THE DECISION MAKING PROCESS OF CANCER PATIENTS: THROUGH A MODEL STILL MORE CLEARLY

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ABSTRACT

The decision making processes of cancer patients are not as yet completely understood--if ever they will be. In three previous co-authored works, the authors introduced and then refined an Equilibrium/Disequilibrium model of the decision making processes of cancer patients (Pinney and Cummings, 1982, 1983 and 1985). Since introducing that model, the author of this paper has become more involved in consumer satisfaction, dissatisfaction and complaining behavior. As a result of this involvement, the Equilibrium/Disequilibrium model is again being revised. In this paper, however, the model has been modified in part to read: satisfaction/dissatisfaction and, in certain contexts, complaining behavior.

MODEL OVERVIEW

The model, as it is now envisioned, has been expanded to take into account the various degrees of satisfaction/dissatisfaction faced by cancer patients. It must be recognized that the search for satisfaction by a cancer patient is not the same as the search for satisfaction derived from consumer products such as a color TV set. The replacement of a TV set that is comparable to or technically better than the one being replaced might leave the consumer with the same or only a slightly higher degree of satisfaction as experienced or sensed with the previous color TV set. The cancer patient, however, may never regain the level of satisfaction experienced prior to being diagnosed for cancer. This situation makes it necessary to recognize various degrees of satisfaction/ dissatisfaction, and the realization for some patients that any form of true satisfaction might not be restored or even again attainable.

In order to take into account the complexity of decision making, the model presented in this paper will focus on the various levels of satisfaction/ dissatisfaction. To analyze this complexity of decision making, the model was revised by incorporating into its design different levels of relative satisfaction/dissatisfaction (see Figure 1). As the cancer patient progresses from diagnosis into treatment(s) and, hopefully, remission, various levels of satisfaction/ dissatisfaction are possible. These psychological states are reflected in a vertical scale including Satisfaction_0, Satisfaction_{-}, $\text{Dissatisfaction}_{1-12}$, Indefinite Satisfaction_{--}, Indefinite Dissatisfaction, and Ultimate Dissatisfaction. Depending on the outcome(s) of the treatment(s), still additional levels of relative satisfaction or dissatisfaction may result. An indepth discussion of the model follows.

DISCUSSION OF THE MODEL

The model of the decision making process actually begins with the emergence of the problem (see PROBLEM_1 in Figure 1), often times totally unbeknownst to the cancer patient. However, with the passing of time, the problem will progress to where at least an identification of the symptom(s) will occur (see SYMPTOMS in Figure 1) which, in and of itself, is a form of problem in the mind of the consumer (see PROBLEM_2 in Figure_1). This can begin with a routine medical checkup or the simple realization by the individual that something might be wrong. At this stage in the decision making process, the person is not aware that he/she has cancer. DISSATISFACTION_1 is established as a result of the possible diagnosis of cancer (see DISSATISFACTION_1 in Figure 1). Solution seeking activity at this stage might be confined to consideration of the alternative institutional solutions (i.e., hospital vs. clinic, generalist vs. specialist, local vs. distant location of such, etc.). The person's past experiences with respect to health care (i.e., see MEMORY in Figure 1) become part of the decision making process at this stage. From the list of initial alternative institutional solutions, the patient selects the feasible alternative institutional solutions (see Figure 2).

Figure 1

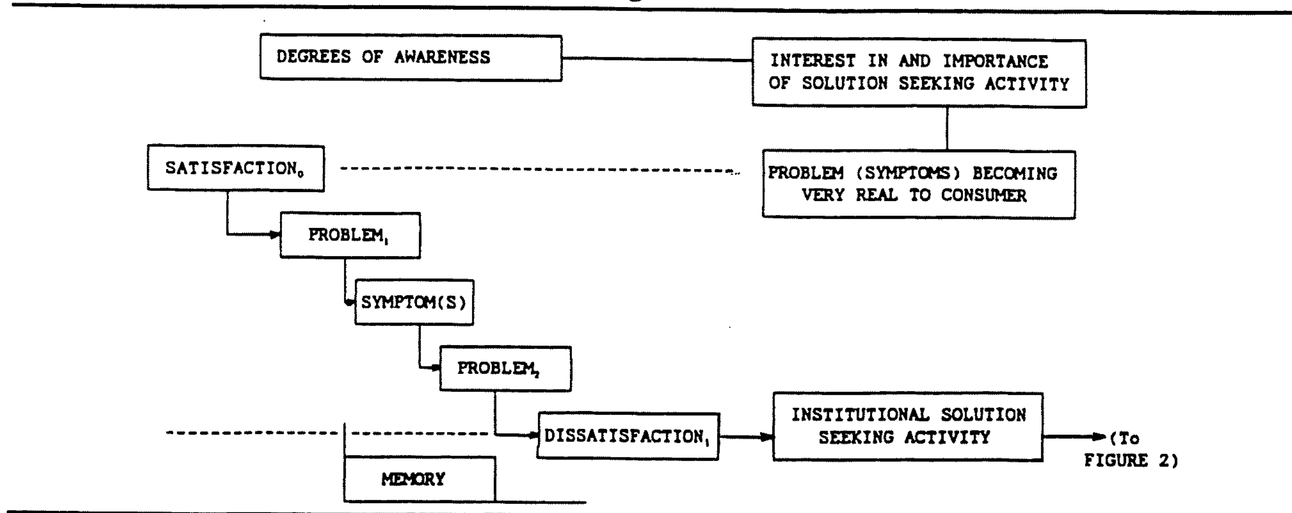
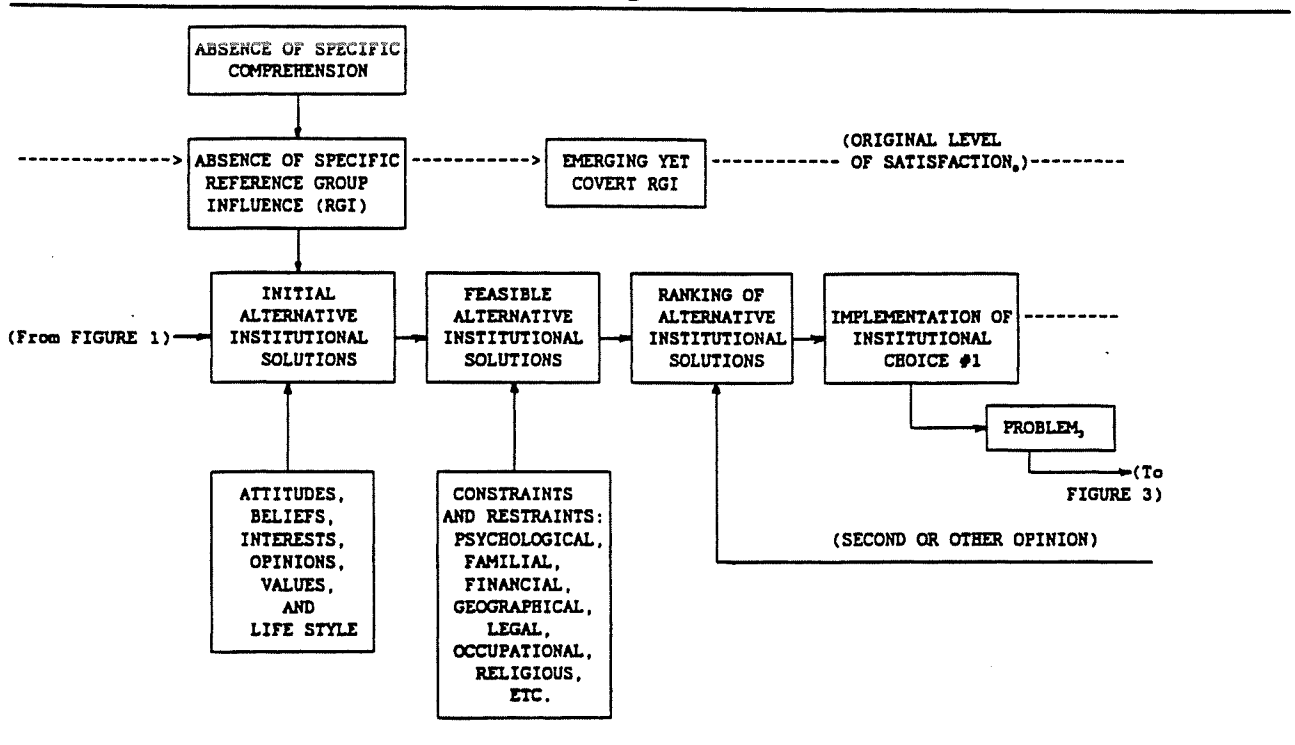


Figure 2



These alternative solutions are subject to numerous constraints or restraints imposed on or by the consumer. They can be financial, religious, occupational, etc. The ranking process may also be influenced by second opinions that are often sought by cancer patients. Selection and implementation of the institutional choice alone can often result in various stages of higher satisfaction--or even short term perceived remission. Alternatively, the choice of institution may not be successful, resulting in the realization of $PROBLEM_3$ (see Figure 2) and subsequent $DISSATISFACTION_2$ (see Figure 3).

Dissatisfaction can result in one of four psychological states: $DENIAL_1$, $ACCEPTANCE_1$, $ACCEPTANCE_2$, and $DENIAL_2$. $DENIAL_1$ is total rejection of the diagnosis and, hence, a psychological sense of relative well being, although the situation may only be temporary. $ACCEPTANCE_1$ describes the situation where the

Figure 3

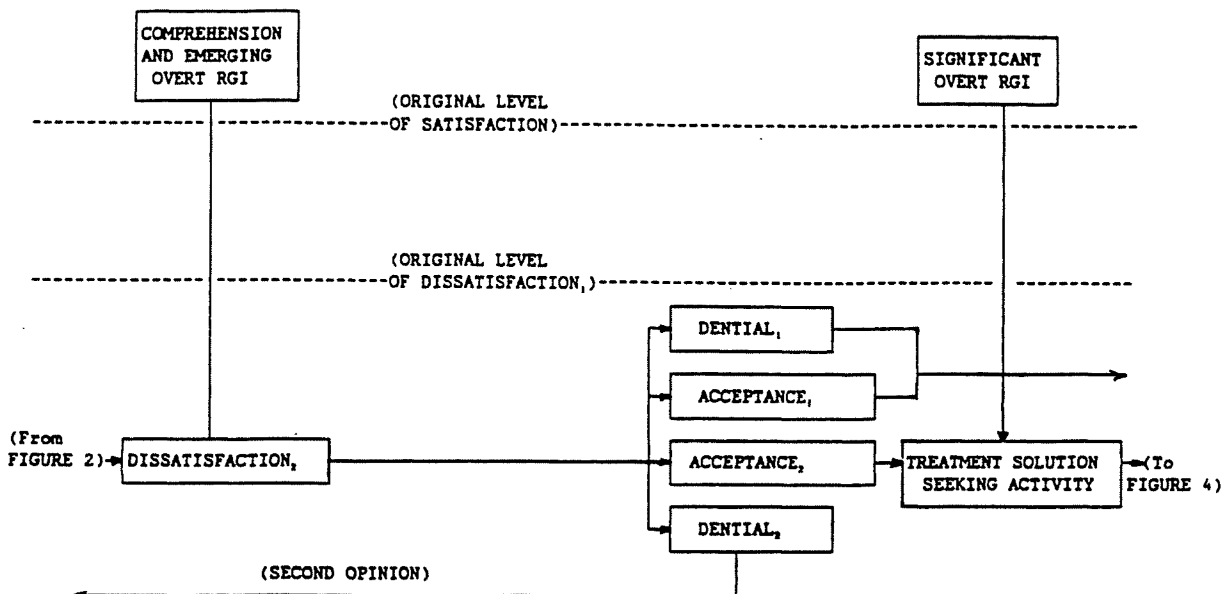
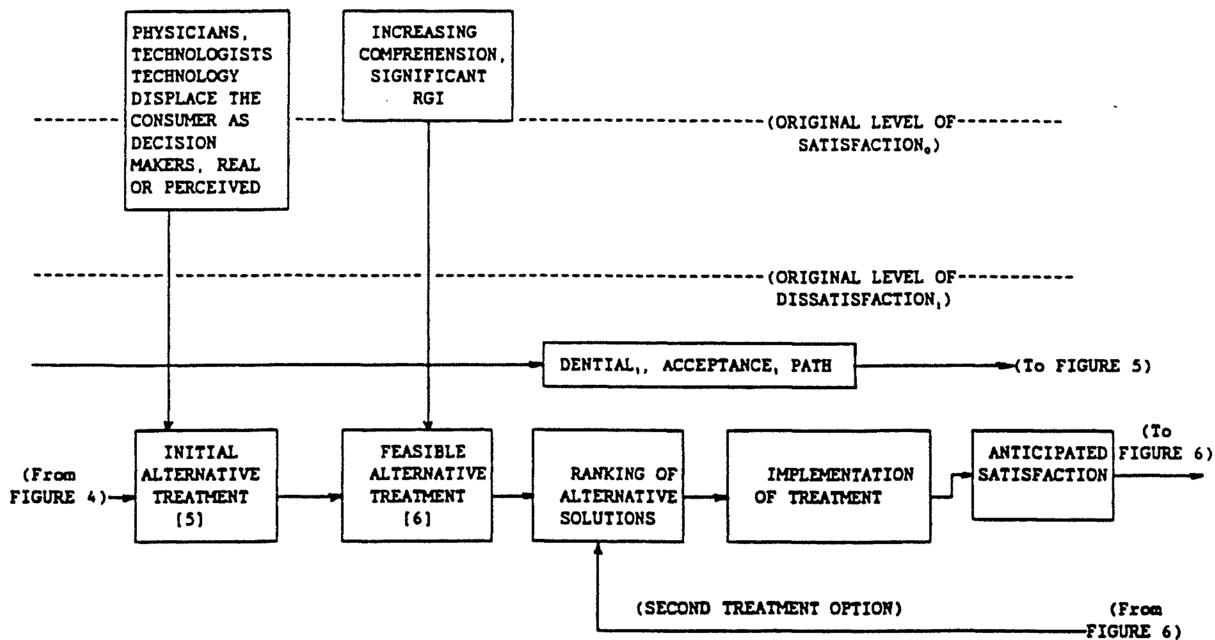


Figure 4



patient accepts the diagnosis but postpones the treatment. ACCEPTANCE$_2$ follows from a brief feeling of denial but, thereafter, immediate movement to consideration of initial alternative treatment solutions. Finally, in DENIAL$_2$, the patient may reject the diagnosis and seek out a second opinion as to institutional choices, circling back to the ranking of alternative institutional

solutions.

Alternative treatment solutions at this stage in the decision making process normally are limited to the traditional forms of treatment that include cobalt, surgery, chemotherapy, immuno-therapy, or various combinations of the above. This portion of the decision making process often involves a significant departure from more traditional models, with the patient involved steadily less and physicians and medical technologists involved steadily more in the decision making process (see Figure 4).

In many cases, this process enhances the sense of dissatisfaction on the part of the patient due to a perceived, if not real, loss of control over the decision process, resulting in DISSATISFACTION_3 (see Figure 6).

Implementation of the treatment(s) may result in ANTICIPATED SATISFACTION. Most patients anticipate a "cure" for their problems. Unfortunately, this often used expression is not totally correct since the best any patient may hope for is long term remission. Once a patient has been diagnosed for cancer, regardless of interim remission(s), there still remains a higher-than-average chance of recurrence. The location and kind of cancer might even change, but the intervening period is treated as a "remission stage" only and not a "temporary cure stage"; and the subsequent cancer is treated as a "recurrence" of the earlier problem, not a new problem. For many patients, just getting started on treatments enhances their feelings of well being, hence a lessening of perceived dissatisfaction from DISSATISFACTION_3 to DISSATISFACTION_4 (see Figure 6).

Denial or Postponed Treatment

Not all patients will accept the diagnosis and the subsequent treatment. For those who choose this path, the result is steadily increasing complicating symptoms, resulting in DISSATISFACTION_5 (see Figure 5). This particular level of dissatisfaction does not occur abruptly; as suggested from the model, this occurs over a relatively long period of time. Some types of cancer, for example, are very slow in developing, creating the illusion of a state of satisfaction or well being. Those patients who refuse to progress forward through the decision-making process--out of desperation or ill-founded hope--will return either to the initial alternative institutional solutions or the initial alternative treatment solutions and/or combinations thereof. Others will pursue a more radical course of treatment often involving unproven alternatives. Unfortunately, the physicians have already eliminated many of the alternative treatments available to the patient. Also, the more radical treatments often are ineffective medically. The results of this time consuming activity is a furthering of this dissatisfaction (see DISSATISFACTION_6 in Figure 5).

From $\text{DISSATISFACTIONS}_{5 \text{ and } 6}$, three reasonable alternatives are possible: Home Care, Hospice Care, or Hospital Intensive Care. This ranking by patients and/or physicians is itself another stage in the decision making process. However, other things equal, the ranking appears quite consistent with responses from the research.

The outcome from this decision process is most often death, or what might be referred to as the ULTIMATE DISSATISFACTION_1. The research recognizes, however, that, for some patients, death comes as a relief, as a "godsend", or as a very acceptable "alternative solution", and not even a problem (see ULTIMATE $\text{DISSATISIFACTION}_2$, Figure 5).

Solutions to Problems Can Be Problems: Enhanced Dissatisfaction and Complaining Behavior

The prolonged treatment which often accompanies certain kinds of cancer will begin to affect many patients' sense of wellbeing and the likelihood of a "cure." This is also the time many patients begin to experience the side effects of the "Solution." Not only does the patient sense a lower level of dissatisfaction, complaining behavior becomes quite evident. It is not uncommon to find patients stating that the side effects of alternative solutions, in particular chemotherapy, are worse than either the problem or its symptom(s). Further, patients become aware that a "cure" is never the outcome; that the best they can hope for is "remission." This realization may affect the attitude of the patient downward in the model, and hence, DISSATISFACTION_7 (see Figure 6).

Often the evaluation of the treatment results in

Figure 5

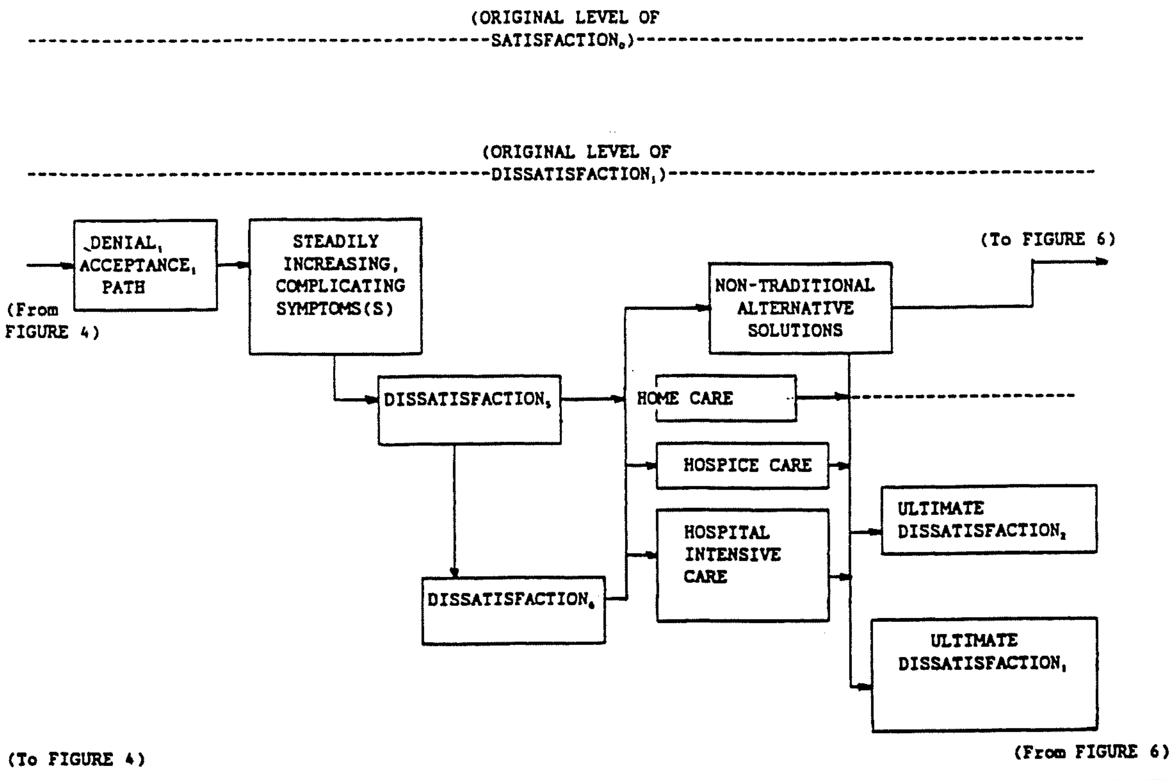
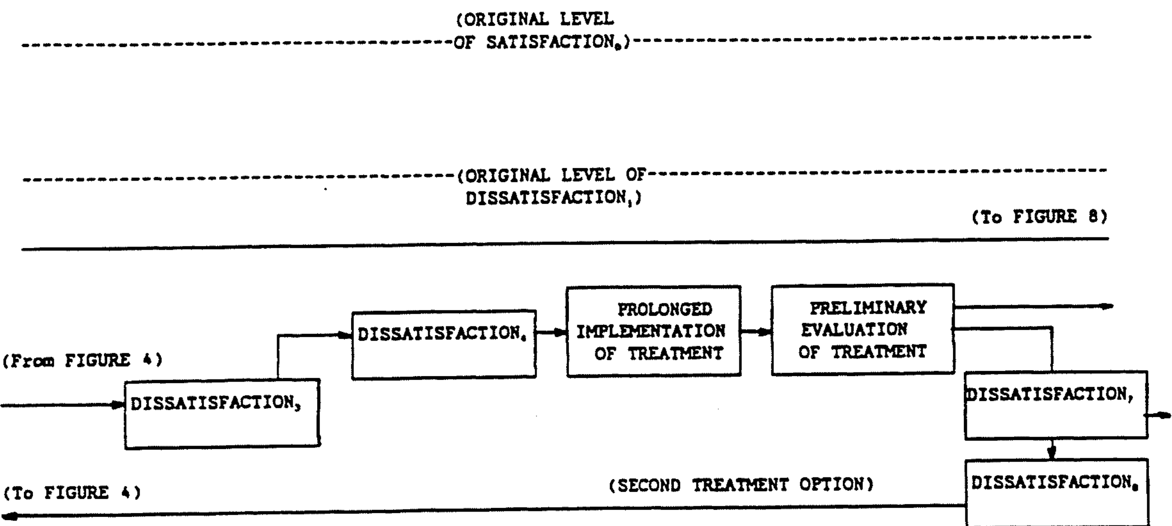


Figure 6



a recommendation by the physician that a subsequent solution must be considered. For many patients, the realization the initial solution was ineffective yields a subtle to traumatic sense of loss of confidence, either in the physician, the institutions and/or combinations thereof, resulting in $DISSATISFACTION_8$ and a substantial opportunity for complaining behavior directed at any one or a combination of these.

Subsequent treatments often result in "remission," however. In 1983, effective for the first time, the likelihood of remission from cancer in general exceeded 50% percent. Therefore, any positive response to treatment should be responded to by an even higher sense of wellbeing on the part of the patient, now more than ever (see $DISSATISFACTION_9$, Figure 7). A lesser level of dissatisfaction may also be obtained, e.g., higher than $DISSATISFACTIONS_{2-9}$, but not necessarily higher than the original level of $DISSATISFACTION_1$, perhaps a sense of $SATISFACTION_{-}$).

$SATISFACTION_{-}$ is defined as a tentative state between the original level of $SATISFACTION_0$ and the original level of $DISSATISFACTION_1$. Were the model to be applied to other circumstances, this situation might be termed a form of "rationalization". The patient attempts to make the best of a disappointing situation, recalling that once a person has been diagnosed with cancer, complete and total restoration to "$SATISFACTION_0$" is not possible. Expressions such as "I now live each day to its fullest," or "I have really come to appreciate my family" are evident. In this instance, remission is not realized but the progressive tendency has been curtailed, slowed down, or at least the undesirable side effects reduced or eliminated.

For other patients, however, now reaching out in desperation, the search will be directed toward nontraditional alternative solutions as described previously. Nontraditional alternative solutions are felt to result from $DISSATISFACTIONS_{7,8,}$and$_9$. These treatments fall into two categories: those at the state-of-the-art fringe within the medical field, and those of a more radical nature.

The search for nontraditional alternative treatments is a rather unstructured activity (see Figure 8). Reference group influence plays an important part. However, since many patients are acting out of desperation, any source of information on alternative forms of treatment is given some credence. Subsequently, these treatments are shared with at least intimate reference group members. Since many patients continue to regard illness that is not readily treated as a sign of weakness or inability to solve problems, their reference group behavior will remain mostly covert.

"Feasible NonTraditional Solutions," in this instance, is a function of a number of evaluative criteria, in particular, legal, financial, and geographic. A case in point is the person who no longer can receive laetrile treatments in Florida due to recently passed legislation and is compelled to move to Nevada. On the positive side, the patient is once again in charge of the decision-making process. However, on the negative side, many of these nontraditional treatments are heavily suspect, at least by the established medical community. Often this decision path makes ULTIMATE DISSATISFACTION an inevitability.

Realization of eventual ULTIMATE DISSATISFACTION (or death) is often accompanied by a radical restructuring or reordering of values, attitudes, and other evaluative criteria. Often this is the stage where patients can be found in the "negotiating" process with some universal god or religious representative, heretofore perhaps disregarded.

For those who enter into prolonged remission (see Figure 8, $SATISFACTION_{-}$), each additional day seems to ensure still another day and, hence, the psychological sense of wellbeing is steadily enhanced. This state results in $SATISFACTION_{-}$, the closest one approaching initial $SATISFACTION_0$. Even for patients receiving nontraditional forms of treatment, remission may have been realized and credit given, correctly or incorrectly. For this group, a certain level of satisfaction is also evident (see Figure 9, $SATISFACTION_{-}$). Unfortunately for the remainder of this group, dissatisfaction sets in as many nontraditional forms of treatment fail to provide remission (see Figure 9, $DISSATISFACTION_{11}$).

Financial Implications

For the overwhelming majority of patients, the cost of treatment is rarely correctly anticipated,

Figure 7

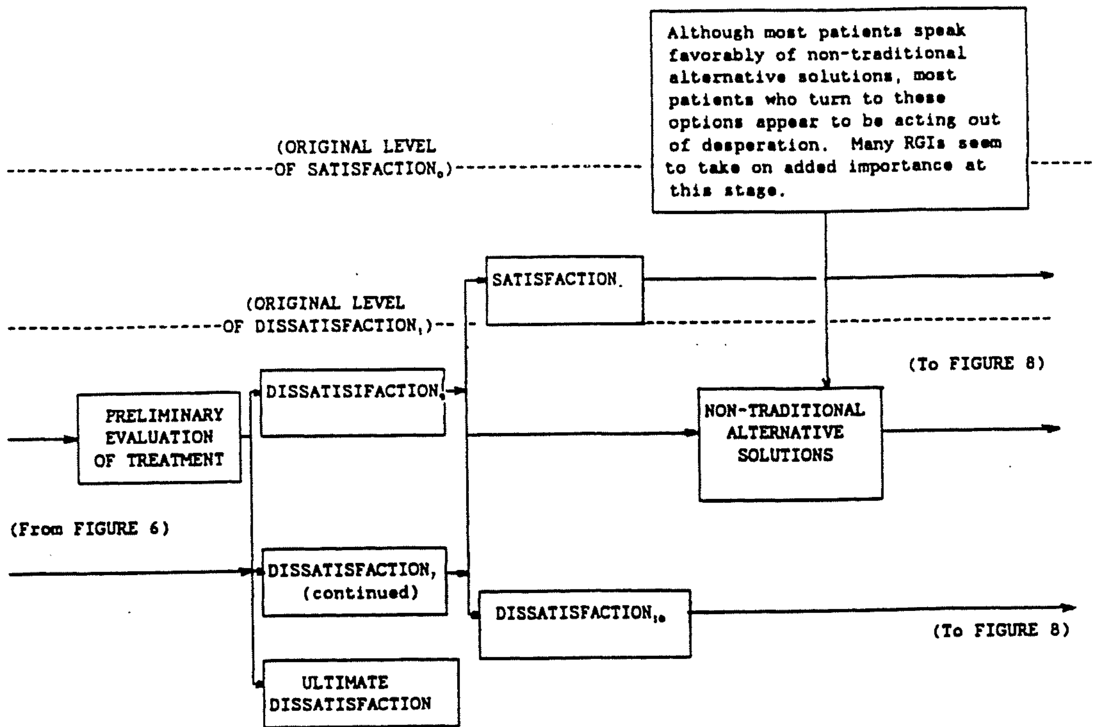


Figure 8

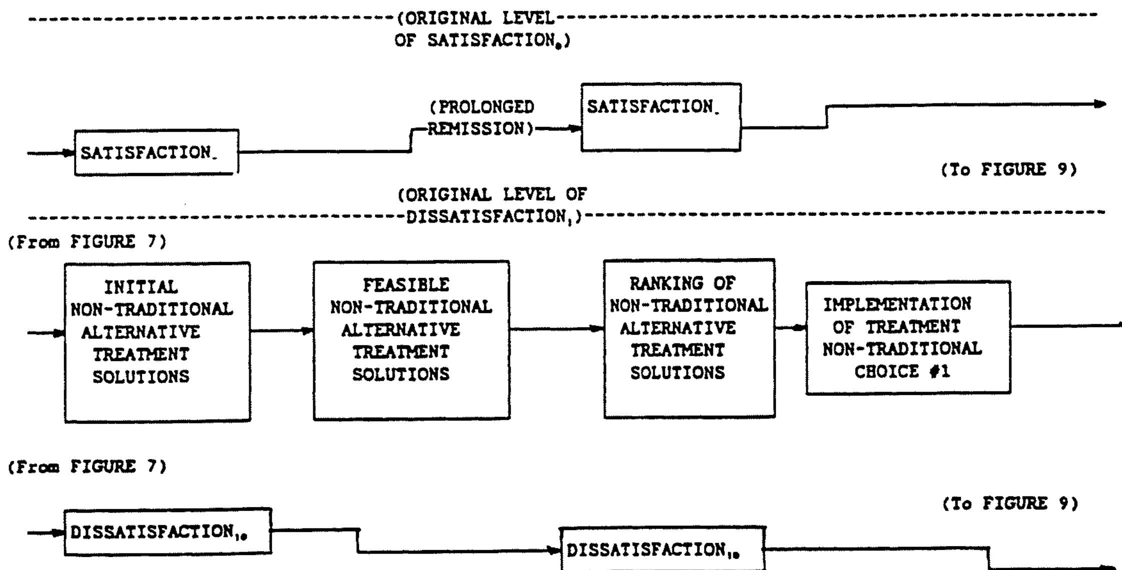
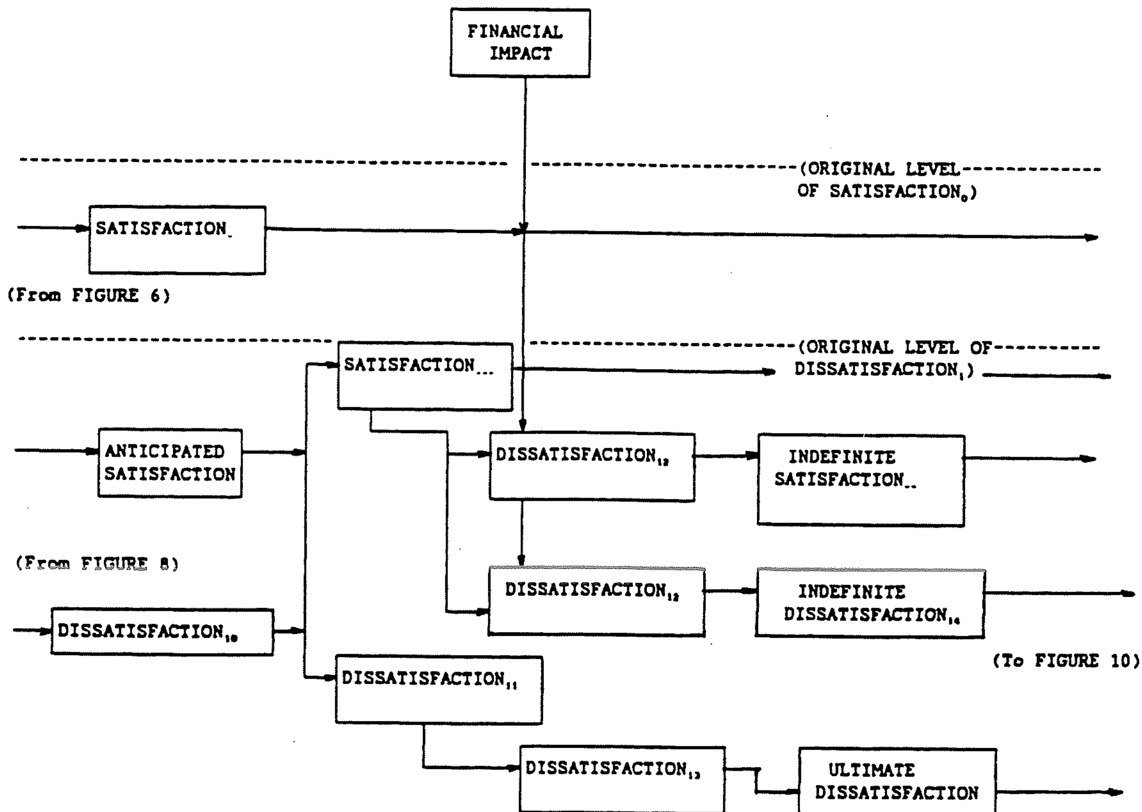


Figure 9



especially under conditions of prolonged treatment. Although many patients have health insurance, many do not have intensive care, acute care, or cancer care insurance. Still others fail to realize the existence of upper limits on their insurance policies. Finally, physicians often refuse to discuss the cost implications with their patients, preferring to "get the patient feeling well" before discussing with the patient the cost of the treatment(s).

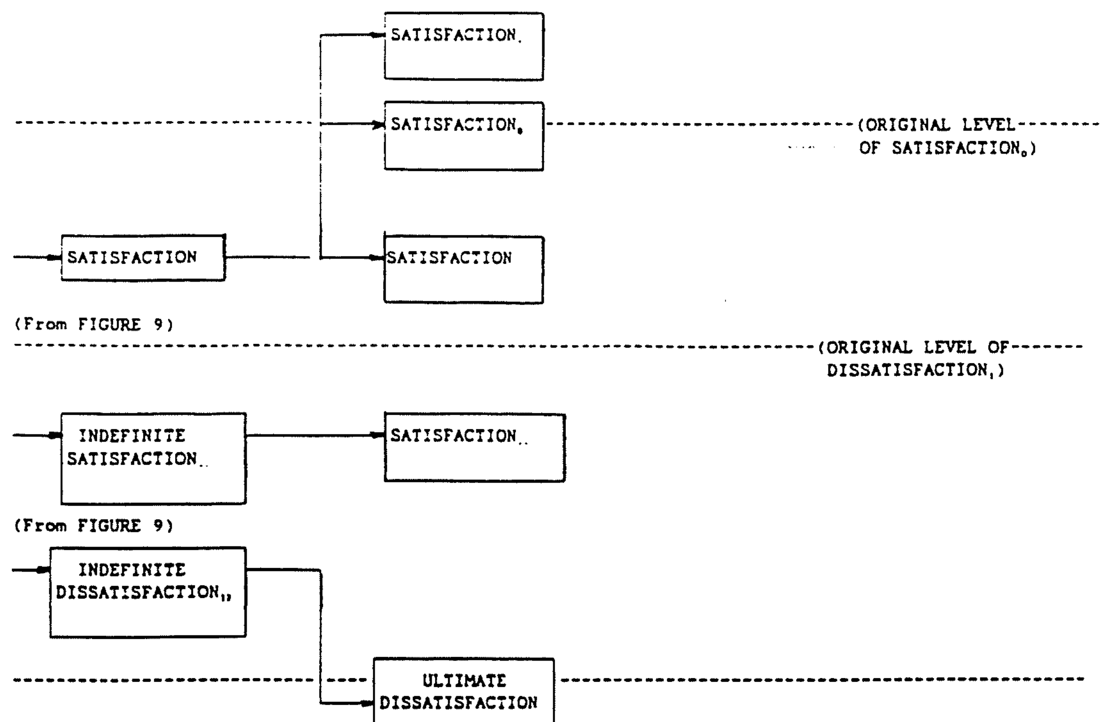
An extension of SATISFACTION$_-$ is INDEFINITE SATISFACTION$_-$ and for DISSATISFACTION$_{12}$ is INDEFINITE DISSATISFACTION$_{14}$. When the financial impact eventually is realized by the patient or the family, those who are adequately insured argue "life or good health at any price". This group experiences long term SATISFACTION$_-$. For those ill prepared to deal with the costs of such medical treatment, the sense of SATISFACTION$_-$ dissipates rather quickly to DISSATISFACTION$_{12}$ and INDEFINITE DISSATISFACTION$_{14}$ (see Figure 9).

These persons become greatly concerned with the financial burden they are bequeathing to their family and this becomes an additional basis for complaining behavior.

The Ultimate Dissatisfaction

Many kinds of cancer linger for tremendous periods of time while others recur from time to time; but under such conditions, many patients manage to adapt to their conditions and circumstances. For some, however, the cancer is terminal or untreatable, and yet the patients may embrace various levels of satisfaction (see Figure 10). "Satisfaction" here simply recognizes that, for some people, death opens the door to a new dimension, hence the expressions, "meeting one's maker," "going home," "the angel of mercy," etc. for some, this may even become a level of

Figure 10



profound acceptance, shown as SATISFACTION$_+$ in Figure 10. For other patients, however, death is acceptable, inevitable, natural, and something simply to prepare oneself for, hence SATISFACTION$_0$ or possibly SATISFACTION$_-$. Finally, for others, terminal cancer is simply a bad situation, hence the expression "the grim reaper," and the stage of ULTIMATE DISSATISFACTION is realized.

SUMMARY

The model presented in this paper is substantially different from the authors' previous works. The changes reflected in the third Equilibrium/Disequilibrium model resulted from additional indepth interviews and a mail survey of cancer patients. The changes in this fourth Satisfaction/Dissatisfaction model have resulted from this author's awareness of a new frame of reference for its development, namely, consumer satisfaction, dissatisfaction and complaining behavior. It is this author's belief that the decision making process of cancer patients is much more complex than originally envisioned. This process will continue to receive the author's ongoing attention with the ultimate objective being to provide quantitative support to these observations and conclusions contained in this, the fourth paper.

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