests that CD subjects used the guideline only for confirmation.

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#### **LAY PEOPLES' PERCEPTIONS OF THE PATIENT GUIDELINE**

To investigate lay peoples' perceptions of the patient guideline, they were asked questions related to the usefulness of the guideline, and whether it changed their views of the two problem scenarios. Table 4 gives representative responses from the subjects regarding their thoughts about the usefulness of the guideline.

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Sixty-seven percent of the subjects felt that the guideline was useful, with the remaining 33% feeling that it would be more useful for others since it did not add anything to their knowledge of depression. A number of the subjects had specific problems with the guideline.



The most common problem was the guideline's focus on medications as the sole form of treatment. The majority of subjects felt that alternative therapies should be included in the guideline as well, rather than only relying on antidepressant medications. In addition, several of the subjects encountered problems related to ambiguities in the guideline, such as what constitutes too much or too little sleep. They found the language to be too subjective.

In terms of the two problems, the guideline appeared to have more of an effect on diagnostic accuracy than the subjects acknowledged. Only 38% and 46% of the subjects said that the guideline helped them in their diagnosis for the simple and complex scenario, respectively. However, based on their protocols during problem-solving for each problem it was observed that the guideline actually helped 50% of the subjects in both cases, where this was judged by assessing the accuracy of each subject before and after reading the guideline. If the subject was inaccurate before reading the guideline, but accurate after reading the guideline, then the guideline was deemed helpful. An accurate assessment of each scenario was defined as a diagnosis of depression and a recommendation to seek treatment from a health care provider. The guideline was more useful in the identification and treatment of depression than the subjects perceived.

## **CONCLUSIONS**

This study examined the interpretation of a patient guideline for depression by lay people, as related to the effectiveness of the guideline in educating the public about the symptoms and treatment of depression. Specifically, this included 1) a description of the conceptualizations of health and illness, including prior knowledge and related beliefs about depression, 2) interpretations of patient problems before and after reading the guideline, and 3) the perceptions

and usefulness of the patient guideline. The results provide support for the use of patient guidelines as an effective tool for educating the public about depression and encouraging them to seek treatment. There are several issues that were also identified, which need to be considered for further discussion

The analysis of the concepts used by lay people as they reasoned about health and illness, as well as the subjects' prior knowledge and beliefs about depression, suggest that lay people rely on their prior knowledge to generate an understanding of health and illness, relating their responses to daily functioning and the maintenance of lifestyle rather than the underlying pathophysiological changes that occur. This is consistent with previous research showing that lay decision-making in health care is often based on evidence acquired through social and cultural exposure, rather than the logically consistent biomedical knowledge used by physicians[23], such as when reasoning about nutritional deficiencies[24], diabetes[20], and when interpreting pharmaceutical labels[17].

Generally, lay people appear to have limited knowledge about the number of symptoms of depression. People with a history of clinical depression are able to recognize more symptoms of depression. However, even when people perceived depression to be a severe problem, only 46% recommended seeking professional help for treatment. This indicates that knowledge and action are decoupled. These results suggest that there is a need for increased education that makes a closer link between the knowledge of signs and symptoms of depression and the consequences of being treated (or not). For example, by increasing lay peoples' understanding about the relationship between suicide and depression, they may be more likely to seek help from mental health professionals.

During spontaneous problem solving, the majority of the lay people were unable to recognize symptoms of depression in the problem scenarios without the help of the patient

guideline. Many of them also did not recommend seeking professional treatment. This alludes to the limited lay knowledge of the nature and treatment of depression in comparison to the more accurate responses of the people previously diagnosed with depression. Often the lay people focused on attributing causality to external factors when evaluating the scenarios rather than on the underlying physiological processes of health and illness. This is common to most lay reasoning and it occurs in many instances, such as when asked about the causality of illnesses like diarrhea [24], and the common cold and fever [17]. Indeed, even when given the more complex scenario, where very few external factors were included, the lay people still looked for such factors as causes and suggested possible explanations when none could be found. This suggests that lay people rely on their personal experience when evaluating the causality of symptoms and are less precise in their explanations of clinical problems.

After the lay people were given the patient guideline the majority of them were able to recognize depression with the help of the guideline. However, they appeared to use the guideline differently depending on the complexity of the task. For the simple case, the guideline mainly aided lay people by increasing the focus of their responses to the relevant clinical information, where they were able to accurately identify symptoms given in the problem and make the proper diagnosis of depression. As task complexity was increased in the complex case, the use of the guideline led to both an increase in focus, as well as assisting in the reorganization of knowledge such that concepts were linked to each other in making a diagnosis. For people that had personal experience with depression, the guideline was mainly used to confirm their reasoning about the problems. The differential usage of guidelines by these subjects is consistent with prior research examining guideline use by physicians, where guidelines were found to serve different functions depending on their degree of expertise (i.e., prior knowledge) [19].

All of the participants felt that the guideline was useful for educating the public about depression. However, a number of people felt it emphasized pharmacological treatments for depression too strongly, rather than providing alternative therapeutic options. Problems related to ambiguities in the guideline were also mentioned by several people, such as difficulties making the appropriate inferences required by the information presented in the guideline. This suggests that while patient guidelines are effective tools for educating lay people, these guidelines should be designed such that they are sensitive to the prior knowledge and beliefs of their audience in order to increase their effectiveness. Nonetheless, the primary objective of the guideline to increase the recognition of symptoms of depression among lay people and their knowledge of treatment was achieved. The increased awareness of depression among lay people through guidelines will encourage health care seekers (e.g. potential patients) to seek professional assistance and hopefully lead to more effective interactions with the professionals as a result of a better understanding of their symptoms and treatment options.

### **ACKNOWLEDGEMENTS**

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**TABLE 1: Representative conceptualizations of health, sickness and depression given by the subjects.**

<b>Response Category</b>	<b>Subject's Response (Subject #)</b>
Description of being healthy	(10) Being healthy means being able to get up every morning under my own power, to walk around and not feel sore...Being able to lead a normal life, carry out everyday activities without feeling sore at the end of the day.
Description of being sick	(17) It's not good. You just want to curl up in your bed, sleep until you don't feel sick anymore because you have no energy. Depending on your symptoms you can't talk or you're always coughing or sneezing or something. It's not fun.
Symptoms of depression	(13) I think fatigue, you sleep a lot. A loss of appetite or more appetite depending on what type of person you are. Withdrawal from other people and general disinterest in a lot of things...Like your work is very important to you and all of a sudden the quality with which you do it is gone and you just do a lot of things that are more isolated. And you get physical problems, like headaches and I already mentioned fatigue.

Effects of depression on daily life	(22) I would be less productive which would be the biggest thing. You get much less done in a day and you feel like your productivity is directly related to how you feel about yourself and my self-esteem would be really awful. I wouldn't treat myself the way I should so then this is when the physical problems begin like headaches and insomnia and fatigue.
Attitude about treatment of depression	(4) I know depression is an illness, but I don't think of it that way. I think of it, just you are unhappy. There is nothing to trivialize because it is important, but I don't consider it a health problem. I understand that you need to get professional help for something like that, and it should be covered by health plans, but I don't necessarily consider it a health problem per se.

**TABLE 2: Representative conceptualizations of simple and complex scenarios on depression during spontaneous and guideline-primed problem solving given by the subjects.**

Response Category	Subject's Response (Subject #)
<i>Scenario 1: Simple</i>	
Spontaneous diagnostic hypothesis and treatment suggestions	(14) She's lonely...because everyone's leaving her. Her two kids have left her and she's just feeling lonely or bored with her life. I would suggest getting out and being active because you meet a lot of people and active people tend to be more energetic, they're a lot friendlier, so it's a good way to meet people.
Guideline-primed diagnostic hypothesis and treatment suggestions	(15) Well, she would have to go see a doctor because here she has trouble sleeping and no appetite...she is depressed. You know, she maybe needs to take a breather and relax and let the doctor help her...And maybe she would need to be treated with medicine.
<i>Scenario 2: Complex</i>	
Spontaneous diagnostic	(12) Sounds to me like he's depressed...You can get

hypothesis and treatment suggestions	medicine for that, to lift your morale because he doesn't feel like doing anything. All he does is eat and he's gaining so much weight because he's not moving around so much. So that's what I think, it could be mental depression.
Guideline-primed diagnostic hypothesis and treatment suggestions	(3) He is probably depressed also, but since he is already going to a clinic and getting help, he is on the right track. Things should be better for him.

**TABLE 3: Diagnostic hypotheses generated by percentage of subjects (%) during spontaneous and guideline-primed problem solving for simple and complex scenarios on depression.**

Diagnoses	Spontaneous explanation %	Primed explanation %
<i>Simple Scenario</i>		
Lonely/feeling of isolation	58	25
Low self-esteem	54	8
Depression	50	92
Stress	33	17

Menopause	13	8
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*Complex Scenario*

Depression	38	83
Mentally/psychologically ill	38	13
Physically ill	21	17
Stress	21	4
Insomnia	17	4
Low self-esteem	8	8

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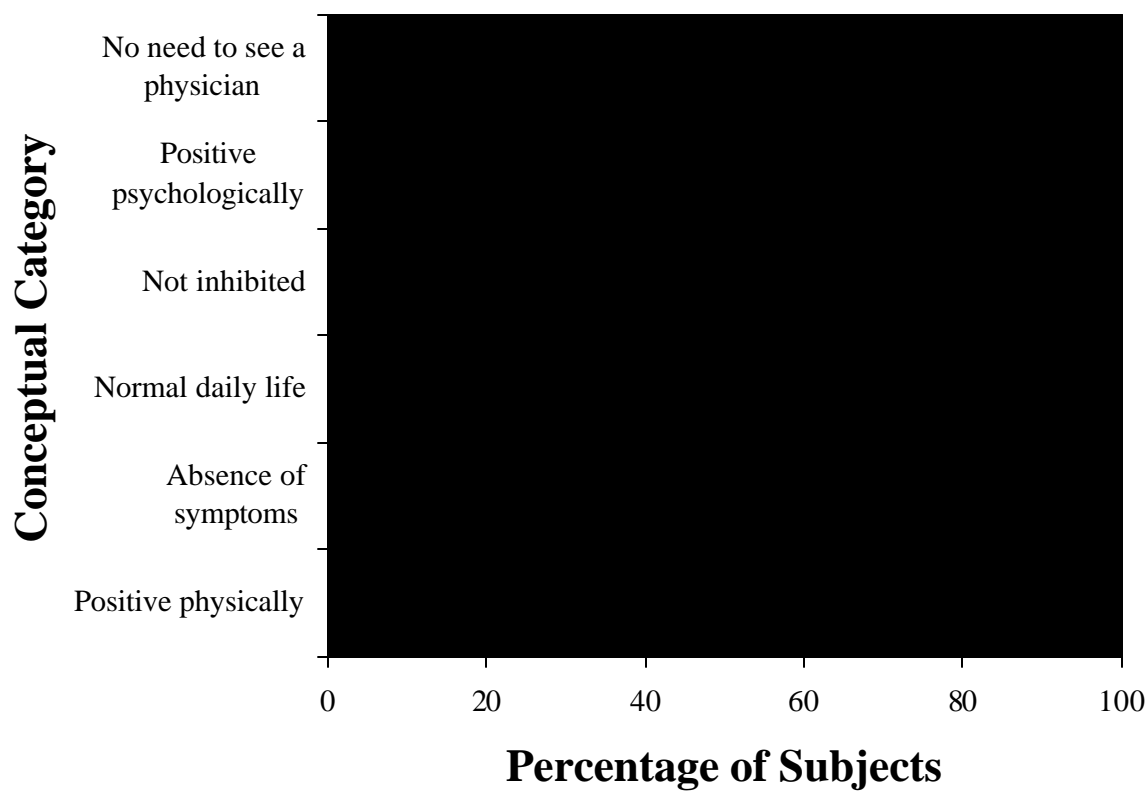
**TABLE 4: Representative evaluations of the patient guideline on depression given by the subjects.**

Response Category	Subject's Response (Subject #)
Overall evaluation of the patient guideline	(3), I think it's useful but I probably need more details. Like what is trouble sleeping, for example, too little or too much? What is too much or too little on average because if I do some strong activity then I would sleep more than usual. So I don't really know if I sleep too much or too little with this information. I need more detail.

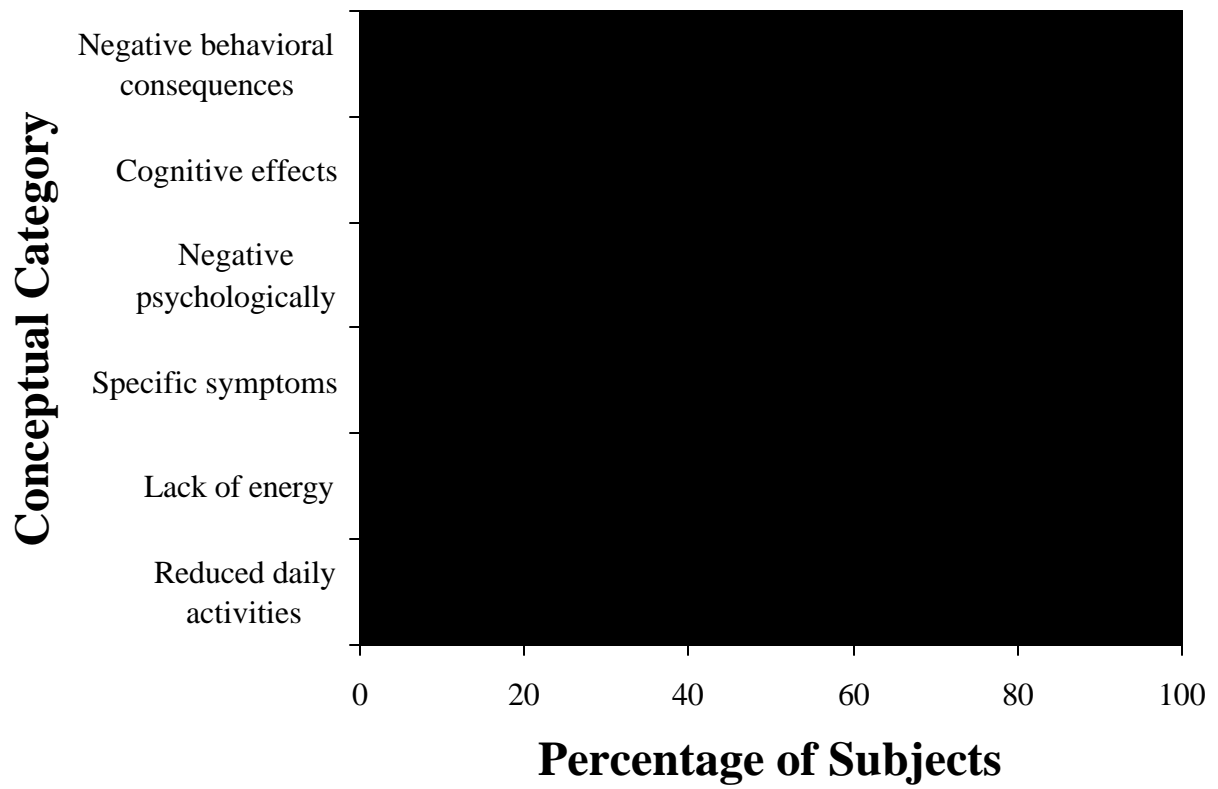
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Evaluation of the treatment options given in the patient guideline	(16) They are too much on the pills, it emphasizes too much on medications. You cannot generalize something like this, what can help one person might not help another. I disagree with a lot of this stuff. I tend to think that individuals who are depressed are treated in such a way that all they are given are pills and that's it. Fine, you might need medications to help you but I think there must be another method that you can use to help this individual, maybe just talking to each other in groups. I think it can be as effective and sometimes even more effective than just talking about these antidepressant drugs.
Presentation of the patient guideline	(19) The guideline is too theoretical, it should be more practical and more presentable so that the person can read it and feel better. The moment I saw these two pages, I didn't feel like reading it. If a person is depressed they might not feel like reading it, so it should be presented in such a manner that the person feels like reading it.
Usefulness of patient guideline in evaluating simple and complex problems	(22) I did not want to use the word depressed before, because I thought depression was more extreme than either of these two cases. I thought depression was when things are really bad.

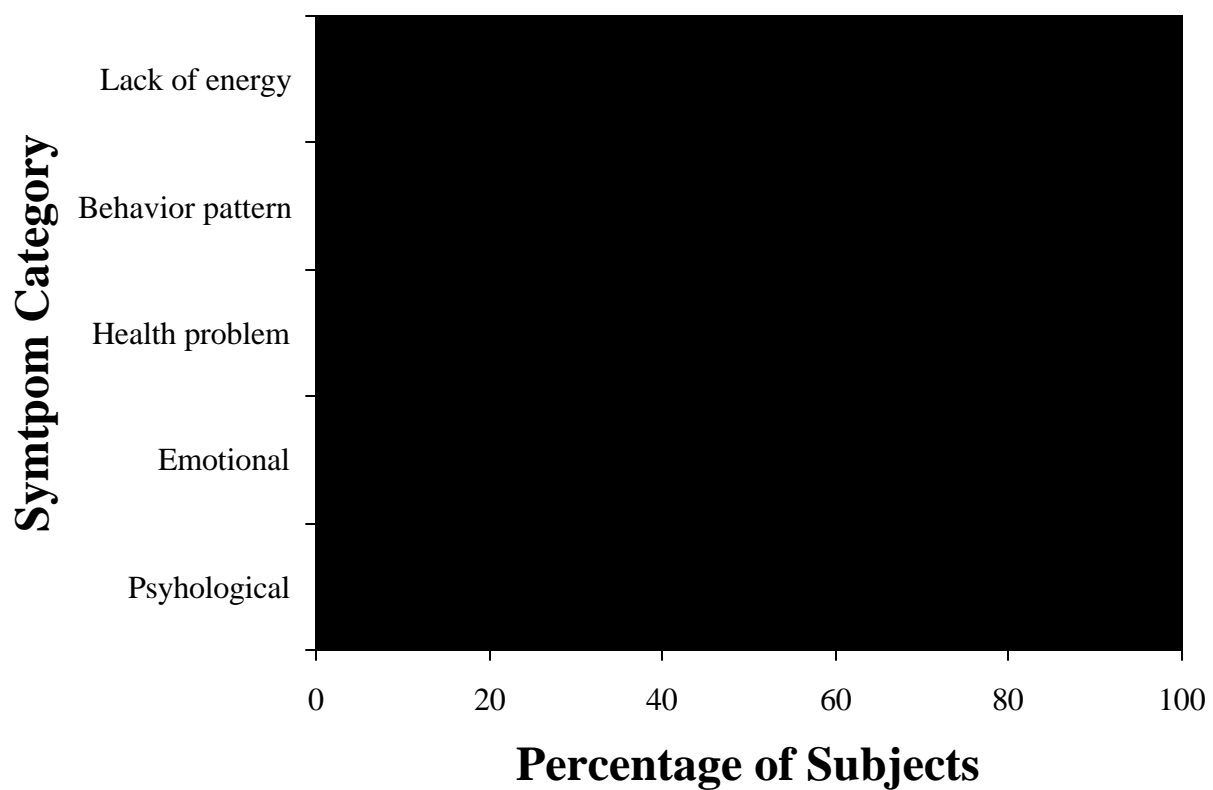
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**FIGURE 1: Percentage of subjects that identified concepts belonging to the main conceptual categories related to being healthy.**

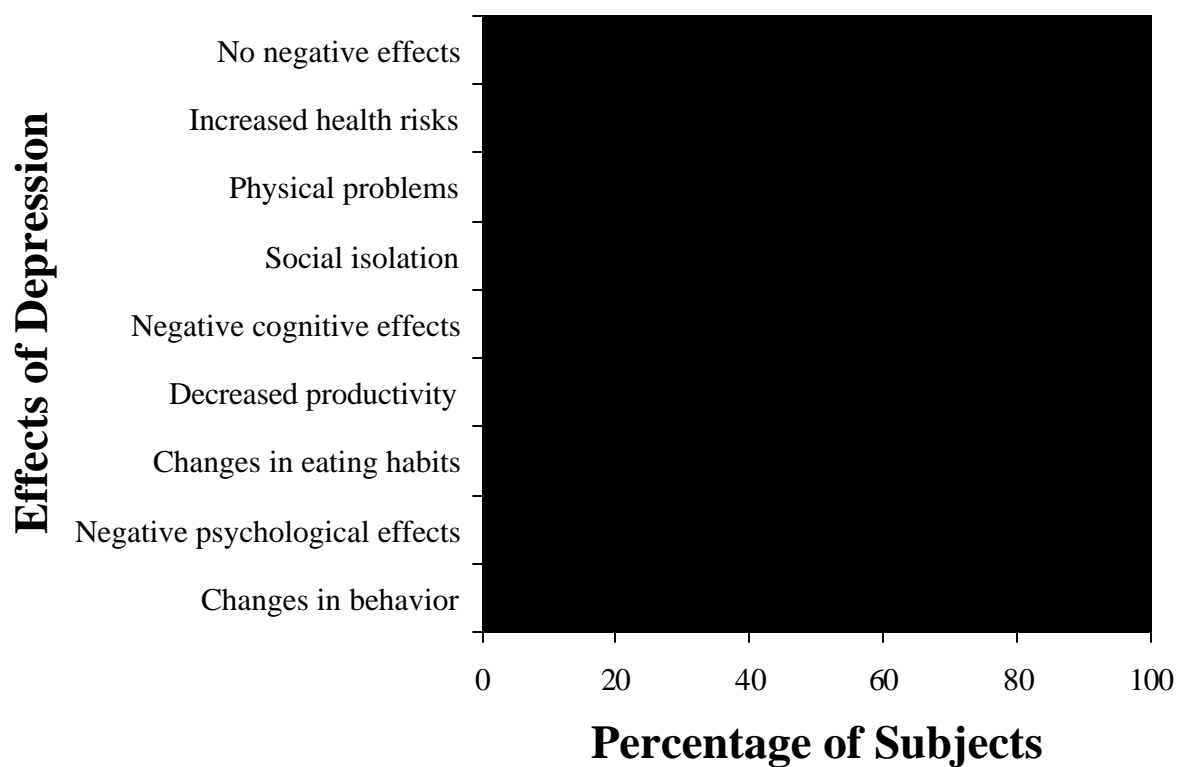


**FIGURE 2: Percentage of subjects that identified concepts belonging to the main conceptual categories related to being sick.**

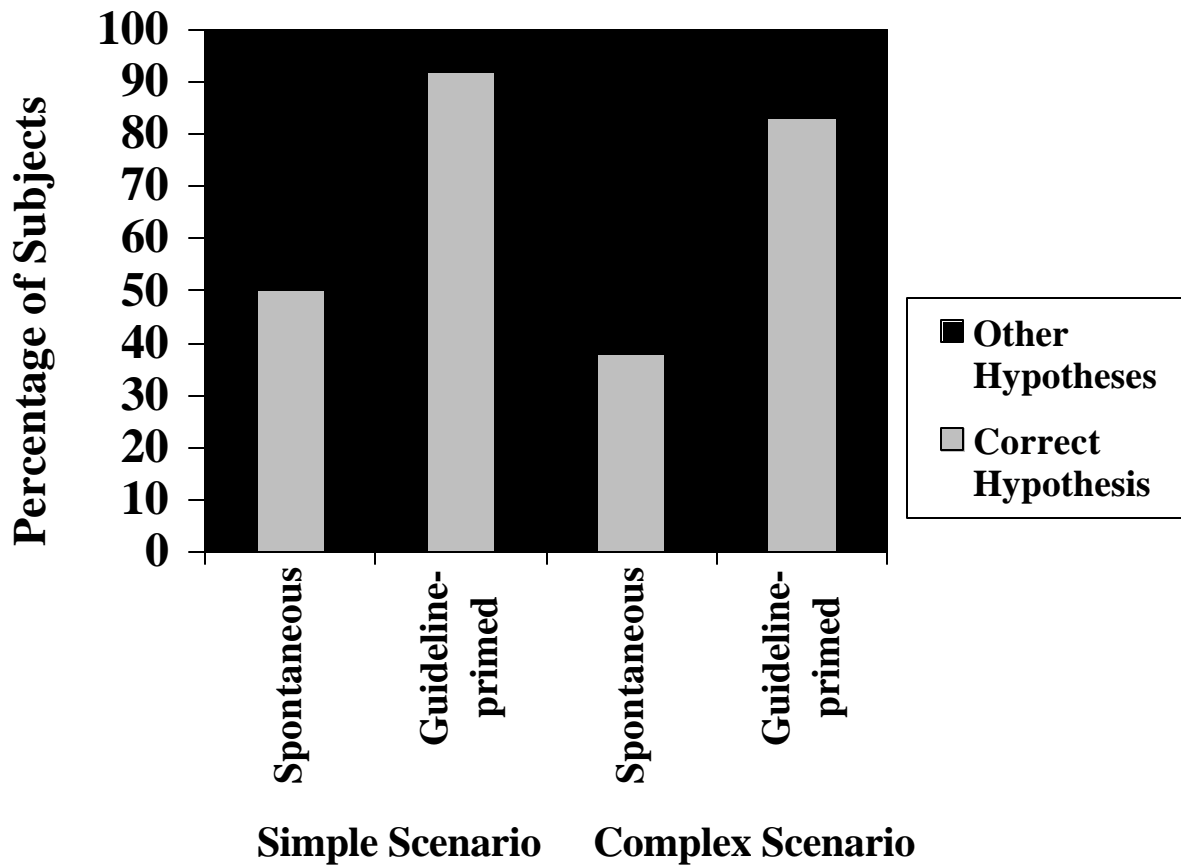


**FIGURE 3: Percentage of subjects that identified symptoms of depression belonging to the major symptom categories.**

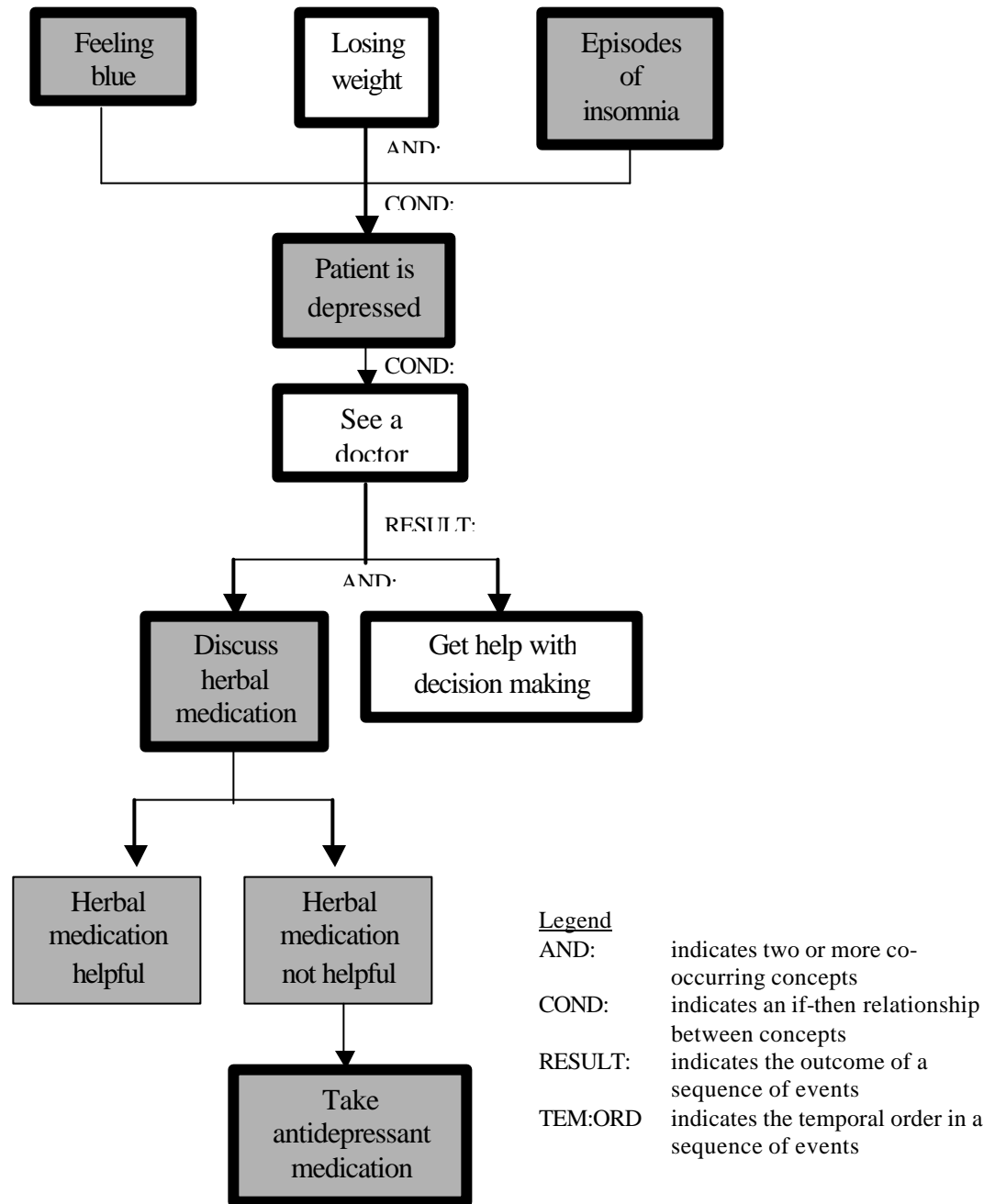




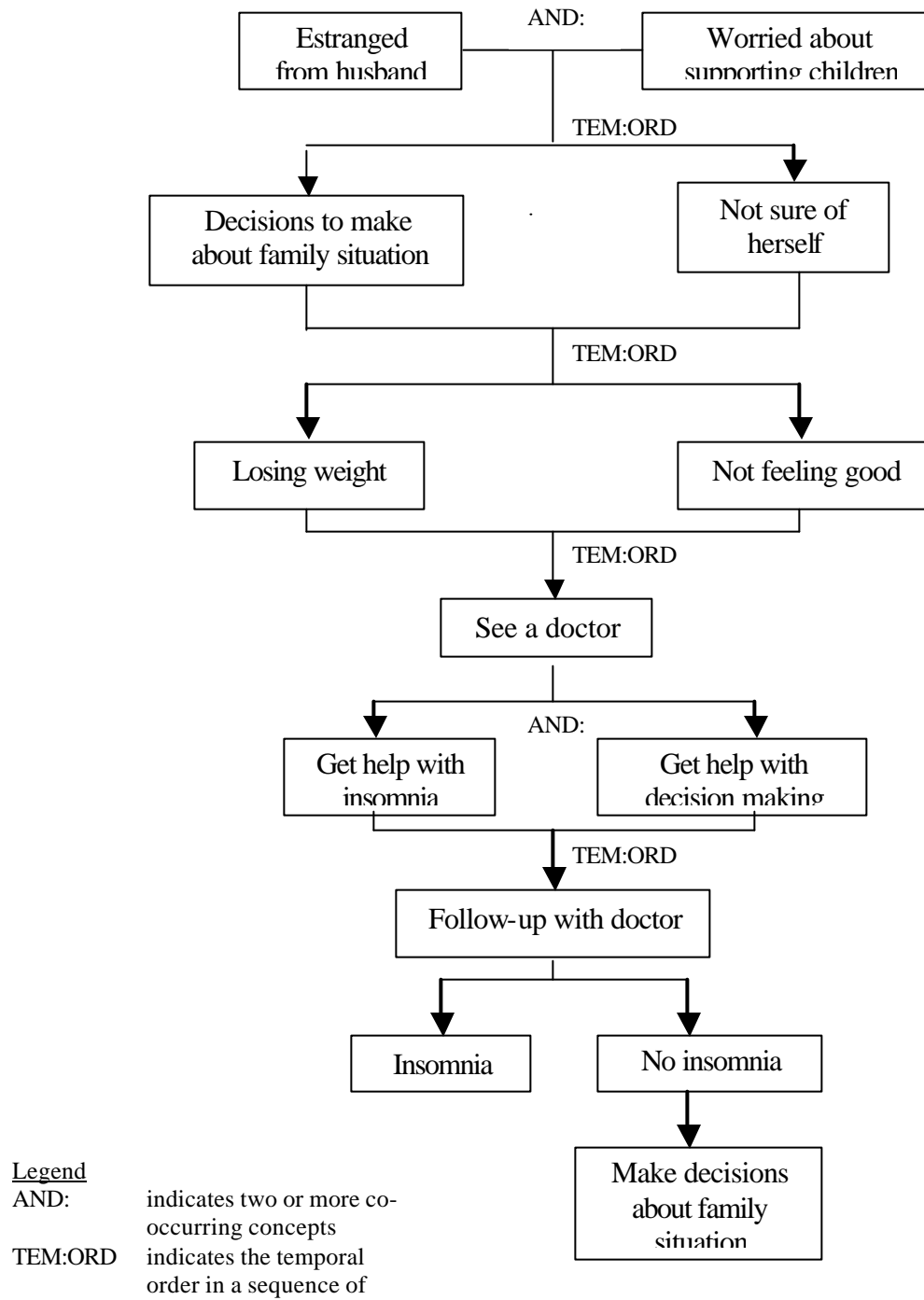
**FIGURE 4: Percentage of subjects that identified effects of depression belonging to the main effect categories.**



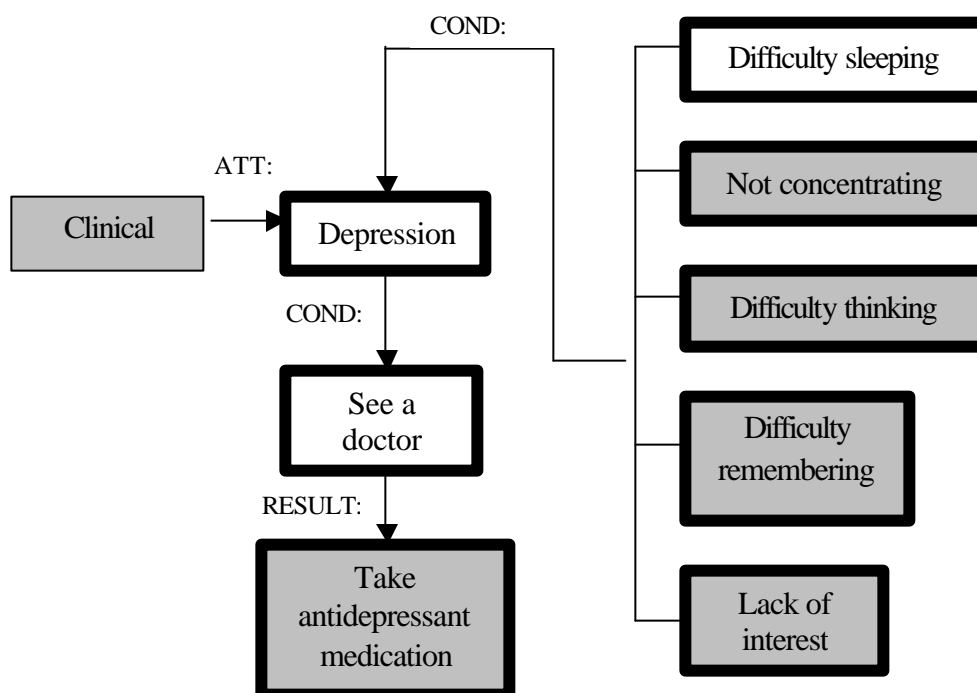
**FIGURE 5:** Percentage of subjects that correctly diagnosed depression during spontaneous and guideline-primed problem solving for simple and complex scenarios on depression.



**FIGURE 6:** Schematic representation of a protocol of a female subject's reasoning for the first scenario after reading the guideline. White boxes indicate information generated before reading the guideline. Gray boxes indicate new information generated after reading the guideline. White and gray boxes with heavy border indicate generated information that also appears in the guideline. Arrows represent the direction of their relations.



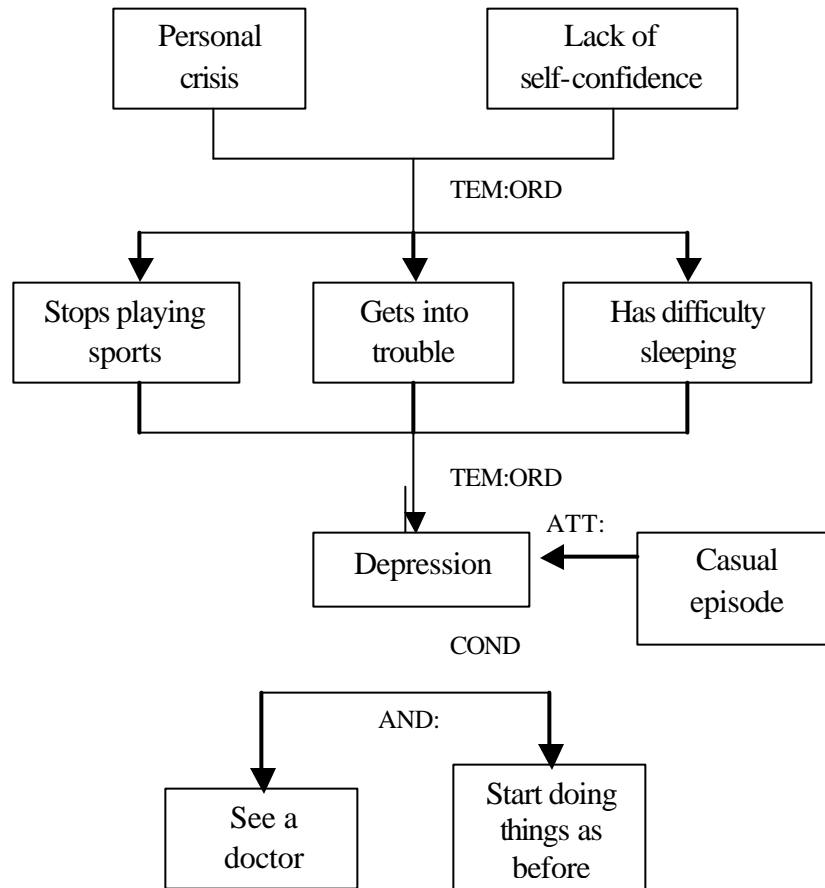
**FIGURE 7: Schematic representation of a protocol of a female subject's reasoning for the first scenario prior to reading the guideline. White boxes represent the concepts that were generated and arrows represent the direction of their relations.**



#### Legend

- ATT: indicates a qualitative attribution made in relation to a concept
- COND: indicates an if-then relationship between concepts
- RESULT: indicates the outcome of a sequence of events

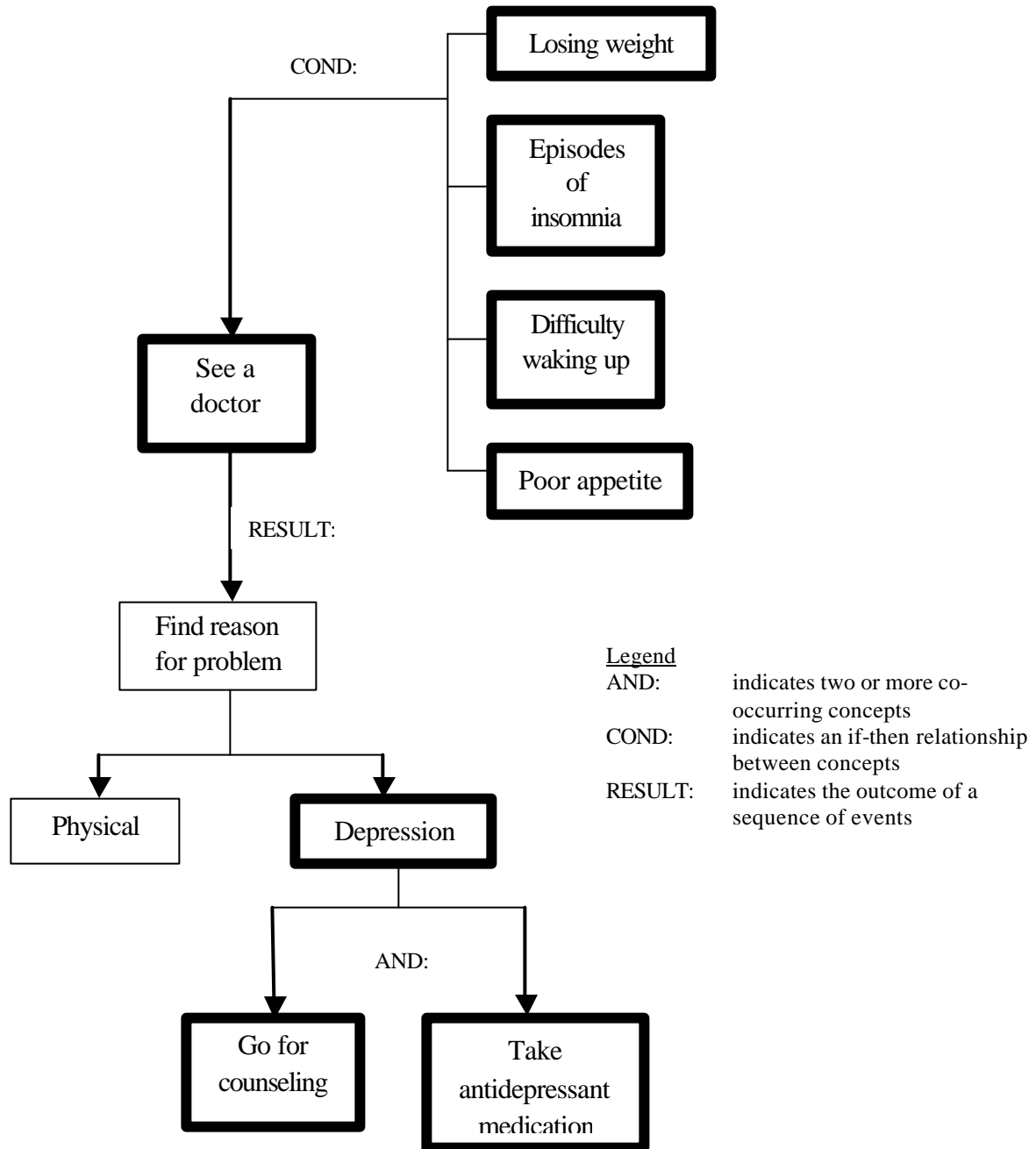
**FIGURE 8: Schematic representation of a protocol of a male subject's reasoning for the second scenario after reading the guideline. White boxes indicate information generated before reading the guideline. Gray boxes indicate new information generated after reading the guideline. White and gray boxes with heavy border indicate generated information that also appears in the guideline. Arrows represent the direction of their relations.**



Legend

- AND: indicates to two or more co-occurring concepts
- ATT: indicates a qualitative attribution made in relation to a concept
- COND: indicates an if-then relationship between concepts
- TEM:ORD indicates the temporal order in a sequence of events

**FIGURE 9: Schematic representation of a protocol of a male subject's reasoning for the second scenario prior to reading the guideline. White boxes represent the concepts that were generated and arrows represent the direction of their relations.**



**FIGURE 10: Schematic representation of a protocol of a depressed subject's reasoning for the first scenario before and after reading the guideline. White boxes indicate information generated before reading the guideline. Boxes with heavy border indicate generated information that appears in the guideline. Arrows represent the direction of their relations. No new information was generated after reading the guideline.**