**Title**

Information needs of recently diagnosed cancer patients

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**Publication Date**

1984

# INFORMATION NEEDS OF RECENTLY DIAGNOSED CANCER PATIENTS

by

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DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF NURSING SCIENCE

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

[redacted]

Date University Librarian

Degree Conferred: JAN - 2 1984

To My Family
For their support and understanding

To My Parents, Haig and Iris Kouyoumjian
and
To My Extended Family
For their encouragement and understanding

# ACKNOWLEDGEMENTS

It is gratifying to acknowledge the unsparing efforts of the committee guiding my dissertation. This committee's faith in my ability to accomplish this study, and their understanding of the difficulties inherent in this approach to research, provided the momentum throughout the conduct of this study. Special gratitude is accorded to Dr. Jeanne Hallburg, the committee chairperson, for her unstinting guidance and help in the formulation and the conduct of the research. Special acknowledgement is given to Dr. Marylin Dodd for her thorough, insightful, prompt advice, and guidance during the development and conduct of the study. Grateful acknowledgement is extended to Dr. Thomas Nolan for his astute critique and advice during the formulation of the conceptual framework and throughout the study as well.

Gratitude is expressed to colleagues Lois Ramer, M.N., Mary Callaghan, M.N., Mary Hoban, M.N., and Linda Sarna, M.N., for their expert service as members of the judge panels. Heartfelt gratitude is given to the Research Assistants without whose help, expertise, loyalty, devotion, and belief in the aims of this study I could not have achieved 60 interviews of patients within the time designated for data collection. Grateful acknowledgement is due to all participating health care facilities, physicians and nurses for allowing the interviews.

The support funds of the University of California, San Francisco in the Academic Senate Fellowship and the Research Patent Fund, the American Cancer Society, California Division, and the United States Public Health Service for Professional Nurse Training Funds are gratefully acknowledged.

To my husband, Ara, daughters Aline and Armine, and to my extended family, heartfelt gratitude is due for their encouragement, support, patience, and understanding shown throughout the study.

Finally, to all the patients who consented to participate, I reserve a profound gratitude and admiration for sharing their thoughts and experiences to contribute to our understanding of the information needs of recently diagnosed cancer patients.

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## Information Needs of Recently Diagnosed Cancer Patients

by

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The purpose of the study is to describe the information needs of recently diagnosed cancer patients in relation to their disease as well as to their personal, family, and social concerns.

The theoretical framework is constructed from theories of coping, appraisal, information seeking, information needs, and hierarchy of needs. Categories of analysis are derived from the theories and findings of previous research.

Methodological, descriptive, and exploratory-comparative designs are simultaneously used. The INA (Information Need Assessment) instrument is developed as a valid, reliable, and comprehensive interview instrument which is used to gather the data. Data gathered from 60 recently diagnosed cancer patients are content analyzed by the researcher. The intracoder reliability is established by percent agreement among data coded and recoded at 6-8 week intervals, and by intercoder reliability using the Derdiarian-Lewis binomial test of proportion of agreements developed during this study.

Information needs and their importance as perceived by the recently diagnosed cancer patients are described according to their nature, i.e., harm, threats, and resources. Disease, Personal, Family, and Social Concerns constitute the major categories of information needs. Dominances in categories of information needs and their importance values are described within, as well as among the major categories. These dominances indicate consistencies with the hierarchy of survival needs, and with the amount, imminence, and likelihood of anticipated harm.

The comparisons of information needs and importance values among patients stratified by person- or situation-related variables indicate few differences by gender, age, and stage of cancer. The findings imply that information needs may be universal, and warrant research in the relationship of information needs to those variables.

The contribution to knowledge is the description of information needs of the 60 recently diagnosed cancer patients. The contribution to methodology is the INA instrument and the Derdiarian-Lewis binomial test for reliability. The contribution to theory is the theoretical development of information seeking and information need as they pertain to the information needs of recently diagnosed cancer patients. The added contributions are the implications of the findings that, in the recently diagnosed cancer patient, information needs may be determined by the hierarchy of survival needs (physical, psychological, social), and by the amount, imminence, and likelihood of anticipated harm; and that they may or may not be universal.

# CHAPTER I

# INTRODUCTION

## Purpose

The purpose of this study is to describe the information needs of recently diagnosed cancer patients in relation to their disease as well as to their personal, family, and social concerns.

## Statement of the Problem

The problem central to this study is the lack of data pertaining to the information needs of recently diagnosed cancer patients in relation to their disease, and to their personal, family, and social concerns. Furthermore, there are no valid, reliable, comprehensive instruments to describe the information needs of these patients.

Patients recently diagnosed as having cancer are faced with numerous new concerns. Although cancer shares many characteristics with other potentially fatal diseases, the diagnosis of cancer introduces stresses of its own based on the presumption that it is invariably lethal, painful, debilitating, pitiable, and distancing from others (Abrams, 1974; Feldman, 1979; Greenleigh, 1979; Strauss, 1975). Because of popular misconceptions about cancer, patients are very often uninformed about the disease at the time of diagnosis. Often, even though suspicious indications of cancer may be recognized, medical intervention is delayed until the clinical evidence becomes blatantly obvious. Information seeking is usually repressed until the initial medical attention is sought (Feldman, 1978; Weisman & Worden, 1980).

Immediately after diagnosis patients must cope with concerns related to their own physical and psychological well-being as well as the impact on spouse or significant other, loved ones, children, parents, siblings, colleagues at work, and peers (Feldman, 1978; Greenleigh, 1979). Coping refers to what the patient does in response to such concerns (Stewart, 1980). It encompasses many cognitive and behavioral responses, simultaneously expressed and aimed at alleviating such concerns through problem-solving and the minimizations of emotions (Cohen & Lazarus, 1979). Information seeking mode is among the most prevalent responses to novel situations. Its main function is to master the tasks relevant to the immediately postdiagnosis stage of the illness (Cohen & Lazarus, 1979). Mages and Mendelsohn (1979) identified these tasks as (a) to appraise the significance of the diagnosis; and (b) to recognize and deal with the realities of the situation, regulate emotions, and integrate the experience of illness with daily life. Recent studies showed that cancer patients generally sought maximum information about their disease following the diagnosis (Cassileth, Zupkis and Sutton-Smith, 1980) as a way of gaining control of their predicament (Averill, 1973; Krantz & Schultz, 1979; Rotter, 1977; Weisman & Worden, 1980). It may be extrapolated that information may have a functional relationship to appraising of a novel situation.

Information seeking behaviors or their determinants are not well understood. Some findings reveal that information-seeking behaviors may be influenced by variables related to personality differences among patients. Butt, Horwitz and Shipley (1979), among others, identified two traits distinguishing those patients who are sensitizers (those who typically want to know how to prepare) and those who are repressors (those who typically prefer not to know). Cohen and Lazarus (1979) failed to support this notion, however; those classified as sensitizers and repressors did not seek or avoid information as predicted. They suggested that other variables may have influenced information-seeking behaviors in patients. Other variables, person or situation-related, influencing information-seeking, such as the cancer site, its stage, and the age and socioeconomic status of the patient, were reported by Weisman and Worden (1980). They postulated that, based on their findings, the nature of information sought may be related to patients' personality or socioeconomic characteristics, and concluded that there was a lack of systematic investigation of the factors influencing the information-seeking behaviors in such patients.

Nor has the nature of the information sought been systematically investigated. McIntosh (1977) reported that although the cancer patients preferred being informed to not being informed, they selectively sought or avoided information about their diagnosis, treatment effects, and prognosis. In more recent studies using large retrospective samples of cancer patients, several researchers described information pertinent to what the patients wanted to know after diagnosis. Feldman (1978) documented accounts of information needed after diagnosis. Similarly, Greenleigh (1979) described information needed at each major event while living with cancer, i.e., the diagnosis, initial treatment, hospitalization, remission, relapse, and terminal stages. Weisman and Worden (1980) showed that cancer patients, regardless of their traits, sought information, and that this behavior and the nature of information needed seemed related to the demographic variables of the patients. Jones (1981) also concluded that a majority retrospectively accounted for their needs for information about their disease, treatment(s), and their physical, psychological, and social well being, as soon after diagnosis as possible. It may be discerned that cancer patients may or may not seek information about their disease, and that this behavior may be related to patient or disease related variables.

The nature of information needs described by patients in all of these studies clustered around four major categories of concern: (a) disease, (b) personal well-being, (c) family well-being, and (d) social well-being. Although retrospective, the patients' accounts were similar in their perceptions and recollections of the needs for the type of information related to those major categories. Although the combined findings in these studies do not represent a comprehensive universe of information needs in the realm of the four major categories, they do reflect a common trend in the possible limitation of information traditionally given in the categories of disease, and personal, family, and social concerns. The findings also reflect the patients' qualifications, in relative terms, regarding the importance of information needed in these areas, at various peak stress times during the illness with cancer (Feldman, 1978; Greenleigh, 1979; Jones, 1981). Information needs and their relative importance can change, therefore, according to the phase of the illness.

These studies shared some common limitations. First, they are retrospective and thus may not represent the information needs of patients recently diagnosed (1-17 days post-diagnosis), inasmuch as these findings may have been influenced by errors of recollection, patient maturity, and other variables. Second, their findings reflect the information needs of patients with various types of disease and in various stages, and may have been variable-specific to the type and stage of cancer. Third, except for one report (Jones, 1981), these studies did not have as their main purpose a description of information needs of cancer patients, although these patients were not recently diagnosed. Consequently, their findings only remotely provide relevant information for the purposes of the present study. Finally, these studies do not clarify the relationship between person or situation-related variables and the nature of information sought or avoided.

There is an increasing trend toward informing patients of their diagnosis, diagnostic and therapeutic procedures, as well as their prognosis; and this trend will continue to increase (Cassileth, 1980a). Because of the heightened awareness of patients, there is growing evidence, too, that educating the cancer patient is regarded as an integral part of comprehensive health care. As consumers of health care services, patients need to exercise their right to paticipate in their own care (Autonovsky, 1979; Cassileth et al., 1980a; Cousins, 1979; Morrow, Goetnick, & Schniale, 1978; Novack et al., 1979; Schain, 1980). In view of these trends, it is increasingly important to know (a) what is the nature, importance, and scope of information needed by recently diagnosed cancer patients, and (b) whether such information is mediated by person-related or situation-related (diagnosis) variables.

Therefore, the purpose of this study is to describe information needs of recently diagnosed cancer patients in relation to their disease, and to their personal, family, and social concerns. The research objectives inherent in the purpose are:

1. To develop a valid, reliable, and comprehensive instrument to the nature, importance, and comprehensiveness of information needs of recently diagnosed cancer patients;
2. To explore whether there are differences in information needs among recently diagnosed cancer patients stratified according to person-related and situation-related variables.

# CHAPTER II

# THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

## Theoretical Framework

The theoretical framework underlying the study is Lazarus' (1966) construct of coping. This framework is chosen because its theoretical components lend themselves to the understanding of the patient, the stresses peculiar to the predicament of the patient, and the patient's coping responses. Aspects of this theory that more directly pertain to the purpose of the study are reviewed. Also, related theories of Maslow (1954) and Heather (1955) are reviewed and used to strengthen some of its theoretical links which are particularly relevant to the study.

Coping is defined as cognitive and behavioral efforts to master, tolerate, or reduce external and internal demands and the conflicts among them (Lazarus & Launier, 1978). It pertains to the cognitive, emotional, and behavioral responses to a present or past confrontation with harm, and to future confrontation with an anticipated harm (Cohen & Lazarus, 1979; Folkman & Lazarus, 1980; Lazarus et al., 1978). Thus, coping represents a network of cognitive as well as intrapsychic processes, which include the active regulating of emotions, planning, avoiding, tolerating, and rehearsing (Cohen et al., 1979). Lazarus et al. (1978) have posited that coping efforts aim at problem-solving as well as palliation of emotions.

The above perspective on coping is further elaborated in the recent theoretical development of the construct, in which it is viewed as a transaction between person and environment in an ongoing relationship of reciprocal action, each affecting and in turn being affected by the other (Folkman et al., 1980). Lazarus et al. (1978) identify two processes that mediate this relationship: appraisal and coping.

## Appraisal

Appraisal is the cognitive process through which an event is evaluated with respect to what has been harmed, what is at stake, and what resources are available to cope with the perceived harm (Lazarus, 1966). It aims at configuring the harm or threat of a harmful situation as well as configuring the resources or alternatives that would potentially counteract the harm or threat. Appraisal denotes an evaluation or judgment, inferred from interpreting data concerning harm, threat, and resources, rather than a simple perception of the noxious stimuli. Harm signifies the actual occurrence of an unpleasant or damaging event which may be consequential to the anticipated threat or could be antecedent to new threats. Appraisal of harm is based on more concrete evaluation of the noxious stimuli insofar as it concerns the nature and extent of the damage sustained.

Threat is distinguished from harm in some ways: it refers to future harm and is therefore anticipated; it results from perception, learning, memory, and thought; it is determined by harmful stimuli that do not exist, rather, the cues indicating their approach are present (Withey, 1962). Its evaluation, therefore, is more subjective than that of harm. Threat cues are also often harbored in the existing harm (Lazarus, 1966). Resources are objects potentially capable of counteracting harms or threat. They are sought and their potential power (ability to counteract) is appraised relative to harms and threats.

Thus, appraisal involves defining harms, threats, and resources as well as evaluating the relative powers among them. Appraisal culminates in determination of the difference of powers between harms and resources and between threats and resources. As an end result of such cognitive processes, appraisals give direction to thought and behavior. Lazarus (1966) postulates, (a) that the degree of threat is primarily the function of the amount, imminence, and likelihood of the anticipated harm, and (b) that all threat can be described as falling on a continuum of degree (p.43).

Appraisal comprises three cognitive processes: primary appraisal, which refers to an assessment of the significance of the harmful or threatening stimulus; secondary appraisal, which refers to an assessment of the resources to contend with the perceived harm or threat; and reappraisal, which refers to the appraisal not only of harm, threat, and resources, but also to the choice of action and anticipated outcomes. The relationship between primary and secondary appraisal may or may not be sequential, although primary appraisal usually precedes secondary appraisal. This relationship may be linear, interactive, and cyclical, inasmuch as completion of the first may or may not be necessary before the second begins.

Appraisal is believed to precede coping (Lazarus, 1966). Coping efforts are made in response to the appraisal of a stressful situation. Appraisal and coping continuously influence each other throughout the stress response. Identifying appraisal as a determinant of coping, or coping as a determinant of appraisal, is therefore temporary, depending upon the point in time that the ongoing, dynamic relationship between the two is interrupted (Folkman et al., 1980). It seems then that coping and appraisal fluctuate in predominance, just as do primary and secondary appraisal.

## Coping

Coping represents cognitive, emotional, and behavioral efforts aimed at solving a problem as well as at regulating emotional distress often present in a stressful experience (Hamburg, Coelho, & Adams, 1974; Lazarus et al., 1978; Murphy, 1974; White, 1974). Cognitive as well as behavioral responses are involved in coping behavior aimed at solving a problem and at managing or minimizing the emotional responses to it (Pearlin & Schooler, 1978). Coping, according to Cohen and Lazarus (1979), never occurs in a vacuum, but in a context, and always takes place in reference to a problem or to emotional outcomes related to that problem. It is the function of the interaction among the variables of harm or threat, variables of resources, and the variables within the individual. It can be inferred that a variability of factors related to the nature of harm, threat, and resources may affect coping in a given stressful situation.

Cohen and Lazarus (1979) have identified five modes or forms of coping: (a) information seeking, (b) direct action, (c) inhibition of action, (d) intrapsychic processes, such as denial, avoidance, intellectualized detachment from the encounter, and (e) turning to others for help and succor. The authors suggest that information-seeking is one of the most basic and early forms of coping with encounters about which information is limited. One task of the patient is to discover whether a problem exists, and what, if anything, can be done about it; the other, to regulate the emotional responses aroused by the encounter. The former is exemplified in actions such as receiving treatments or taking preventive measures, and the latter in actions such as denying, avoiding, or rationalizing. Cohen and Lazarus further posited that coping never occurs in a vacuum but requires understanding the context in which it occurs as well as the specific stress with which the individual copes.

## Variables Affecting Coping

Cohen and Lazarus (1979) have identified two types of variables that may influence coping behaviors: person-related and situation-related. Person-related variables include personal traits or disposition to utilize a particular mode or pattern of coping with various harmful or threatening stimuli. Some attempts to measure the dispositional pattern of coping behavior have been reported that indicate a general tendency either to avoid or to seek information (Shapiro, 1965). This relationship between disposition and coping behavior was weak as shown in subsequent studies (Cohen & Lazarus, 1974; Hoffman, 1970; Palmer, 1968). Also, differences in age, gender, past experience with the threat are shown to influence coping behavior. Lipowski (1970), Pritchard (1977), and Bard (1952) described how different meanings derived from similar situations affect ways of coping in different individuals, e.g., variables such as age and stage of life. Rosen and Bibring (1966), for example, demonstrated differences in coping behaviors among adults with myocardial infarctions who were in different phases of life. Personal history or previous experience with the threatening situation also influences coping behavior, rendering it more or less threatening, depending on the nature of past experience (Mages & Mendelsohn, 1979). Gender, too, affects coping behavior. In retrospective and prospective samples, males suffered more than females negative effects of cancer regardless of age (Mages & Mendelsohn, 1979). Derdiarian (1982) also described differences in responses to cancer among males and females, presented later.

Situation-related factors also can influence coping behavior, although the relationship between a specific coping behavior and a specific type of stress is not well understood. Data convincing of the specificity of coping behaviors to given types of stress in individuals were lacking in several research attempts. Hofer (1972a, 1972b) suggested that coping behaviors may change in individuals according to the changes in the stressful stimuli, thus, contended that a relationship may exist between the nature of coping behavior and the events of the stressful situation. Parkes (1975) described oscillations between denial and reality testing used by individuals coping with different phases of grief. Similarly, Horowitz (1976) discussed alterations in coping behaviors from denial to seeking information and reality orientation in individuals throughout the events of the stressful situation. Mages and Mendelsohn (1979) also outlined different demands and strategies of coping according to the various stages of cancer. It is evident that although relationships between person and situation-related variables and coping may exist, they are not well understood.

## Information-Seeking

Although several modes of coping may be employed in a stressful event (Cohen et al., 1979), information-seeking is the coping mode most pertinent to this study. Lazarus (1966) and his followers do not explicitly present a conceptual or theoretical relationship between information-seeking and appraisal or coping. Information is functionally related to the processes of appraisal and coping in mediating both (White, 1974).

It is contended in this paper that information may be the mediating factor among the individual, the noxious stimuli, the appraisal, and the coping behavior, and it may play a determinant role in configuring the harms, threats, and resources associated with a stressful experience. This contention is supported in the premise that information is the knowledge, factual, theoretical, or experiential, which is relevant to an object or situation (Dodd & White, 1980). It is supported as well by Lazarus (1966) --

> The notion of appraisal has utility in pointing us toward the empirical conditions that determine threat and coping. It does this because it helps us to ask what sorts of information are relevant to the appraisal process. For example, what does this feature or that feature of the stimulus situation signify concerning the welfare of the individual? How harmful is the anticipated event? How likely is the harm? How able am I to deal with it? How soon will the harm occur? (p.88).

The functional relationship of information to the processes of appraisal and coping have been shown in clinical studies. More accurate expectations about threats of physical harm were developed when information regarding it was provided to patients. Consequently, patients coped more effectively with such harm through problem-solving and reduction of emotions (Janis, 1968; Johnson, 1974; Johnson & Leventhal, 1975; Lazarus & Alfert, 1964; Speisman et al., 1964).

Information also may be avoided. Cohen and Lazarus (1979) found that those who sought information and those who avoided information showed similar abilities to cope with stresses of illness postsurgically. Goss, Hamburg, Lebovitz, and Visotsky (1961) identified avoidance of information about extremely life-threatening illness to be prevalent in the coping behaviors of patients. Avoidance of information is discussed later as it pertains to the nature of information sought or avoided.

## Information Need

The mechanism that mediates interaction of the individual with noxious stimuli by means of information-seeking is not clearly explained in the constructs of Lazarus (1966) and Cohen and Lazarus (1979). Inherent in the definition of information as knowledge, factual, theoretical, or experiential form, relevant to an object or situation (Dodd et al., 1980) is the implication that a need for information derives from its lack. The degree of need for the information may be characterized by the degree of its lack. Adler, Cohen and Stone (1979) suggested that a need for information refers to that which is lacking, incomplete, faulty, or distorted in situations needing decision-making.

Heather (1955b) defines need as a perceived deficit that is requisite, which, when fulfilled, achieves satisfaction of a goal. The need for information, therefore, is determined by the degree of lack of information and by the degree of relevance of the information to the situation. A lack of information may act as a motivating force moving the individual toward securing it (Atkinson, 1964; Bandura, 1976). It may be extrapolated, then, that relevance and lack of information may increase the need, and therefore the motivation, toward securing it.

A hierarchy placing basic needs higher than secondary (acquired or learned) ones is postulated by Maslow (1954, 1973). He further suggests that basic needs may energize behavior more potently than secondary needs at times of high threat to survival. It is plausible to contend, then, that the relevance of need for information can be predominently determined by the association of the need with survival. Concerns related to the harms, threats, and resources associated with survival are more likely to prompt information-seeking behavior than those unrelated or more remotely related to the individual's survival. A hierarchy of relevant needs may be indicated by the relative importance of the information sought regarding those needs, i.e., the importance of information sought may be equal to that associated with and necessary to survival. It may be plausible to also contend, then, that the lack of information as well be indicated by the hierarchy of needs. It may be extrapolated, then, that the nature of the information sought may be determined by the nature and importance of the perceived harms, threats, and resources associated with survival needs.

### Information-Seeking Mode of Coping

Since information-seeking is a mode of coping (Cohen & Lazarus, 1979), it can be assumed that it has similar characteristics: it exists in response to noxious stimuli; it aims at mastering novel situations by problem-solving and by controlling or reducing emotional distress; its nature may be determined by the relevance of harms, threats, and resources to survival; and it is influenced by variables of the context in which it occurs, namely, by person or situation variables (Cohen & Lazarus, 1979). Therefore, it may be extrapolated that to understand the nature of information sought, it is essential to understand the person or situation-related variables as well.

Whether information seeking mode of coping takes place singly or together with other modes is not known. It is known, however, that it occurs early in the coping process as it is a basic mode of coping according to Cohen and Lazarus (1979). Weisman and Worden (1980) showed that information seeking was an active coping mode predominant at peak stress periods, especially at the time of diagnosis. It is extrapolated that it coexists with other modes of coping and it is influenced by the interaction of the variables of person and situation.

As for the function of information seeking, it is contended in this paper that its functions are the same as those of coping, i.e., that it aims at problem solving and regulation of emotion. Furthermore, that itself as a mode of coping facilitates, and even potentiates, the functions of the other modes of coping. These contentions are based on the definition that "information is one of the most basic modes of coping" (Cohen et al., 1979, p.221).

Since the initial aim of coping is to determine whether a problem exists, and what, if anything, can be done about it (Cohen et al., 1979), it is obvious that the initial aim of information seeking also is to configure the noxious stimulus, its implications, and the resources. In other words, information is needed to define the harms, the threats, and the resources - namely, to bring about an appraisal of the net balance of the threatening event and the resources to counteract it. In so doing, it may have a function of its own in problem solving and regulating emotions and a function of facilitating other modes of coping.

Finally, it is extrapolated that, like coping, it is subject to the influences of the person and situation-related variables. So, whether and to what extent it will be exercised may be determined by the interaction of these variables. Moreover, its aim, the very nature of information sought or needed, also may be determined by these variables. Therefore, to understand it, it is essential to understand these variables and their relationship to it.

## Review of Literature

### Information Seeking in Recently Diagnosed Cancer Patients

Coping behaviors have been investigated in general health behavior research. Although their findings enhance understanding of coping behavior in cancer patients, they do not directly pertain to the problem of information seeking of the recently diagnosed cancer patients. Therefore, the review of the literature will be limited to those relevant to information needs of cancer patients.

Recent studies have shown that cancer patients generally seek maximum information about their disease after its diagnosis as a way of gaining control of their predicament (Averill, 1973; Krantz & Schultz, 1979; Rotter, 1977; Weisman & Worden, 1980). McIntosh (1977) documents the selectivity of these patients in seeking or avoiding information regarding their diagnosis, treatments, and prognosis. He does not allude to possible explanations for such behavior such as the influence of person or situation-related variables. In later studies, the behavior of cancer patients indicating need to gain control through seeking information has been reported by Cassileth et al. (1980) and Rotter (1977).

The possible determination of the information seeking behavior and the nature of information sought by cancer patients' personality traits or socioeconomic characteristics are shown by Weisman and Worden (1980). These findings are not totally consistent with the conclusion drawn by Lazarus and Launier (1978), that those typically information seekers or avoiders did not behave as expected, and that factors other than personality traits may influence information seeking behaviors.

There are no studies that had, as their primary aim, the investigation of the nature of information needed by recently diagnosed cancer patients. Information regarding such needs are apparent, however scantily, in the findings of studies related to the general coping behaviors of these patients, reported by Feldman (1978), Greenleigh (1979), Jones (1981), and Weisman and Worden (1980). The analysis of the findings reported in the patients' accounts, often retrospectively, indicates that needs for information during the period soon after their diagnosis fall in four major categories of concerns: disease, personal, family, and social.

## Major Categories of Concerns

*Disease concerns*. The surveys of cancer patients' retrospective accounts of their concerns and needs reveal that the most immediate and pronounced concern after diagnosis was physical survival. Information needs were expressed in four categories: the cancer, the tests, the treatments, and the prognosis. Information relevant to these categories were perceived as inadequate and hindering effective coping (Feldman, 1978; Greenleigh, 1979; Jones, 1981; Weisman & Worden, 1980).

Personal concerns. The concerns related to their psychological and social survival also were pronounced. Information needs were expressed in four categories in terms of the impact of the diasease and/or the treatments on: their physical well-being and ability to function, their psychological well being and emotional stability, their job or career, and plans and goals. Information as to what to expect and how to contend with such concerns also were deemed as inadequate by the patients and contributing to intense emotional and psychological upheaval (Feldman, 1978; Greenleigh, 1979; Jones, 1981; Weisman & Worden, 1980).

Family concerns. The concerns related to the family members or loved ones were perceived as very intense during the period immediately after the diagnosis. Information needs were of four types: the spouse or the significant other, children, parents, and siblings. The impact of the diagnosis on the physical and psychological well being as well as on the economic resources of the family was of great concern. Of major concern also was an inability to communicate with loved ones to alleviate emotions and concerns. Worry about maintaining relationships with loved ones as a result of fears and physical disability were among major concerns. Information about how to cope with then present and anticipated concerns was not provided, which patients perceived as a lack of vital resource to have coped better (Beaudette, 1976; Feldman, 1978; Greenleigh, 1979; Mages & Mendelsohn, 1979; Weisman & Worden, 1980).

*Social concerns*. Concerns about social relationships included worry about communicating and interacting with friends and peers about the diagnosis of cancer. Also, concerns about maintaining affiliations with leisure or special interests such as political, religious, or philanthropic groups were reported, although with lesser emphasis (Derdiarian, 1982). Concern about making new relationships with other patients or families of patients and contacts with health-care resources were mentioned as prevalent soon after the diagnosis. Information regarding these concerns, how to contend with them or prepare to face them, was perceived as lacking.

## Variables Influencing Information Needs

The two types of variables that may influence the nature of information needed are those related to the person and those related to the situation of the diagnosis of cancer. The relationship of both of these types of variables to the nature of information seeking are not well understood. Some findings that support such relationships are presented and are used as the basis for sample selection criteria, as well as for the exploration of whether such variables influence the nature of information sought. Since studies showing the relationship between the person or situation-related variables and the nature of information sought by recently diagnosed cancer patients are scarce, only when possible, such studies will be mentioned.

*Person-related variables*. Several person-related variables are believed to influence information seeking behavior, and perhaps even the nature of information sought in the recently diagnosed cancer patient. Of those, only variables that were examined in previous research and which are pertinent to the study are presented. Their findings were used as the basis of selecting the sample and exploring whether such variables influenced the nature of information needed.

Age and stage of life: The influence of the stage of one's life on coping behavior has gained considerable attention recently. Based on Erikson's (1955) work, Newgarten (1968a), Schain and Gribbin (1975), and others, identified variables specific to the stage of life which may influence the perception, the definition of the situations, and coping behavior. Such differences in coping were shown by Arlin, Binger, Feurerstein, Kushner, Mikkelsen, and Zoger (1969), Eason (1968), Holton, Martin, and Moore (1969), and Schowalter (1970) in their studies of patients after myocardial infarction. The influence of the stage of life variables on the coping behavior have not been studied in cancer patients to an appreciable extent. Some problems related to the particular stages of life of cancer patients were identified by Mages and Mendelsohn (1979). Cassileth et al. (1980a) concluded that younger patients tended to seek more information than the older patients.

Although there are no clear indications of whether the age variable influences the information seeking behavior or the nature of information sought in recently diagnosed cancer patients, the general indications of such a relationship shown in these studies were used as the basis for patient selection criteria as well as the exploratory objectives of the study. It is important, however, that such influences be explored in view of the growing number of older individuals, and thus the growing potential of cancer incidence.

In young adults (19-35), Mages and Mendelsohn (1979) found that cancer impaired the development of self-sufficiency, i.e., it delayed and disrupted efforts to establish independent adult roles such as parent, breadwinner, spouse, or others. Particular strain was imposed on intimate relationships, especially marriages. These findings relate remotely to understanding the relationship of the stage of life variable to the information needs of recently diagnosed young adult cancer patients, because the study did not control for other relevant variables which would possibly explain the findings. Also, these patients had been diagnosed as having cancer for some time. Similar findings were reported by Rosen and Bibring (1966) for this same age group in men with myocardial infarction.

In mid-life adults (36-55), according to Butler (1975a) and Newgarten (1968b), assessment of self-worth in this age group is guaged by career and family-related events. Adult roles are well established and a need to contribute is paramount (Erikson, 1955). In the Mages and Mendelsohn study (1979), it was shown that cancer disrupted the established roles and forshortened the time remaining to complete tasks. This, in turn, intensified concerns about unfulfilled personal, family, and social commitments. The greatest variation in general coping was found in this age group; some patients took events in stride while others were not able to cope at all.

In older adults (56-70), Busse and Pfeiffer (1969), Butler (1975a), Cumming and Henry (1961), and Erikson (1976) documented the several losses that this age group naturally suffers because of failing physical vigor or by increasing social restrictions, which force individuals to become more dependent and withdrawn. Weisman and Worden (1980) showed that, after adjustment for differences of site of cancer, older patients tested with lower ego strength scores on the MMPI, wanted no more information about their condition, and tended not to use the word "cancer" in referring to their disease. Mages and Mendelsohn (1979) found that patients in this age group suffered personal and social losses far more rapidly as a result of cancer. Several retired earlier, disengaged earlier from leisure and social activities, and lost interest in the future more markedly. Their anger reflected their sense of deprivation of enjoyment of a later life they had worked hard to realize. In a case study of a young adult male and an older adult male, both of whom had identical testicular cancer, consequences, and prognosis, Mages and Mendelsohn found that their reactions differed in a way directly related to their respective ages.

Sex: Mages and Mendelsohn (1979) found, in their retrospective as well as prospective studies, that men experienced more negative outcomes than women, regardless of age. Subsequent to the diagnosis and throughout the peak stress periods, men were more fearful, irritable, withdrawn, and blamed others for their distress. Men also were less religious, used more alcohol, and coped with stoic submission at the time soon after diagnosis (Weisman & Worden, 1976). Derdiarian (1982), in a retrospective survey of 163 patients with cancer, found that men reported more decline in their achievement, dependence, aggressiveness, and sexual performance, viewed these changes more negatively, and attached higher importance to them than did women. These findings are compatible with those of Rosen and Bibring (1966), who studied patients with myocardial infarction, who found also that men experienced a greater loss of positive self-regard.

There seems to be a relationship, then, between the variable of gender and the experiences and perceived needs of patients coping with life-threatening illness. It is important to note that these findings only peripherally relate to the dependent variable of this study, insofar as they (a) reflect the experiences of patients later in their illness, and (b) are explained by plausible alternate intervening variables such as site, type, stage of cancer, or other demographic variables which were not controlled.

Marital status: Weisman and Worden (1980) observed that the diagnosis of cancer had generally adverse effects on spouse relationships. Only in a few instances did a weak relationship become stronger; more often they were dissolved. Derdiarian (1982) found that the most affected variables in the marital relationship were sexual desire and ability to perform, and open communication about fears, doubts and feelings. These findings are compatible with those reported by Feldman (1978) and Greenleigh (1979). These and other similar findings related to the impact of cancer on marital or intimate relationships indirectly reflect the fact that the patient's need for information following diagnosis may be determined in part by the patient's marital status as to how the diagnosis may affect it.

Education: The relationship of education to coping behavior with cancer is not well understood. After adjusting for the cancer, newly diagnosed cancer patients (randomly selected) showed differences in coping behavior according to differences in demographic characteristics

(Weisman & Worden, 1980). Those patients of lower socioeconomic status tended to be from larger families, but expected less support from family and friends, compared to the high socioeconomic group. They also were more concerned with problems related to finances and work. They coped with withdrawal more often, experienced poorer resolution of their problems, and felt like giving up more often.

Antonovsky (1979) demonstrated that income influenced medical advice-seeking behavior, whether second opinions were obtained, the search for relevant information, and whether household help or professional counseling was sought. Because education is only one of three indicators of the socioeconomic status index (SES), its relationship to the coping behaviors of cancer patients cannot be discretely discerned from these studies. Although Aday and Eichorn (1972), and Higgins and Pooler (1968) did show that socioeconomic status was a consistent predictor of when heart attack patients return to work: patients with higher socioeconomic status were more likely to seek counseling and education, and so to return to work earlier, these findings do not explain the relationship of education and coping behavior in cancer patients.

The theoretical premise linking education to coping behavior is referred to as cognitive control by Averill (1973), who contends that how one interprets life events depends upon one's ability to process the potentially threatening information so as to reduce the net long-term stress and/or the psychic cost of adaptation. Jones (1981) found that those with better education sought significantly more additional written materials about their condition. Information is required to configure and appraise the problems, their relevance, and solution, and may be sought, obtained, and processed more expeditiously by patients with higher education. It may be seen, then, that the variable of education may influence the information seeking behavior or the nature of information sought. However, in the absence of evidence that other intervening variables were controlled, it is difficult to know this.

Having read about cancer following the diagnosis: This variable is similar to the variable of education in its relationship to the purpose of this study. A clear relationship predicting that those who read about cancer after diagnosis may subsequently need more or less information or appraise their problems differently than those who do not read about their condition is not demonstrated in the literature. It has been shown that some patients do need information about the disease and its consequences, regardless of the fact that they may have received it from health care professionals, other patients, friends or family, or read about it themselves (Mages & Mendelsohn, 1979; Weisman & Worden, 1980). This need is due to the high anxiety and denial that exist following diagnosis which tend to inhibit information from being processed (Cassileth et al., 1980; Horowitz, 1976). Erroneous or insufficient knowledge about cancer obtained from unreliable sources before or after the diagnosis hinders an understanding of the information given. Having read about cancer following diagnosis is a variable that may or may not influence the information-seeking behavior. As such, this variable was used as criterion for sample selection as well as an exploration of whether information needs vary according to it.

Personality differences (traits): Although no clear linkage between personality traits and certain coping modes has been shown in patients coping with illness, it has been shown that patients with high internal locus of control benefit from information sought to gain and maintain control over their situation (Averill, 1973; Krantz & Schultz, 1979). Johnson (1975) found, for instance, that providing patients with information about what sensations to expect from noxious medical procedures reduced the complications of distress. Similarly, Krantz and Schultz (1979) found that providing patients with information about expected symptoms reduced postsurgical complications. Shipley, Butt, and Horowitz (1979) noted that information about noxious medical procedures was beneficial for the patients who typically sought information, but increased anxiety for those who typically avoided it.

Denial/avoidance: These cognitive behaviors can influence the information-seeking behaviors of recently diagnosed cancer patients. Denial and avoidance may exist in the early stage of life-threatening disease (Visotsky, Hamburg, Goss et al., 1961). Avoidance is a conscious effort to set aside, to postpone dealing with a threatening event. Although patients may accept the reality of the harm or threat, they may deliberately avoid thinking or talking about it (Cohen & Lazarus, 1979). Denial is a cognitive process by which the individual selectively misinterprets the facts of a threatening situation (Lipovsky, 1970).

Although studies clarify the influences person-related variables have on the coping behavior of cancer patients, they are not readily generalizable to the recently diagnosed cancer patient. This is because most of the studies involved patients who had lived with cancer for some time, and because they produced data based on retrospective surveys. Moreover, findings do not elucidate whether such variables influence information-seeking modes of coping in the same way that they do coping behavior in general.

Situation-related variables. Time of diagnosis: Determination of the diagnosis marks the first phase of the patient's life after the diagnosis of cancer. This phase is charged with intense anxiety, despair, and the immense burden of decisions to be made and resources to be mobilized. Mages and Mendelsohn (1979) identified the major issue peculiar to this phase as recognition of the disease and its implications, and the major tasks as appraisal of the significance of the discovery and initiation of appropriate treatment. Feldman (1978) found that most patients surveyed indicated that the time of diagnosis was the most intense compared to other major stress periods. Greenleigh (1979), in their survey of cancer patients and families, reported that patients and families identified the diagnosis as the most stressful aspect of cancer. In both studies, fear of the unknown was the prime stressor identified by patients and families alike; and all expressed an insatiable need for information. These findings are compatible with those of other studies, which indicate that one way of coping with this stressor may be information seeking (Hamburg, 1974; Hinton, 1973; Miller, 1977; Peck, 1977; Sensecue, 1963; Shands, 1951, 1966; Sutherland, 1977). It is assumed, then, that the time surrounding the diagnosis may influence the information seeking behavior. What is not clear is the particular influence this time has on the nature of information sought.

Type of cancer: Weisman and Worden (1980) concluded that the single most important factor determining the adjustment a cancer patient must make to the disease is the concrete nature of the cancer. Having studied a random sample of first-time diagnosed patients with modal stage II cancer, at the time of the diagnosis, they observed differences in the amount and frequency of information sought among those with various types of cancer (melanoma, breast, lung, colon, and Hodgkin's disease) in their information-seeking behavior. Patients with colon cancer avoided referring to their disease as cancer, while those with Hodgkin's disease, breast cancer, and melanoma spoke openly and requested as much information as possible. Concern about death, prognosis, treatment, and what events to expect were common to all patients regardless of site or prognosis, and most communicated freely their concerns regardless of the site or the type of cancer. Although the findings of this study indicate that the type of cancer may not influence the need for information, in light of numerous demographic variables as well as personality variables which were not controlled, it may not be concluded that the type of cancer diagnosis may not influence the need for information.

Stage of cancer: Weisman and Worden (1980) reported that patients with more advanced cancer showed more emotional disturbance and less optimism, coped by withdrawal, and behaved generally with more stoicism than those in earlier stages. Mages and Mendelsohn (1979) outlined different demands and strategies found in various stages of the disease. In a longitudinal (two-time interview) study of a group of 31 adult patients, heterogeneous with respect to site of cancer, prognosis, race, and socioeconomic status, they concluded that the patients' efforts to adapt to the disease were determined by the immediate stresses imposed by the particular stage of the disease. Stresses peculiar to each phase differed commensurately with the changes in demands of the disease peculiar to that phase. It may be assumed, then, that although some differences in concerns and, therefore, in information needs, may vary according to the stages of cancer, such an extrapolation is made cautiously, since other intervening variables were not controlled by Mages and Mendelsohn.

Treatment of cancer: Mages and Mendelsohn (1979) discuss the intervening influence treatments may have on information-seeking behaviors of patients. Cancer treatments were found to evoke a need for information with respect to the nature of the treatment, its procedures, physical and psychosocial implications, and effectiveness. Patients perceived several negative possible outcomes associated with cancer treatments. Damage to one's body from treatment which would cause functional impairment and disfigurement, as well as mental and emotional disturbances, were most prominent (Blacker, 1970; Mages & Mendelsohn, 1979; Schoenberg & Carr, 1970).

Patients generally hoped that the initial treatments would eradicate the cancer; they also knew that several years might pass before they could be certain that cancer would not recur. Also, the objectives of the treatments were often not clearly understood, and the effectiveness of the treatments, although hoped, were often tinged with repressed doubt. The information needed about initial treatment included a need to know whether and how effective the initial treatment would be, and whether alternative treatments existed if the primary treatment failed to arrest the cancer (Greenleigh et al., 1979; Mages & Mendelsohn, 1979). It is apparent that although the type, number, and consequences of treatments may influence the information seeking behavior, it is not known, however, whether it or the nature of information sought would be affected by the type or number of treatments.

Time from suspected symptoms to the diagnosis (time lapse): Weisman and Worden (1980) have referred to the time from when symptoms of cancer are first suspected by the individual to the diagnosis as lagtime. In their sample, it averaged 3 to 6 months. Those with a longer lagtime evidenced more emotional and psychological disturbances, such as apprehension, hopelessness, health concerns, guarded expectations, and physical disturbances. Those who delayed seeking medical attention for 3 months expressed greater denial and more optimism than their prognosis warranted. The contention of the authors was that those who denied the symptoms denied the cancer, but their findings did not support this. They indicated no clear relationship between person-related or disease-related salient intervening variables such as the type or site of cancer, prognosis, age, or education to the lagtime.

Time since diagnosis: Because there were no studies that examined the relationship between time since diagnosis and the nature of patient concerns or information needs, it was deemed as important to explore such a relationship here, based on clinical knowledge. Patients seek information, to learn about their condition or to secure support, and those who knew of their diagnosis longer may have gathered more information and support, which may have influenced their needs for information at the time of their interview. Therefore, patients who had known about their diagnosis longer than 17 days were excluded from the study. The exclusion also was based on the fact that most patients undergo treatment of some form after this period of time.

Source of patient referral: There were no studies in the literature showing a difference in the general coping behavior, or in information-seeking behavior, among patients according to the difference in sources of their referral. Because the nature or amount of information sought may be related to the nature and amount of information given at the time of diagnosis, soon after, according to a particular health care facility's patient informing procedures, it was decided to explore whether differences in information needs existed among patients on the basis of their sources of health care.

The findings of these surveys are not directly representative of recently diagnosed cancer patients, but rather of patients in various stages of their illness, and they are based on retrospective accounts and thus their validity and reliability is suspect. However, the findings emphasize that information needed and sought is pervasive and vital in the initial adaptive attempts of cancer patients, and it may play a determinant role in helping the patient to initiate an effective response to living with cancer.

# CHAPTER III

# RESEARCH DESIGN

## Presentation of Design

Three designs were utilized simultaneously in conducting this research: (a) a descriptive survey design was used to describe the nature, scope, and importance of information required by patients recently diagnosed with cancer; (b) a methodological design was employed for the development of an instrument by which to gather essential data to describe the information needs of cancer patients; and (c) an exploratory-comparative design to explore differences in the nature of information needs of patient subgroups stratified according to person-related and situation-related variables. Because the methodological design was required to precede the other two, it is presented first.

### Methodological Design

Rationale. The methodological approach was adopted as the first step of the study because there were no valid, reliable instruments by which to gather data pertaining to the nature, importance and scope of information needs of recently diagnosed cancer patients. The semi-structured interview was chosen as an effective method to help these patients communicate their information needs through a personal medium.

Objectives. The objectives of this design were:

1. to develop the Information Needs Assessment (INA) instrument;
2. to establish the validity and reliability of the instrument;
3. to establish the comprehensiveness of the universe of the INA instrument.

## Descriptive Design

Rationale. The descriptive approach was chosen as the second step of the study to describe the nature, scope, and importance of information needed by the recently diagnosed cancer patient.

Objectives. The objectives of this design were:

1. to produce descriptive data of the nature, importance, and scope of information needs of these patients;
2. to produce comprehensive data of the information needs of these patients;
3. to measure the importance value of information needed by these patients.

## Exploratory-Comparative Design

Rationale. The exploratory-comparative design was chosen as the last step of the study to produce data to explore the differences in information needs and importance values of those needs that may exist among the groups stratified by person-related variables and by situation-related variables.

Objectives. The objectives of this design were:

1. to explore whether there were differences in the information needs of patients stratified according to person-related variables and situation-related variables;
2. to explore whether there were differences in importance value attached to information needs of patients stratified according to person-related variables and situation-related variables.

## Operational Definitions

Appraisal. Theoretically, appraisal is a cognitive process which involves evaluation of the harmful stimulus and the resources which act or have the potential to counteract harm (Arnold, 1968; Lazarus, 1966).

For the purposes of the study, appraisal is defined as the patient's statement indicating a definition of a harm (actual), or a threat (potential harm), or resources (objects or individuals potentially helpful in counteracting harm or threat related to an aspect of one's physical, psychological, emotional, or social well-being). Appraisal of harm, threat, or resources may be in relation to the patient's physical, psychological, and social well-being. Appraisal is indicated by the patient's verbal indication of need for information about harm, threat, or resources in response to the interview items in the four major categories of Disease, Personal, Family, and Social Concerns of the INA instrument.

Harm. Theoretically, harm signifies the actual occurrence of the harm or damage, so it is consequential to the harmful event (Lazarus, 1966).

For purposes of the study, harm is defined as the patient's statement of perceived damage, such as disruption, discontinuity, loss, malfunction, discomfort, or change as having occurred or begun to occur physically or in personal, family, social activities. It will be measured by the frequency count of the patient's verbal response to the interview items of the INA instrument.

Threat. Theoretically, threat is a cognitive response to a perceived harmful event and is distinguished from harm in that it refers to future harm, and is therefore anticipated and consequential to harm, which provides the cues for future harmful consequences (Lazarus, 1966).

For purposes of this study, threat is defined as the patient's perception of anticipated noxious outcomes of cancer, such as damage, disruption, discontinuity, loss, malfunction, discomfort, change, or their noxious effects, likely to occur because of cancer. This perception will be measured by the frequency count of the patient's verbal indication of such anticipated, noxious outcomes, or their noxious effects, in response to the interview items of the INA instrument (Cohen et al., 1979; Mages et al., 1979).

_Concerns_. Theoretically, concerns are indications of perceived harm, actual or potential, in relation to valued objects, persons, motives, abilities, ideas, relationships, and the like (Cohen et al., 1979; Mages et al., 1979; Stewart, 1981; Weisman et al., 1980).

For purposes of the study, concerns is defined as the verbal indications of perceived noxious effects of the disease, such as damage, disruption, discontinuity, loss, malfunction, discomfort, or change as having occurred, or expected to occur, in relation to the patient's health and personal, family, and social activities (Cohen et al., 1979; Mages et al., 1979; Stewart, 1981; Weisman et al., 1980). These indications will be measured by the frequency count of the patient's verbal responses to the interview items.

_Resources_. Theoretically, resources are defined as powers existing within the individual or in the environment which have the potential to counteract harm or threat (Lazarus, 1966).

For purposes of the study, resources are defined here as helpful or potentially helpful abilities (physical, mental, psychological, financial, and social) within the individual, or in the objects, individuals, or agencies in the environment, which when used will minimize, eradicate, prevent, or control harm or threat (Cohen et al., 1979; Lazarus, 1966; White, 1974). These will be measured by the frequency count of the patient's verbal responses to the interview items.

Information. Information means knowledge, factual, theoretical, or experiential, that are relevant to an object or situation (Dodd et al., 1980).

For the purposes of the study, information is defined as the knowledge which the patient seeks to obtain, which may be based on the scientific/technical knowledge or the experience of the physician, the nurse, the other patient, the other(s) in the environment, through which the patient attempts to gain new knowledge, confirm existing knowledge, clarify existing knowledge, in relation to the items, and the like ( Cohen et al., 1979; Janis, 1979; Mages et al., 1979; White, 1974). It will be measured by the frequency count of the patient's verbal response to the interview items.

Need. Theoretically, need is defined as a perceived deficit which is requisite and which behaves as a drive in which, when fulfilled, achieves satisfaction of a goal (Heather, 1955a). In decision-making, need refers to information which is lacking, incomplete, faulty, or distorted (Adler et al., 1979).

For purposes of the study, need is defined as a lack of or incomplete knowledge about cancer or its effects on the personal, family, and social life as perceived by the patient (Beaudette, 1981; Sarna, 1979; Vetesse, 1976). It is the patient's verbal indication wanting knowledge or information not already possessed, confirmation of existing knowledge, clarification of knowledge thought to be inaccurate or incomplete. It will be measured by the frequency count of the patient's verbal response to the interview items.

Source of Information. Theoretically, source of information is defined as the reservoir from which information may be solicited (Festinger, 1957; Osgood et al., 1969).

For purposes of the study, source of information is defined as an individual, such as the physician, the nurse, other professionals, other patients, or other individuals; objects such as books, other literature, video or audio tapes; or agencies such as seminars or groups that provide a source of information (Greenleigh, 1979; Klagsbrun, 1970). It will be indicated by the frequency count of the patient's verbal response to the interview items.

Importance. Theoretically, importance is defined as the value attached to an object determined by the individual according to a desired attribute inherent in the object.

For the purposes of the study, importance is defined as the patient's assigned numerical value attached to the information identified in relation to the items of the INA instrument. The numerical value will be chosen from 0-100.

Disease Concerns (or Cancer-related Issues). Theoretically, cancer concerns or issues are those related to the facts of the diagnosis and treatment of the cancer (Cohen et al., 1979; Mages et al., 1979).

For the purposes of this study, disease issues are defined as the concerns related to the diagnosis, tests, treatments, and prognosis of cancer in relation to which the patient may need information. Information needs related to these concerns will be measured by the frequency count of the patient's verbal response to the items of the major category of Disease Concerns of the INA instrument.

Personal Concerns (or Personal Issues). Theoretically, personal concerns or issues are those related to the impact of cancer on the patient's physical, psychological, and social existence which is interrupted by the occurrence of serious and long-term disease such as cancer. The individual must not only face the illness, but also reorganize life-style, goals, expectations, and values (Cohen et al., 1979; Mages et al., 1979; Moos, 1974).

For the purposes of this study, personal issues are defined as the concerns related to the job or career, plans and goals, physical well-being, and psychological well-being, in relation to which the patient may need information. Information needs related to these concerns will be measured by the frequency count of the patient's verbal response to the items of the major category of Disease Concerns of the INA instrument.

Family Concerns (or Family Issues). Theoretically, family concerns or issues are those related to the impact of cancer on the members of the family which interrupts role performance, communication, relationships, and interactions evolving from one's family roles (Cohen et al., 1979; Hill et al., 1976; Mages et al., 1979).

For the purposes of this study, family issues are defined as the implications of the facts of diagnosis, tests, treatment, and prognosis of cancer for the patient's, the spouse, children, parent(s), and sibling(s), in terms of potential physical and/or psychological and/or financial hardships in relation to which the patient may need information. Information needs related to these concerns will be measured by the frequency count of the patient's verbal response to the items of the major category of Family Concerns of the INA instrument (Cohen et al., 1979; Greenleigh, 1979; Mages et al., 1979).

Social Concerns (or Social Issues). Theoretically, social concerns or issues are those related to the impact of cancer on the patient's social existence which interrupts performance of responsibilities, relationships, and interactions evolving from one's social roles (Cohen et al., 1979; Hill et al., 1976; Mages et al., 1979; Nye, 1976).

For the purposes of this study, social concerns are defined as the implications of the facts of the diagnosis, tests, treatments, and prognosis for the patient's social relationships such as job or career, special interest, leisure, and future relationships in terms of performance in such roles, in relation to which the patients may need information. Information needs related to these needs will be measured by the frequency count of the patient's verbal response to the items of the major category of Social Cocerns of the INA instrument (Feldman, 1978; Greenleigh et al., 1979).

Diagnosis. Diagnosis is a definition by the physician as to the type, site, and extent of cancer. It is referred to by the patients in verbal responses as foci of concern and/or information needs related to any one or more of these aspects of diagnosis.

Tests. Tests are defined as the diagnostic procedures performed to determine the type, site, extent, and stage of the disease; and to determine the suitability of blood, urine, or other body fluids or tissues to receive chemical, radiological, or surgical treatment. These procedures may be radiological, chemical, physical, surgical (biopsy), or a combination. They are referred to by the patient in verbal responses as foci of concern and/or information needs related to any one or more test types, modes, or purposes, or their consequences.

Treatments. These are defined as the prescribed means or agents of therapy, such as chemotherapy, radiation therapy, surgery, immunotherapy or a combination to arrest or eradicate the cancer and/or treat deficiencies in the body such as nutritional aids, pain medications, physical therapy or other related procedures intended to treat or prevent conditions related to the cancer and/or its treatments. These are referred to by the patients in their verbal responses as foci of concerns and/or information needs related to one or more treatments, their induction modes, purposes, or their consequences.

Prognosis. This is defined as a statement of the physician implied in the diagnosis of the disease that refers to the severity of the cancer, based on its type, site, and extent that imply an estimated length of survival time for the patient, and an estimated series of events, and an estimated time frame in which they occur. These will be referred to by the patient in verbal responses as foci of concerns and/or information needs related to one or more of these aspects of prognosis.

<u>Other Aspects of Patient's Disease</u>. These are defined as any aspect of the disease treatment, or other aspects not mentioned by the interview schedule, which the patient deems important to discuss, mention, inquire about, and regarding which the patient may express need for information, confirmation, or any other input, as measured or determined by the patient's verbal responses to the "other" questions of the interview.

<u>Job or Career</u>. These are defined as the activities in which the patient has been involved in earning a living, rendering a service, maintaining a position at work, or building future financial or career security. These are identified by the patient's verbal responses as foci of concerns and/or informational needs related to any one or more of these or the like.

<u>Plans and Goals</u>. These are defined as the aims and strategies to be attained in the near or distant future such as a trip, a hobby, a promotion, obtaining a degree in education, or financial investment, buying a home, getting married, having children, and the like. These are referred to by the patient's verbal responses as foci of concerns and/or information needs related to any one of these or the like.

<u>Physical Well-being</u>. This is defined as the physical comfort, ability, vigor, and function related to physical health necessary to maintain life activities as perceived by the patient. It is referred to by the patient's verbal responses as foci of concern and/or informa-

tion needs about one or more concerns.

Psychological Well-being. This is defined as the mental, i.e., the cognitive, abilities to problem solve, make desisions, maintain emotional stability or control emotional fluctuations. It is referred to by the patient's verbal response expressing concern and/or need for information about any one or more of these or the like.

Other Aspects of Personal Life. These are defined as any aspect of one's personal life related to the above or similar aspects as discussed by the patient in terms of a concern or information needs. They are referred to by the patient's verbal responses as foci of concerns and/or information needs related to any one or more aspects of personal life.

Spouse or Significant Other. This is defined here as the individual with whom one lives, shares experiences, plans and shares activities related to the near or distant future, in whom one confides and finds comfort, trust, physical and psychological support, and for whom one feels love, admiration, respect, and to whom one feels to belong and be committed for long periods of time. It is referred to by patients' verbal responses as foci of concerns and/or information needs related to any one or more of these aspects of one's role and relationship or the like which contribute to such a relationship.

Children. These are defined as the offspring or the adopted children for whom one feels parental responsibilities of providing physical, psychological, emotional, and social necessities for normal growth and development, and with whom one lives or shares space and time or interaction more than casually, and with whom one shares psychological and emotional experiences and for whom one conceives love, sense of belonging, and trust. They are referred to by the patient's verbal responses as foci of concerns and/or information needs about one or more of these aspects of one's role and relationship, or the like which contribute to such a relationship.

Siblings. These are defined as the other individual(s) with whom one shares natural or adopted parent(s), space, experience, time, takes responsibilities related to each other or to their family, and for whom one conceives love, sense of belonging, and trust. They are referred to by the patient's verbal responses as foci of concerns and/or information needs related to one or more of these aspects of one's role and relationship, or the like which contribute to such a relationship.

Parents. They are defined as the adults of whom one is the natural or adopted offspring, with whom one has lived and continues to live in the same locality or through contact by phone, visitation or correspondence, and in whom one invests love, trust, sense of belonging, and on whom one depends for physical, psychological, and social security, support, sustenance and guidance, and for whom one feels physical, psychological, and social responsibility, from whom one receives or expects to receive love, and support (physical, psychological, social), and with whom one is expected to reciprocate these responsibilities and sentiments. These are referred to by the patient's verbal responses as foci of concerns and/or information needs related to any one or more of these aspects of one's role and relationships, and the like which contribute to such a relationship.

Other Aspects of Family Life. These are defined as any aspect of family life related to the above or other categories about which the patient may express concern and/or need for information.

Job or Career-Related Relationships. These are defined as the regular and frequent interaction with individuals with whom one works to earn monetary reward, or engages in activities leading to achievement of common job or career goals, with whom one feels alliance, comradery, and peer relationship. These are referred to by the patient's verbal responses as foci of concerns and/or needs for information related to any one or more of these aspects of such relationships and the like which contribute to such relationships.

Special Interest Group Relationships. These are defined as the regular and frequent interaction with individuals with whom one works to achieve common goals that are relatively short-term compared to career or job relationships, requiring less sharing of time, space, and experience, such as political, religious, philanthropic, committee or task force, or similar associations. These are referred to by the patient's verbal responses as foci of concerns and/or information needs related to one or more of these aspects of such relationships and the like which contribute to such relationships.

Leisure Group Relationships. These are defined as the relatively regular and frequent interaction with individuals with whom one aims at achieving leisure, relaxation, and other goals not demanded for purposes other than pleasure or relaxation, such as hobbies, games, sports, fishing, expeditions, exercise, attending movies, plays, concerts, restaurants, cooking, sewing, painting, and the like. These are referred to by the patient's verbal responses as foci of concerns and/or information needs related to any one or more of these aspects of such relationships and the like that contribute to such relationships.

New Group Relationships. These are defined as the development of relationships with groups to whom one did not previously belong. The intent of such relationships emanates from needs, interests, goals one did not have before and which are now strong enough to move the individual toward seeking such relationships for the purposes of (a) sharing knowledge, experience, feelings; (b) reciprocating help in problem-solving, physical tasks and other such activities; (c) sharing the sense of belonging to such groups for support, and group goals. These are referred to by the patient's verbal responses as foci of concerns and/or information needs related to one or more of these aspects of such relationships.

Other Group Relationships. These are defined as any other frequent interaction with other(s) related to any one of the group relationship categories mentioned above, or related to an aspect of social life which the patient recognizes as part of her/his social life and social support system not mentioned in the interview. These will be referred to by the patient's verbal responses as foci of concerns and/or information needs related to any one or more such relationships.

The foregoing definitions formed the basis for the derivation of categories, subcategories, and items (smaller categories) according to which the patients' responses were analyzed and classified.

## Assumptions

There are two types of assumptions necessary to describe the information needs of recently diagnosed cancer patients: theoretical and methodological.

### Theoretical

Recently diagnosed cancer patients perceive the diagnosis and its many implications as threatening to their physical, personal, family, and social lives; they perceive the diagnosis as a novel, unfamiliar, and threatening event that imposes a need to appraise and problem-solve; and they perceive a need for information to be able to appraise and problem-solve. Patients seek information as an early attempt to appraise and cope with the threats imposed by the diagnosis of cancer.

### Methodological

Because of the lack of data pertaining to the reliability and comprehensiveness of the INA instrument, some methodological assumptions were made: patients are able to respond accurately and unbiased to the interview questions; the information needs of these patients are probably similar to the information needs of other recently diagnosed cancer patients not included in this sample; the INA instrument interview elicits information needs of recently diagnosed cancer patients without unduly biasing their responses.

## Limitations

Limitations of the investigation are also of two kinds: theoretical and methodological.

### Theoretical

Because of the lack of prospective data pertaining to the response behavior of the patient during the period 1-17 days, some theoretical limitations are considered. Recently diagnosed cancer patients may find the task of thinking and responding about their needs for information psychologically and emotionally taxing, and, therefore, not of priority during the 1-17 days postdiagnosis. The patients may prefer to cope with their perceived threats through other means, such as denying, postponing to learn, or to find out, completely trusting the decisions of others on their behalf, intentionally withdrawing from reality, and the like.

### Methodological

Because of the lack of data pertaining to the reliability and comprehensiveness of the INA instrument, and that random selection of the sample was prohibited, some methodological limitations were considered. The size of the sample limits the statistical interpretation of the data pertaining to the described differences in information needs and their importance among groups stratified according to demographic variables chosen to analyze such descriptive differences. Although all eligible patients were recruited to participate, the sample tended to represent one major comprehensive cancer center that attracts certain types of cancers, based on medical expertise and research protocols. This poses limitations to the generalizability of the findings to recently diagnosed cancer patients not represented in this sample.

Although all eligible patients were recruited to participate, due to the sources of patients and due to high incidence of melanoma in the Southern California region, the large number of melanoma patients in the sample poses limitations to the generalizability of the findings to recently diagnosed cancer patients not represented in this sample. The necessity to limit the test-retest reliability of the interview questions of one major category per patient poses limitations to the generalizability of the findings concerning the reliability of the Information Needs Assessment research instrument, even though high statistical values indicating high test-retest reliability of the items of the instrument were achieved.

# CHAPTER IV

# METHODOLOGY

## Sample

A nonprobability sample of 60 patients, homogeneous in characteristics as defined in the selection criteria, was drawn from a variety of sources. Physician unwillingness to allow contact of recently diagnosed cancer patients during such a sensitive time as well as the projected number of new cancer patients in the 6 to 12 months during data gathering, made the random selection of the sample impracticel.

### Sample Selection Criteria

Derived from a review of the literature and from the researcher's expertise in the theoretical and clinical knowledge underlying the objectives, the sample selection criteria were that the patients in the sample:

1. be 18 to 70 years of age;
2. have been diagnosed with cancer for the first time, aware of the diagnosis, and within 1-15 days post-diagnosis, at the time of interview;
3. not be confronting medical, surgical, or radiation intervention that would necessitate exploratory surgery, amputation of limb(s), breast(s) or testicles, or cause removal of large masses of muscle, bone, or skin tissue which would cause extensive visible disfigurement;
4. not have cancers in a terminal stage;
5. not have documented psychiatric or central nervous problems that would affect cognitive or speech processes;

6. not have experienced any unusually stressful event(s) in their lives or in those of their loved ones, during the 6 to 12 months before diagnosis; these could include death, serious physical or mental illness, major medical or surgical intervention, divorce or separation, accident, loss of job, immigrated to the United States for residence or for treatment, or facing such events; or serious, life-threatening medical problems;
7. be conversant in English, and willing to participate in the study.

## Sample Description

The actual data collection period was 12 1/2 months. The sample was drawn from the greater Los Angeles area. Thirty-one (52%) of the patients were males and 29 (48%) were females. Ages ranged from 18 to 70 years; the median age was 42 years. The age distribution of the sample, following Newgarten's (1968a) developmental stages, was as follows: 18 (30%) young adults (18-35 years of age); 30 (50%) adults (36-55 years of age); and 12 (20%) were older adults (56-70 years of age). Forty-one (68%) of the sample were married; 9 (15%) were widowed, separated, or divorced; and 10 (17%) were single. The mean education level was 16 years. Seventeen (28%) had obtained high school or equivalent diplomas; 26 (44%) had obtained associate or baccalaureate degrees; 11 (15%) a master's degree; and 6 (10%) the doctorate or an equivalent professional degree (Table 1).

The ethnic makeup of the sample was predominantly white: 58 (97%) were Caucasian; 2 (3%) were Hispanic women born in the United States and comparable to the other subjects (in socioeconomic variables). Forty-eight (80%) of the patients were employed; 2 (3%) had been unemployed longer than 6 months; and 10 (17%) were retired. Twenty-two (37%) of the patients had read about their cancer after diagnosis (Table 1).

Forty-one (70%) of the patients lived with their spouses or with significant others. Forty (69%) had one or more children; 42 (70%) had one or more siblings; and 38 (63%) had one or both parents still living. Socially, 50 (83%) reported job or career peer relationships; 19 (31%) special interest group memberships; and 26 (43%) relationships with others in frequent, ongoing leisure activities. Thirty-six (60%) of the patients indicated religious beliefs and practices to be very important, 13 (22%) somewhat important, 10 (17%) not very important, and 1 (<1%) not at all important (Table 3).

Almost half (29, 48%) of the patients had melanoma; 24 (40%) had solid tumors (cancer of the colon 1, kidney 2, bladder 1, scrotum 1, squamous cell carcinoma of the neck 1, basal cell carcinoma of the lung 1, sarcoma 4, and fibrosarcoma 1, stomach 1, bile duct 1, pancreas 1, breast 6, bone 3); seven patients (8%) had cancer of hematopoetic origins (non-Hodgkins lymphoma 3, acute myelocytic leukemia 2, chronic leukemia 1). Twenty-three (38%) patients had local cancer; 23 (38%) regional cancer; and 14 (22%) disseminated (but nonterminal) cancer. More than half (37, 62%) of the patients awaited surgery; 22 (36%) chemotherapy; and 1 (1.6%) radiation therapy as initial, primary mode of medical intervention plan (Table 2).

The length of time from diagnosis to interview ranged from 1 to 17 days with a median of 12 days. Twenty-four (40%) patients were interviewed 1 to 6 days post-diagnosis; 27 (45%) 7 to 12 days post diagnosis; and 7 (11%) 13 to 15 days post diagnosis, and 2 (3.3%) patients 17 days post diagnosis. The last two patients were interviewed later than 1-15 days period because of a discrepancy between the time of diagnosis indicated in the chart and the actual time of the diagnosis. These patients had consented to the interview before the discrepancy was discovered, and thus were included in the sample (Table 2).

The lapse of time from the first awareness of signs or symptoms of cancer and the seeking of medical attention ranged from 1 week to as long as 2+ years; the median time lapse was 14 weeks. Before seeking medical attention, 13 patients (22%) had waited approximately 1 to 2 weeks; 9 (12%) 2 to 4 weeks; 5 (8%) 4 to 12 weeks; 13 (22%) 13 to 26 weeks, and 20 (33%) had waited 16 to 2+ years (Table 2).

The self-ratings of health status ranged from excellent to poor. At the time of the interview, 23 (39%) patients rated their health as "excellent," 30 (51%) as "good," 3 (7%) as "fair," and 4 (3.5%) as "poor."

All possible attempts were made to draw as many subjects as possible from a variety of facilities. The majority (50, 83%) of the patients were drawn from one major comprehensive cancer center; 8 (13%) from oncologists in private practice; and 2 (3%) from health maintenance organization (HMO) clinics. All potentially eligible patients were contacted and screened by the researcher and the interview team (Table 2).

## Setting

The setting for the study included the clinic, the inpatient section of the health care facilities, and the home or office of the patient. These settings were chosen by the patient for convenience, and to ensure patient comfort and confidentiality. Thirty-one (52%) interviews took place in the hospital either in the patient's room or in a private office on the same hospital floor; 13 (21%) at the patient's home; 9 (15%) in a hospital clinic, and 7 (12%) at the patient's place of work. The interviews were private and uninterrupted, except in two instances when they were interrupted briefly to allow medical residents to converse with the patient.

All health care facilities had similar routines in informing the patients and their families of diagnosis, treatment modalities, and prognosis. None had systematic patient teaching or counseling protocols following the diagnosis. Nor did they have formal support group referral schedules for patients or families, or a system of patient referrals for such groups. All of the patients had met with their physician at least twice at the time of the interview. All of the patients had been informed of their diagnoses, recommended primary treatment modalities, and (except for one patient) prognosis of their disease. All had undergone diagnostic test(s).

## Data Collection Procedures

### Patient Recruitment

Following approval by the Human Subject Use Committee at the University of California at San Francisco and University of California at Los Angeles, and by facilities and physicians willing to participate, the interviewers called facilities to inquire about eligible patients. One of the team members was kept "on call" throughout the data collection period, and an answering machine attached to the researcher's home phone to increase access to all potentially eligible patients. Once a patient was reported, one of the interviewers screened the patient's record to evaluate eligibility and obtain the consent of the physician in charge. The patient was then contacted by phone and informed of the study based on a standardized information form. The patients were asked whether they would be interested in participating, and were given a day to think about the proposal if a definite response was not initially volunteered. Once a decision had been made to participate, the time and place of interview were arranged.

### Administration of Interview

Following an introduction, the purpose of the study and standardized instructions for patient and interviewer conduct during the interview was given, a consent form was read and signed. The interview proceeded and was taped, except when the patient was emotional or needed to express feelings privately or to rest. Patient inquiries regarding the questions were dealt with according to standardized procedures. Following the interview, the patient was asked whether additional questions could be posed. If there was agreement, the retest major category was administered following a short break (15-20 minutes). The patient had no knowledge of this retest before the interview to prevent response bias and to give the interviewer an opportunity to assess whether the patient would be able to be retested.

## Instruments

The Demographic Information (DI) instrument is an interview schedule designed to produce demographic data needed for sample screening and data analysis. It consists of 20 fixed-alternative and open-ended items which were constructed on the basis of review of the literature, and it was administered with the INA. The Information Needs Assessment (INA) instrument, a semistructured interview schedule was developed to produce necessary data. Its structure and content derive from the theoretical framework and the review of the literature.

### Development

Interview schedules are scientific measuring instruments (Kerlinger, 1983), therefore the INA instrument was developed methodically to produce patient responses to carefully contrived questions which could then be translated into measures of variables. The INA was subject to the same criteria of validity, reliability, and objectivity as other measuring instruments. By means of a thorough review of the literature on the information needs of cancer patients, a universe of categories was derived: Disease Concerns, Personal Concerns, Family Concerns, and Social Concerns. Each major category, in turn, contained four subcategories and an "other" category to capture any patient information need that are not elicited by the existing categories. There were, thus, 20 categories in all. All these categories were defined in operational terms that formed the basis for constructing the items in the INA interview instrument.

A set of 7 open-ended items per category were formulated which were scheduled in funnel form, a design that guides the patient's responses from broad to progressively more specific content subject to the inquiry (Kerlinger, 1983). Each of the four major categories of the INA instrument comprised 35 items. Item 1 inquired whether the patient was told about the category in question, and item 2 whether or not the information provided was adequate. The patient's response then would be categorized as "yes," "no," or "not applicable." Item 3 inquired whether the patient had a main concern about the category in question, to which the patient would respond "yes" or "no." If yes, then item 4 required that the patient disclose the main concern. Item 5 asked whether information was needed in relation to the concern, and item 6 required that the patient disclose the information needed.

Although not directly related to the research question, it was thought important to determine which source(s) the patients perceived as desired type of information needed. Such descriptive data would form the basis for hypotheses pertaining to the relationship between the nature of information needed and the source(s) of that information. Owing to the consideration that the source of information is tangentially related to the research question, it was decided, with guidance from the Chairperson of the Dissertation Committee, that that inquiry be conducted at a later time.

Because it was important to measure the relative importance of all the information needed in all the categories, a question was formulated that required the patient to attach a relative value, on a scale of 0 to 100, to each category where information was needed, so that all 100 points could be used to evaluate the categories in a major category. The question was repeated at the end of all four major categories in the instrument. Altogether, then, the INA instrument contained 144 items. The design and items of the instrument are provided in the Appendix.

### Validity

The validity of the DI instrument was established by means of the face validity approach (Kerlinger, 1983). Three experts were given the objectives of the instrument, its theoretical framework, a summary of the review of the literature, and the items of the instrument. They were asked to judge (1) whether the items would produce data the researcher assumed, and whether the items were adequate to produce the amount of data the researcher needed in relation to the objectives of the instrument. It was predicted by the researcher that 100% agreement among the panel members would be reached.

The validity of the INA instrument was to be established by means of content validity approach (Kerlinger, 1983). Three experts (two faculty members in a cancer nursing graduate program in a university school of nursing and a doctoral student in nursing comprised the panel) were chosen on the basis of their expertise on the theoretical and clinical substance underlying the study and the instruments, instrument development methods, and research methods, and content analysis. The members were given the theoretical framework, the operational definitions of the categories, and the INA instrument, and were asked to evaluate, independently, whether the operational definitions and the categories were derived from the theoretical framework, whether the instrument items were derived from the operational definitions and the categories, and whether the universe of the items was comprehensive.

It was predicted by the researcher that there would be 80% or more agreement among the three members in all four major categories that (1) the operational definitions and categories reflected the theoretical framework, (2) the items of the instrument reflected the operational definitions and categories, and (3) the universe of the instrument items was comprehensive.

## Validity of Content Analysis Categories

The panel members were given the theoretical framework, the operational definitions of the major categories, and the categories generated from the content of the responses of the first ten interview transcripts analyzed by the researcher. They were asked to judge, independently, whether the generated subcategories and their operational definitions were compatible with the operational definitions of the existing categories and of the major categories, and the theoretical framework. This step was necessary, as a review of the literature pertaining to this population yielded inadequate information and theory from which the smaller categories (or units of analysis) necessary to analyze the content of the data could have been identified and operationally defined in advance.

It was predicted by the researcher that there would be 80% or more agreement among the 3 members that the subcategories generated from the content analysis and their definitions were compatible with the definitions of the major categories and the theoretical framework.

### Comprehensiveness

The comprehensiveness of the DI and INA instrument was measured by the percentage of agreement among the three experts, the minimum-maximum response frequency count (to the categories and subcategories of items generated by the instrument) (pre-data collection) and by those generated by content analysis (post-data collection), and the analysis of the patient responses elicited by the "other" category.

It was predicted by the researcher that: there would be 80% and more agreement among the panel members that the categories of questions represented a comprehensive universe; all categories of the instrument would elicit a minimum number of responses greater than zero (n = 60); and all responses elicited by the "other" category questions would be classified, by content analysis, under existing categories, and the generation of new categories or subcategories of questions would not be needed.

### Reliability

The reliability of the INA instrument was established by the test-retest approach. The researcher's prediction, based on clinical knowledge of the population, was that the highly intense emotional experience of the patient immediately following diagnosis would preclude any other approach to reliability evaluation. The alternate-form, split-half, and even test-retest of each of the 144 items of the instrument were considered too taxing for the patients, and likely to have increased the probability of confounding the validity and reliability of the data. Instead, one major category items (n = 36) per interview was to be tested. A random permutation schedule was computed, assigning the retest of one major category per interview instrument. The instruments forms were coded and later attached to the retest category according to the permutation, so that the interviewer could not influence the match between the retest component and the patient.

It was expected by the researcher that there would be no significant difference ($p<.05$) between test and retest counts of responses to the INA items, using the McNemar test of symmetry.

Interrater (Interviewer) Reliability

Five primary (including the researcher) and three secondary interviewers were trained to administer the two interview protocols. The secondary interviewers interviewed patients if the primary interviewers could not be present. There was 94% agreement among the researcher and seven other interviewers on interview procedures, based on a standardized evaluation form. This form included scaled criteria as to the introduction procedure, explaining the purpose of the study and instructing the patient; the style of interaction, measured on a scaled continuum of "extreme friendliness" to "extreme formality"; and procedures to safeguard and handle the patient's emotional expressions and questions about the interview. Interrater reliability was maintained by regularly reviewing randomly selected interviewer tapes and by independent reviewer evalution, based on the criteria used for training. The reliability percentage of agreement ranged from 90% to 96% throughout the data collection period.

### Intercoder Reliability

All operational terms were assigned codes. Two coders worked with the researcher to perfect and systematize the coding practices. The three independently coded several transcriptions until there was more than 90% intercoder reliability. The researcher coded all of the patient responses accordingly. One interview out of every subsequent group of 10 was randomly selected and coded independently by the other two coders to evaluate the researcher's intracoder reliability. At the end of the 60 interviews, 10% of the interviews were coded to maintain the intracoder reliability (Klippindorf, 1980).

It was predicted by the researcher that there would be agreement among the three coders of six interviews, at the level of $p<.05$, using the Derdiarian-Lewis binomial test of proportions of agreements.

### Intracoder Reliability

The intracoder reliability was measured in another way as well. Six randomly selected transcriptions were coded twice by the researcher at 8 to 10 week intervals to secure intracoder reliability on a "constant" content. This measure checked the potential of research bias induced by interpatient variance of responses. It was predicted by the researcher that there would be 80% or more agreement between coded data #1 and coded data #2 for all 6 sets of data.

## Scoring

All interview tapes were coded to maintain confidentiality and the transcriptions were made by an expert in research transcriptions. Frequency counts of responses were classified according to the operational definitions of the categories and subcategories. Each response was given a count of 1, even if it was repeated during the interview. An aggregate count of similar responses from individual respondents, with 1 count per response per respondent, was produced for each subcategory, category, and major category to produce categorical quantifiable data. The responses indicating the relative importance value (0-100) were treated as continuous data and mean scores (X) were computed for each category.

## Data Analysis

### Pertaining to Instruments

Percent agreements among the three judges were computed to evaluate the face validity of the DI instrument, intercoder reliability in classifying the sample according to relevant demographic variables, and the intercoder reliability of the DI instrument.

McNemar's chi square (Test of Symmetry) statistics were used to estimate the test-retest reliability of the instrument. Where observations were less than cells, percent agreements were computed. Paired T-test statistics were used to test the test-retest reliability of the importance value items of the INA instrument.

To estimate the intracoder reliability, a binomial distribution of proportion of agreements test was designed to evaluate the proportion rather than the percent of agreements as a basis for a stronger confidence that the probabilities of successful agreement was not due to chance. This measure was chosen to eliminate the probability that the researcher (intracoder) agreement was not based on common biases. A description of the theory and procedure is presented in the Appendix. All statistical analysis values mentioned before were estimated on the major category, category, and subcategory levels for detailed analysis of the data.

### Pertaining to Research Objectives

Frequency distributions were computed to describe the sample according to demographic variables and to describe the patients' needs for information in respective categories. Mean scores (X) were computed to describe the relative importance value attached to information needs in respective categories. Pearson chi square statistics were used to describe significant differences among subgroups stratified according to the variables relevant to the study. Fisher Exact test (1-tail) statistics were used to describe significant differences among subgroups where sample sizes were small. Two-Group T-test (Levene) statistics were used to describe significant differences in the importance value attached to information in categories among subgroups stratified according to the variables relevant to the study.

## Pilot Testing

After the INA instrument was constructed, its content validity established, and inter-interviewer reliability training completed, the study was pilot tested using 4 male and 4 female patients who were diagnosed as having cancer 3 to 7 days prior to the interview. Observations were recorded with regard to patients' emotional reactions, endurance, and comments about the value of the interview, patients' observations about the interview questions in terms of clarity, relevance, sequence, comprehensiveness, and retesting, and interviewer procedure.

Outcomes indicated that the patients experienced common but sporadic reactions to certain question areas, but they were not specific to any one area. The questions were viewed as clear, relevant, well-sequenced, comprehensive, thought-provoking, and helpful. The patients' endurance span was about 45-50 minutes of interview time; all eight felt that the interview was very relevant and wished to have had the opportunity to participate earlier. Retesting of the items on even one major component was perceived as demanding, both in terms of endurance and time. Interviewers found the experience rewarding but emotionally taxing, and agreed that retesting of the entire interview would not be appropriate. Interviews used for pilot testing were not included in the sample analyzed for the study.

# CHAPTER V

# RESULTS

Results of the study are presented in the order of the data collection process. Data are presented pertaining to patient participation, the instruments, information needs and their importance values, and exploratory comparisons of information needs among groups described by person and situation-related variables.

Because it was not possible to present all of the data in tabular form, much of it is being presented in the body of the chapter. Therefore, the reader is forewarned that this presentation is tedious and long, and that close examination of this presentation perhaps should be directed to portions that are of particular interest to the reader.

## Results Pertaining to Patient Participation

Data were gathered from 60 patients over a period of 12 1/2 months. All patients completing the 45-minute interview expressed positive comments about it. Fifty-one wished that such interviews were done routinely as soon as possible after diagnosis of cancer. Thirty-two patients expressed the wish that their family members, or loved ones, and business associates be given the opportunity to express their information needs.

The number of patients who participated in the retest was smaller than the number designated according to the permutation schedule. The number of patients scheduled for retest and the number actually retested were as follows: Disease Concerns, 17 of 17 patients; Personal Concerns, 16 of 16 patients; Family Concerns, 9 of 14 patients; and Social Concerns, 13 of 13 patients. In the major category of Family Concerns, four patients refused to be retested because of emotional responses in discussing their loved ones, one patient was not retested because the interviewer determined that the patient was having difficulty maintaining emotional control and showed signs of fatigue.

## Results Pertaining to Instruments

### Validity

One hundred percent agreement was achieved among the judge panel members that the DI instrument would produce demographic data pertinent to the objectives of the study. One discrepancy was found in the operational definition and in an item of the INA instrument in the major category of Social Relationships. Following the revision and resubmission of the item, 100% agreement was reached that the items and the categories of the INA instrument reflected the operational definitions and the theoretical framework (Table 4).

### Validity of Content Analysis Categories

One hundred percent agreement was reached among the panel members judging that the subcategories which emerged in some major categories, based on the content analysis of the ten interviews, were consistent with the operational definitions and the theoretical frameworks (Table 5).

### Comprehensiveness

One hundred percent agreement was reached among the judge panel members that the DI instrument was comprehensive in its universe to produce data relevant to the objectives of the study. The comprehensiveness of the INA instrument was also supported based on the results of the evaluation designs that there were no patient responses to the "other" categories of the major categories of the instrument, and all categories defined within the major categories of the instrument elicited a minimum number of responses greater than zero (0). The range of response counts per single item was 3 to 39 (Table 9).

Reliability of Information Needs

The results of the McNemar Test of Agreement (Symmetry) indicated, overall, a high test-retest reliability of responses to the items of the INA instrument, in the categories measured. Also, estimated percent values of agreement between test-retest response counts to items, when observations were less than cells, indicated a strong agreement between their respective items. Summaries of the test outcomes are presented in Tables 6 and 6a.

Disease concerns. The McNemar test-retest agreement values ranged from 68% ($p< .001$) to 100% ($p< 1.00$). Significance of agreement in responses was obtained at varying degrees: 44% of test-retest items achieved 100% ($p< 1.00$) agreement; 34% achieved 94% ($p< .37$) agreement; 13% achieved 88% ($p< .14$) agreement; and 4% (1 item) achieved 68% ($p< .001$) agreement. Four percent (1 item) of items achieved 100% agreement when observations were less than the cells.

Personal concerns. The McNemar test-retest agreement values ranged from 80% ($p< .100$) to 100% ($p< 1.00$). Significance of agreement was obtained at varying degrees: 45% of test-retest items achieved 100% ($p< 1.00$) agreement; 25% achieved 94% ($p< .37$) agreement; 4% achieved 88% ($p< .14$); 4% achieved 82% ($p< .05$); and 4% achieved 80% ($p< .01$). Seven percent achieved 100% agreement; 4% achieved 88%

agreement; 4% achieved 86% agreement when observations were less than cells.

Family concerns. The McNemar test-retest agreement values ranged from 88% (p< .14) to 100% (p< 1.00). Significance of agreement in responses was obtained at varying degrees: 58% of test-retest items achieved 100% (p< 1.00) agreement; 23% achieved 94% agreement; and 6% achieved 88% agreement. Seven percent achieved 100% agreement; 3% achieved 88% agreement; and 3% achieved 86% agreement, when observations were less than cells.

Social concerns. The McNemar test-retest agreement values ranged from 88% (p< .14) to 100% (p< 1.00). Significance of agreement in responses was obtained at varying degrees: 65% of test-retest items achieved 100% agreement; 20% achieved 94% agreement; and 15% achieved 88% agreement. Three percent achieved 100% agreement when observations were less than the cells.

### Reliability of Importance Value Items

Disease concerns. The results of t-tests indicated significant differences in the test-retest importance value scores attached to the category of Prognosis Concerns (p< .03). There were no significant differences in the test and retest importance value scores attached to categories of Diagnosis, Test(s), and Treatment(s) Concerns. Thus, the findings supported a high degree of reliability reflected in the items of the INA in these three categories.

Personal concerns. The results of t-tests indicated no significant differences in the test and retest importance value scores attached to the categories of Job/Career, Plans/Goals, Physical Well-being, and Psychological Well-being Concerns in the major category of Personal Concerns. The findings support a high reliability reflected in the items of INA instrument in all four categories of this major category.

Family concerns. The results of t-tests showed a significant difference ($p < .04$) in the test and retest importance value scores attached to the category of Spouse Concerns. The findings supported a high degree of reliability of items of the INA in the remaining categories of Children, Parent(s), and Sibling(s) Concerns in which the t-test results showed no significant differences of test and retest importance value scores attached to these categories.

Social concerns. The results of t-tests indicated no significant differences in the test and retest importance value scores attached to the categories of Job/Career Relationship, Special Interest Group Relationship, Leisure Group Relationship, and Future Relationship Concerns, which supported a high degree of reliability reflected in the items of the INA instrument in the major category of Social Concerns was fully supported by the findings (Table 6b).

## Intercoder Reliability

The results of the Derdiarian-Lewis (1983) binomial test of proportion of agreement indicated a high intercoder reliability among the three coders. A summary of test outcomes is presented in Table 7.

Disease concerns. A total of 56 items were coded in this category. The Derdiarian-Lewis binomial proportion of agreement test values ranged from 83% ($p < .004$) to 100% ($p < .0002$). Significance of agreement was obtained at varying degrees: 71% of items achieved 100%

(p< .0002) agreement; 31% of items achieved 83.3% agreement.

Personal concerns. A total of 56 items were coded in this category. The Derdiarian-Lewis test values ranged from 67% (p< .03) to 100% (p< .0002). Significance of agreement was obtained at varying degrees: 74% of items achieved 100% (p< .0002) agreement; 20% of items achieved 83.3% (p< .004) agreement; 5% of items achieved 80% (p< .02) agreement; 2% or one item achieved 67% (p< .04) agreement.

Family concerns. A total of 82 items were coded in this category. The Derdiarian-Lewis test values ranged from 67% (p< .04) to 100% (p< .0002). Significance of agreement was obtained at varying degrees: 92% of items achieved 100% (p< .0002) agreement; 2% of items achieved 83% (p< .004) agreement; 2% of items achieved 80% (p< .02) agreement; 2% of items achieved 75% (p< .03) agreement; and 1% or one item achieved 67% (p< .05) agreement.

Social concerns. A total of 57 items were coded in this category. The Derdiarian-Lewis binomial proportion of agreement test values ranged from 83.3% (p< .004) to 100% (p< .0002). Significance of agreement was achieved at varying degrees: 89% of items achieved 100% (p< .0002) agreement; 11% of items achieved 83.3% (p< .004) agreement.

## Intracoder reliability

The percent agreement achieved between first and second time coding of six randomly selected interviews by the researcher indicated 98.3% overall agreement. The percent agreements reached in recoded patient responses in four major categories were: patient #1 = 100%; patient #2 = 97.5%; patient #3 = 98%; patient #4 = 99.5%; patient #5 = 98.5%; and patient #6 = 98.5%. Data are presented in Table 8.

## Results Pertaining to Information Needs

Patient responses indicated needs for information about cancer related to the items, subcategories, and categories were obtained within the major categories of Disease Concerns, Personal Concerns, Family Concerns, and Social Concerns. These responses indicated needs for information in relation to harm, threat, and resources associated with the four major categories.

Description of the patient responses follows a consistent pattern of presentation. An overview of the major category presented is given according to the relative magnitudes of response counts in the major categories of the universe. Next, each category is introduced with an overview of its relative rank in magnitude of response counts in relation to the other categories within the major category of concerns. Lastly, the description of information needed in relation to the subcategories and their items is presented. All percent expressions of response counts have been computed based on 60 (n = 60) to express their relative magnitude of response counts. Exceptions are noted. The response frequency counts are presented in aggregate form except for response counts to the items.

### Disease Concerns (Major Category)

This consisted of four categories, 11 subcategories, and 31 items. The (overall) category aggregate response counts ranged from 33 to 54; the subcategory response counts ranged from 17 to 54, and the item response counts 6 to 39. This major category ranked first among the four in the universe in magnitude of response counts shown in the ranges of category and subcategory response counts. The high counts were seen primarily in the categories of Treatment Concerns and Prognosis Concerns (Tables 9, 9a and 9b).

Diagnosis concerns. This category consisted of 3 subcategories and 8 items. Forty-eight (80%) responses indicated a need for information in one or more subcategory(ies), ranking second in magnitude among the four in this major category. The subcategory response counts ranged from 17 to 39, and the item response counts 6 to 33 (Tables 9, 9a and 9b).

Thirty-nine (65%) (the highest subcategory) responses indicated need for information about the nature of cancer in terms of the type (22, 37%), site (9, 15%), and arrestibility (27, 45%). Thirty-eight (63%) patient responses showed need for information related to the extent (24, 40%), and the meaning of the stage of their cancer. Seventeen (28%) responses indicated need to know whether some suspected factor, e.g., biological (heredity) (9, 15%), behavioral (habits) (10, 16%), and environmental (work, air pollution) (6, 10%), may have caused their cancer (Tables 9, 9a and 9b).

Test concerns. This category consisted of 3 subcategories and 8 items. Thirty-three (55%) patients indicated need for information in one or more subcategory(ies), ranking fourth (least) in magnitude among the four in this major category. The subcategory response counts ranged from 21 to 25, and the item response counts 6 to 20 (Tables 9, 9a and 9b).

Twenty-five (42%) responses indicated a need for information about the nature of the test(s) regarding type (19, 32%), purpose (18, 30%), and procedures (16, 27%). Twenty-eight (47%) responses indicated a need to know about accuracy of the results of the test(s), their implications for treatment(s), and recurrance (20, 33%). Relatively fewer (21, 35%) responses indicated a need for information about the unintended consequences of test(s) such as pain (6, 10%), loss of tissue (6, 10%), and loss of physical and/or physiological function (9, 15%) (Tables 9, 9a and 9b).

Treatment(s) concerns. This category consisted of 3 subcategories and 10 items. Fifty-four (90%) patients indicated need for information related to one or more subcategory(ies), ranking first in magnitude (the second highest) among the four in this major category. The subcategory response counts ranged from 37 to 54, and the item response counts 4 to 39 (Tables 9, 9a and 9b).

Thirty-seven (62%) of the responses revealed a need for information related to the nature of the anticipated treatment(s) such as type (20, 33%), purpose (14, 23%), procedures (19, 32%), whether the treatment would be experimental (4, 7%), and whether adjuvant treatments would be necessary (24, 40%). Forty-six (77%) responses indicated a need for information related to the results (intended outcomes) of the treatments such as treatment effectiveness (38, 63%), alternate treatments if the initial attempts failed (22, 37%), and treatment means to control the symptoms following the disease progress and/or the treatments (14, 23%). Fifty-four (90%) responses indicated a need for information about the unintended outcomes such as physical (39, 69%) and functional (34, 57%) changes (Tables 9, 9a and 9b).

Prognosis concerns. This category consisted of 2 subcategories and 6 items. Fifty-four (90%) responses indicated a need for information related to one or more subcategory(ies), ranking the second of the first (highest) in magnitude among the four in the major category of Disease Concerns. The subcategory response counts ranged from 45 to 52, and the item response counts 6 to 36 (Tables 9, 9a and 9b).

Fifty-two (87%) responses indicated a need for information about the facts of prognosis, such as knowing the prognosis (10, 17%); the implied morbidity (36, 60%) or the potential recurrence of cancer (31, 52%), the potential of failure to control the current cancer (31, 52%), and the morbidity rate (6, 10%). Forty-five (75%) responses identified a need for information related to the implications (meaning) for the patients in terms of survival (chances for living) (30, 50%), events expected to occur, e.g., the nature of follow-up, the natural history of the disease (25, 42%), advice related to the arrangements for domestic and financial matters, or preparing a will (21, 36%) (Tables 9, 9a and 9b).

Personal Concerns (Major Category)

This consisted of four categories, 12 subcategories, and 34 items. The (overall) category response counts ranged from 35 to 44; the subcategory response counts 19 to 39, and the item response counts 6 to 39. This major category ranked second among the four in the universe in magnitude of response counts shown in the ranges of category and subcategory counts. It ranked second, also, in magnitude among all of the category counts (Tables 9, 9a and 9b).

Category of job/career concerns. (Fifty patients were employed.) This category consisted of 2 subcategories and 5 items. Thirty-eight (76%) responses indicated a need for information related to one or more subcategory(ies), ranking third in magnitude among the four in this major category. The subcategory counts ranged from 19 to 36, and the items 9 to 29 (Tables 9, 9a and 9b).

Nineteen (38%) responses indicated a need for information regarding the implications of the diagnosis for their work place or their jobs or careers. Thirty-six (72%) responses indicated a need for information about the implications of the diagnosis for: their physical ability to work due to the disease progress (29, 58%) or the treatment (25, 50%); financial loss (22, 44%) due to reduced earnings (9, 18%), cost of treatment (10, 20%); and for losing or having to change jobs (12, 24%), rights for promotions or benefits (16, 32%) (Tables 9, 9a and 9b).

Plans/goals concerns. This category consisted of 2 subcategories and 6 items. Thirty-five (58%) patients indicated a need for information related to one or more subcategory(ies), ranking fourth in magnitude among the four in this major category. The subcategory response counts were 27 and 30, respectively. The item response counts ranged from 8 to 22 (Tables 9, 9a and 9b).

Twenty-seven (45%) responses indicated a need for information related to the implications of the diagnosis for their plans and goals such as disruption of plans/goals (21, 35%) or postponement (17, 28%). Thirty (50%) responses reflected a need to know about the implications for modification of plans and goals in view of the diagnosis, such as assessing the physical abilities to pursue plans and goals (22, 37%) or pursuing plans and goals (22, 37%) in view of the potential of recurrence (8, 13%). Seventeen (28%) indicated a need to know about the time needed for treatment, whether treatments would interfere with plans and goals (17, 28%); and whether the goals will regain their incentive value diminished in light of the diagnosis (13, 22%) (Tables 9, 9a and 9b).

Physical well-being concerns. This consisted of 3 subcategories and 7 items. Forty-four patients (73%) requested information related to one or more subcategory(ies), ranking first in magnitude among the four in this major category. The subcategory response counts ranged from 20 to 39, and the item response counts 11 to 29.

Twenty-three (38%) responses indicated a need for information related to the implications of the diagnosis for their general sense of well-being, such as loss of "feeling well" (23, 38%) due to symptoms of cancer (18, 30%) or the treatments (11, 18%), or infections contracted as a result of a weakened immune system (12, 20%). Thirty (50%) responses reflected a need to know about the implications for their physical functioning due to potential effects of the disease (29, 48%) or the treatment (24, 49%). Thirty-nine (65%) responses indicated a need for information about resources to prevent recurrence of the existing or a new cancer (24, 49%) or to early detect signs of recurrence of cancer (26, 43%), to prevent contracting other diseases (24, 40%), and to minimize the unavoidable symptoms of the disease or the treatment (20, 33%) (Tables 9, 9a and 9b).

Psychological well-being. This consisted of 5 subcategories and 15 items. Thirty-nine (65%) patients indicated a need for information related to one or more subcategory(ies), ranking third in magnitude among the four in this major category. The subcategory response counts ranged from 20 t0 38, and the item response counts 6 to 34 (Tables 9, 9a and 9b).

Thirty-eight (63%) responses indicated a need for information regarding their emotional disturbances, e.g., how to handle the anxiety (34, 57%), the shock (13, 22%), or the fear of losing control over their emotions (15, 25%). Twenty (33%) responses indicated a need to know how to handle the cognitive disturbances, e.g., constant awareness of the cancer (10, 17%), inability to concentrate (14, 23%), fear of losing hope (15, 25%), and inability to make decisions due to lack of knowledge about the disease and its implications (7, 12%). Thirty-eight (63%) responses demonstrated a need to know about assistance (resources) to cope with the psychological (emotional/cognitive) disturbances, and to maintain cognitive control over their fate (17, 28%). Several wanted to know about resources such as faith in God, the spiritual leader and/or objects, the power of prayer, the health professionals' competence and one's otherwise healthy body (21, 35%) (Tables 9, 9a and 9b).

Thirty-two (53%) responses indicated a need for information about potential psychological disturbance, e.g., what to anticipate and how to handle emotional disturbance (19, 32%), and maintain a positive attitude (13, 22%). Twenty-nine (48%) responses reflected a need to know how to handle uncertainty about recurrence (10, 17%), the potential diminished functioning (21, 35%), and change in self concept (17, 28%). Twenty-two (37%) responses reflected a need to know about assistance from professionals such as counselors (13, 22%), friends and relatives (6, 10%), from other patients or families of patients (10, 17%) (Tables 9, 9a and 9b).

Family Concerns (Major Category)

This major category consisted of 4 categories, 20 subcategories, and 45 items. The overall category response counts ranged from 8 to 29; the subcategory response counts ranged from 6 to 25, and the item response counts from 4 to 23. This major category ranked third among the four in magnitude of response counts shown in the ranges of category and subcategory response counts in the universe (Tables 9, 9a, and 9b).

Spouse concerns. (Forty-one patients lived with spouses.) This category consisted of 6 subcategories and 17 items. Twenty-nine (71%) patients indicated need for information related to one or more subcategory(ies), ranking first in magnitude among the four in this major category. The subcategory response counts ranged from 6 to 29, and the item response counts 6 to 23 (Tables 9, 9a, and 9b).

Twenty-five (68%) responses indicated a need to know how to alleviate the existing impact of the diagnosis on the spouse, such as the psychological/emotional strain (19, 46%) and the physical strain (11, 27%). Twenty-two (56%) responses indicated a need to know how to handle the strained relationship in terms of lack of open communication (17, 41%), interaction (14, 34%), and mutual support (18, 44%). Sixteen (39%) responses indicated a need for information about assistance (resources) to support the spouse, e.g., help from health professional in providing information (13, 32%), counseling, leading the spouse to other patients' spouses (11, 27%), or by referring the spouse to support (self-help) groups (7, 17%) (Tables 9, 9a, and 9b).

Nineteen (46%) responses indicated a need for information about the potential threats implied for the spouse and for marital relationships, such as what to anticipate and how to deal with the implied physical (12, 29%), psychological (13, 32%), and financial (10, 24%) strains. Twelve (29%) responses indicated a need to know what to anticipate and how to deal with the implications for the marital relationship, in terms of strained communication (6, 15%) and spouse role performance (10, 24%), such as to care, provide, parent, and support the spouse (6, 15%). Nineteen (46%) responses indicated a need to know about assistance (resources) for the spouse such as providing counseling (9, 22%), or giving appropriate literature (13, 32%), leading the spouse to other patients' spouses (20, 49%), or referring the spouse to support groups (10, 24%) (Tables 9, 9a, and 9b).

Children concerns. (Forty, 67%, patients had children.) This category consisted of 4 subcategories and 8 items. Twenty-nine (71%) patients indicated a need for information related to one or more category(ies). The category response counts indicated a need to know about harms (23, 58%) and threats (23, 58%). This category ranked second in magnitude of category response counts among the four in this major category. The subcategory aggregate counts ranged from 12 to 19, and the item response counts 4 to 15 (Tables 9, 9a, and 9b).

Twenty-three (58%) patients indicated a need for information about how to handle the existing impact of the diagnosis on the children. Twelve (30%) responses indicated a need to know how to alleviate the psychological, emotional, and physical (6, 17%) strain already imposed on the children. Fifteen (38%) responses indicated a need to know what and how to communicate about the diagnosis.

Twenty-three (58%) responses indicated a need to know what to anticipate and how to cope with potential implicatons for children (19, 48%), such as psychological/emotional reactions (10, 25%), and children contracting cancer (owing to heredity factors) (7, 17%). Fifteen (38%) responses indicated a need to know about the implications for the relationship with children and means to cope with them, such as strained communication (14, 35%) and problems of interaction (18, 45%) such as inability to parent (14, 35%), and inability to support children (8, 20%). Seventeen (43%) responses indicated a need to know about assistance (resources) for children such as support from health professionals by providing information (15, 38%), counseling (15, 38%), and leading children to support groups (4, 10%) (Tables 9, 9a, and 9b).

Parent(s) concerns. (Thirty-eight (63%) patients had parents.) This category consisted of 5 subcategories and 11 items. Twenty-three (61%) indicated a need for information in one or more subcategory(ies), ranking second (the second second) in magnitude in this major category. The subcategory response counts ranged from 6 to 14, and the item response counts 4 to 20 (Tables 9, 9a, and 9b).

Twenty-two (58%) responses indicated a need for information about how to handle the existing impact of the diagnosis on their parent(s), such as the psychological/emotional strain (20, 33%), physical strain (11, 29%), and on the relationship, such as strained communication (13, 34%), not knowing what, how, and how much to tell them, and interaction (12, 32%) such as how to deal with the parent(s)' reactions (10, 26%).

Eight (21%) responses indicated a need to know what to anticipate as potential threats implied for the parent(s) (6, 16%), such as potential psychological (6, 16%) and physical (6, 16%) strain, and for the relationship with parent(s), such as communication (6, 16%), interaction (7, 18%), and ability to care for parent(s) (6, 16%). Nine (24%) responses indicated a need to know about assistance (resources) to help parents, such as help from health professionals by providing information (8, 21%), counseling (8, 21%), or referring them to self-help groups (7, 19%) (Tables 9, 9a, and 9b).

Sibling(s) concerns. (Forty-two (70%) patients had siblings.) This category consisted of five subcategories and nine items. Eighteen (34%) patients indicated a need for information related to the sibling(s) in one or more subcategory(ies), ranking last (fourth) in magnitude among the four in this major category. The subcategory response counts ranged from 6 to 12 and the item response counts 3 to 12 (Tables 9, 9a, and 9b).

Fifteen (36%) responses indicated a need for information about how to handle the existing impact of the diagnosis on the siblings such as their psychological/emotional strain (12, 29%), the relationship (9, 21%), such as the strained communication (12, 29%), interaction (10, 24%), ability to support (5, 12%), and be supported by the sibling(s) (6, 14%).

Nineteen (45%) responses indicated a need to know what to anticipate as information related to potential threats implied for the siblings, such as psychological/emotional strain (9, 21%), e.g., fears of vulnerability (7, 17%), and for the relationship, such as strained communication (8, 19%) and interaction (6, 14%). Twelve (29%)

responses indicated a need to know about available assistance (resources) to help siblings such as support from health professionals by providing information (10, 24%) (Tables 9, 9a and 9b).

Social Concerns (Major Category)

This major category consisted of 4 categories, 12 subcategories, and 28 items. The overall category response counts ranged from 12 to 25; the subcategory response counts ranged from 5 to 23 and the item response counts 3 to 22. This major category ranked fourth (last) among the four in magnitude of response counts shown in the ranges of category and subcategory response counts in the universe.

Job and career relationship concerns. (Fifty (83%) patients had jobs.) This category consisted of 3 subcategories and 7 items. Twenty-eight (56%) patients indicated a need for information related to one or more subcategory(ies), ranking first in magnitude in this major category. The subcategory counts ranged from 19 to 23, and the item response counts 11 to 20 (Tables 9, 9a, and 9b).

Twenty-eight (56%) patient responses indicated a need for information about the implications of the diagnosis for job/career peer relationships in terms of strained communication (23, 46%), such as whether to disclose the diagnosis (20, 40%), what, how, how much to tell (19, 38%), and how to handle the heightened curiosity of peers (18, 36%); and in terms of changed amount or mode of interaction (19, 38%) due to the patient's diminished physical stamina (17, 34%), the avoidance (9, 18%) or the overly protective behavior of peers (7, 14%), or due to perceptions (18, 36%) that the patient will be different from others (17, 34%), or less capable than before (11, 22%). Twenty-one (42%)

responses indicated a need to know about assistance (resources) for patients from health professionals such as counseling or appropriate literature (13, 26%), or contact with other patients (11, 22%) (Tables 9, 9a, and 9b).

Special interest relationship concerns. This category consisted of 3 subcategories and 7 items. Twelve (20%) patients indicated need for information related to one or more subcategory(ies), ranking third in magnitude among the four in this major category. The subcategory response counts ranged from 5 to 11, and the item response counts 3 to 10 (Table 9, 9a, and 9b).

Twelve (20%) responses indicated need for information about the implications of the diagnosis for relationships with peers of special interests (10, 17%) in terms of communication such as whether to disclose the diagnosis (8, 13%), what, how, and how much to tell (6, 10%), and how to handle the heightened curiosity of peers (10, 17%), and in terms of potential changes in amount of interaction with peers (11, 18%) due to the patient's diminished physical stamina (5, 8%) or avoidance (7, 12%), or overly protective behavior of peers (6, 10%). Information was also needed in relation to potential changes in the quality of interaction due to the perception of peers that the patient may be different from others (6, 10%), or different than before the diagnosis (6, 10%), or less capable than before (7, 12%). Five (8%) responses indicated a need to know about assistance (resources) from health professionals such as counseling (3, 5%), literature (4, 7%), or contact with other patients (4, 7%) (Tables 9, 9a, and 9b).

Leisure relationship concerns. This category consisted of 3 subcategories and 7 items. Seventeen (28%) patients indicated need for information related to one or more subcategory(ies), ranking third (the second third) in magnitude among the four in this major category. The subcategory counts ranged from 5 to 13, and the item response counts 3 to 13 (Tables 9, 9a, and 9b).

Seventeen (28%) responses indicated a need for information about the implications of the diagnosis for relationships with peers in terms of strained communication (13, 22%), such a whether to disclose the diagnosis (8, 13%); what, how, how much to tell (6, 10%); and how to handle the heightened curiosity of peers (13, 22%). Information was also needed in relation to the potential changes in the amount of interaction (13, 22%) due to reduced physical stamina (11, 18%), or avoidance (6, 10%), or overly protective behavior of peers (6, 10%), as well as the quality of interaction with peers due to the perception of peers that the patient may be different from others (6, 10%), or different than before (7, 12%), or less capable than before (6, 10%). Fifteen (25%) responses reflected need for information about assistance (resources), such as support from health professionals through counseling, literature (13, 22%), and contact with other patients (9, 15%) (Tables 9, 9a, and 9b).

Future relationships concerns. This category consisted of 3 subcategories and 7 items. Twenty-five (42%) patients indicated need for information related to one or more subcategory(ies), ranking second in magnitude of category response counts in this major category. The subcategory counts ranged from 14 to 23, and the item response counts 6 to 22 (Tables 9, 9a, and 9b).

Twenty-five (42%) responses indicated a need for information related to the implications of the diagnosis for future relationships. Twenty (33%) responses indicated a need to know what to anticipate and how to handle the potential implications for future intimate relationships due to potential perceptions of deterrant factors on the part of the other(s) (8, 13%), such as that cancer may recur (8, 13%), and that it may be contagious or somehow offensive (10, 17%). Eighteen (30%) responses indicated a need to know strategies for communication, such as whether and when to tell (10, 17%), and what and how to tell (8, 13%), and how to handle potential implications for future less intimate, or contractual relationships (14, 23%) such as business or professional associations (6, 10%). Twelve (20%) responses indicated a need to know about strategies for communication, such as whether and when to tell (6, 10%), and what and how to tell (4, 7%).

Twenty-three (38%) responses indicated need for information about making new friendships with their patient peers and wanted to know how to contact other patients (22, 37%) to share common experiences (18, 30%), to learn from their experiences (8, 13%), and to help other recently diagnosed cancer patients (8, 13%). Thirteen (22%) wanted to know ways for their families to contact other families of patients for support (9, 15%), education (8, 15%), or help other families of recently diagnosed cancer patients (7, 12%). Thirteen (22%) responses indicated need to know how to contact and join support (self-help) groups (Tables 9, 9a, and 9b).

## Patterns in Responses

The frequency of responses varied within and among the four major categories. Examination of the rank order of category aggregate response counts among the major categories revealed that Disease Concerns contained the categories with the highest aggregate response counts, and that the rank order of the other major categories was consistent with their order in the universe, i.e., there were progressively smaller, category frequency counts in Personal Concerns, Family Concerns, and Social Concerns. Progressively smaller category aggregate frequency counts were seen in successive major categories (Tables 9a). (The term "universe" pertains to the structural units of the major categories, categories, subcategories, and items of the INA instrument with respect to which patient responses were organized.)

Also, the rank order of the five subcategories with highest response counts within each of the four major categories maintained a group (five subcategories) rank order in their respective major categories in the same order of category response counts which was Disease Concerns, Personal Concerns, Family Concerns, and Social Concerns (Table 9b).

These observations indicate a hierarchy in patient needs for information commensurate with the rank order of the major category, category, and subcategory (top five in each major category) response counts from highest to lowest throughout the universe. Although an alternative plausible explanation could be that the patients may have grown progressively more fatigued and less conversant, evidence from the interviewer's notes as well as careful examination of the interview tapes indicate otherwise. The patients actually seemed to become more at ease during the interview as well as more conversant. Rather than fatigue factor, a better explanation for the patterns of rank order in response counts could be the relevance of the nature of information to the needs of the patients. There may be a relationship between the nature of the perceived harm, threat, or resources and the nature and amount of information needed.

## Results Pertaining to Importance Value

The relative importance values of information needs related to the categories within the major categories were measured by the relative values the patients attached to the categories. These values were chosen from values "0" (not important) to "100" (most important). Patients attached varied values to those categories (Table 10).

### Disease Concerns

Thirty-seven (62%) patients attached percent values to the category of Diagnosis ranging from 10 to 75, with a mean value of 31.2 (SEM 2.3). Thirty (50%) patients attached percent values to the category of Test(s) ranging from 1 to 50, with a mean value of 15.2 (SEM 2.6). Forty-six (77%) patients attached percent values to the category of Treatment ranging from 10 to 99, with a mean value of 40.1 (SEM 2.8). Forty-five (75%) patients attached percent values to the category of Prognosis ranging from 2 to 99, with a mean value of 34.9 (SEM 4.4) (Table 10a).

### Personal Concerns

Twenty-seven (45%) (54% of those who worked) patients attached percent values to thes category of Job/Career ranging from 10 to 100, with a mean value of 35.1 (SEM 5.3). Twenty-six (43%) patients attached percent values to the category of Plans and Goals ranging from 10 to 100, with a mean percent value of 29.7 (SEM 3.8). Forty (67%) patients attached percent values to the category of Physical Well-being ranging from 1 to 99, with a mean value of 28.5 (SEM 4.0). Thirty-eight (63%) patients attached percent values to the category of Psychological Well-being ranging from 3 to 100, with a mean value of 49.2 (SEM 4.0) (Table 10a).

## Family Concerns

Thirty-four (57%) (83% of those who had spouses) patients attached percent values to the category of Spouse ranging from 25 to 100, with a mean value of 55.9 (SEM 4.0). Twenty-one (35%) (53% of those who had children) patients attached percent values to the category of Children ranging from 0 to 100, with a mean value of 25.6 (SEM 5.4). Twenty-two (37%) (58% of those who had parents) patients attached percent values to the category of Parents ranging from 5 to 99, with a mean value of 30.3 (SEM 5.5). Seventeen (28%) (40% of those who had siblings) patients attached percent values to the category of Siblings ranging from 0 to 50, with a mean value of 16.2 (SEM 3.3) (Table 10a).

## Social Concerns

Twenty (33%) (40% of those who worked) patients attached percent values to the category of Job/Career Relationships ranging from 2 to 90, with a mean value of 40.1 (SEM 5.7). Seven (11.2%) patients attached percent values to the category of Special Interest Group Relationships ranging from 25 to 100 with a mean percent value of 42.1 (SEM 6.0). Eleven (18%) patients attached values to the category of

Leisure Group Relationships ranging from 5 to 99, with a mean value of 49.4 (SEM 8.0). Twenty (33%) patients attached a percent value to the category of Future Relationships ranging from 10 to 100, with a mean percent value of 62.9 (SEM 7.2) (Table 10a).

## Patterns in Importance Values

The importance values attached to categories varied in degrees throughout the universe as shown in the mean percent values in Table 10a. A consistent trend of progressively increased or decreased order of importance values commensurate with the order of the major categories of the universe was not seen. Unlike the response counts measures, the importance value measures indicated a descending rank order of categories which transcended the boundaries of the major categories. However, the numbers of patients evaluating the categories were also decreasing across the major categories.

Two observations were made: One is that the relative magnitude of importance value attached to a category ranked according to the magnitude of the measures of importance value means (Table 10a), although this ranking was not commensurate with its magnitude of response counts (Table 9b). Thus, while the major category of Disease Concerns ranks first on response counts, based on the magnitude of response counts of its five subcategories (Table 9b), the major category of Social Concerns ranks first on the importance value scale based on the magnitude of mean values of its subcategory of Future Relationships with Other Patients (Table 10a).

This may suggest that the breadth of information needs reflected in the response counts may not be sufficient measures of patients' information needs. Also, that while breadth (measured in counts) is important, depth measured in importance values attached to selected information needs may indicate priority for fulfillment. Value measures, in other words, may complement the truer description of information needs represented in counts and importance values. However, these observations should be analyzed in view of the number of patients who attached the importance values of information in the given categories.

The second observation is that categories with the highest importance value within their respective major categories tended to be those that contained subcategories with the highest response counts. For example, the category of Future Relationship had a mean percent value of 62.4 with the highest aggregate response counts among categories of the major category of Social Concerns. The categories of Spouse and Children Concerns, which had the highest importance mean values of 55.9 and 30.3, respectively, were the categories containing subcategories with the highest response counts, within the major category of Family Concerns. Thus, each category with an importance value as shown in Table 10a had corresponding subcategories in the top five subcategories with the highest response counts in their respective major categories as shown in Table 9b.

This trend was consistent for all categories except those of Leisure Relationships, Special Interest Relationships (both in the major category of Social Relationships), Siblings, and Tests. It indicates that patients may have a sense of priority with respect to certain types of information. This suggests the notion that measures of importance values, coupled with count values attached to given information needs may be more representative of patients' needs for information than either response counts or importance values alone. It must be noted that because of the relatively fewer numbers of patients who evaluated the categories of Social Concerns, the high importance value means of Future Relationships, Leisure Relationships, and Special Interest Relationships may not necessarily represent the priorities of the general patients sampled simply reflect, instead, the priorities of those who responded. The few patients who did indicate a need for information in Social Concerns tended to attach high importance values to its categories. This observation is supported in the large importance value ranges (minimum-maximum) shown in Table 10a, as well as in the large scores of the standard errors of the means (SEM, Table 10a).

## Results Pertaining to Differences in Information Needs and Importance Values Among Groups

Fisher Exact (1-tail) tests, Pearson chi square tests, and (Levene) Two-Group t-tests were used to explore whether there were differences in information needs or importance values related to all categories and subcategories among groups described by the variables of sex, age, education, marital status, type of cancer, stage of cancer, type of treatment, reading about cancer since diagnosis, time since diagnosis, and patient source. The results are presented in Tables 11, 12, 13, and 14 according to the categories in which significant differences in response counts were shown among the groups compared.

## Differences In Information Needs Among Patients According to Person-related Variables

Differences according to sex. The results of Fisher Exact (1-tail) tests indicated significant differences in the aggregate response counts of males and females which indicated that females needed more information than did males regarding Prognosis ($p< .01$), Psychological Well-being ($p< .0002$), and Siblings ($p< .04$) (Table 11).

Differences according to age. The results of Pearson chi-square tests indicated differences in the aggregate response counts among young adults (18-35), adults (36-55), and older adults (56-70) in information needs, which implied that young adults and adults tended to need information more than did older adults regarding Spouse ($p< .04$), Parents ($p< .01$), Siblings ($p< .02$), and Job/Career Relationships ($p< .05$) (Table 12). However, inferences regarding the differences in information needs among males and females or among the age groups may not be made based on these data, because other intervening variables were not controlled.

## Differences in Information Needs Among Patients According to Situation (Disease)-related Variables

Differences according to stage of cancer. The results of Pearson chi-square tests indicated differences in the aggregate response counts among patients with local, regional, and disseminated cancer in information needs, which implied that patients with local and regional cancer tended to need information more than did patients with disseminated cancer regarding the Spouse (Table 13).

The results of Pearson chi-square tests indicated no differences in the aggregate response counts related to categories or subcategories in the major categories of Disease, Personal, Family, and Social Concerns, among patients stratified according to the variables:

Education, in years: 10-16, 17-18, 19-22+.

Marital Status: married, widowed, separated, and divorced.

Time Since Diagnosis, in days: 1-6, 7-12, 13-17.

Time Lapse Since First Symptoms, in weeks: 2-6, 7-11, 12 or more.

Source of Health Care: a cancer center, community oncologists, Health Maintenance Organization.

Treatment Modalities: surgery, chemotherapy, and radiation therapy.

Type of Cancer: melanoma, other hard tumors, hematopoetic.

The results of Fisher Exact tests (1-tail) indicated no differences in the aggregate response counts related to categories or subcategories in the major categories of Disease, Personal, Family, and Social Concerns, among patients who had read about their cancer since the diagnosis and those who did not. Inferences regarding the differences and no differences in information needs of groups compared cannot be made based on these data because of lack of control of other intervening variables.

### Differences in Importance Values of Information Among Patients According to Person-related Variables

Differences according to sex. The results of the Two-Group t-tests indicated differences in the importance value mean scores between males and females which implied that males tended to attach more importance than did females to information regarding Diagnosis ($p < .004$), Physical Well-being ($p < .01$), and Spouse ($p < .04$); and females tended to attach more importance than did males to information regarding Parents ($p < .0007$).

Differences according to age. The results of the Two-Group t-tests indicated a difference in importance value mean scores among the young adults (18-35), adults (36-55), and older adults (56-70) which implied that adults tended to attach more importance than did young or older adults to information regarding Implications for Spouse ($p < .04$).

The results of Two-Group t-tests indicated no differences in the importance value mean scores attached to information needed related to the categories or subcategories in the major categories Disease, Personal, Family, and Social Concerns, among patients stratified according to variables:

Marital Status: married, widowed, separated, divorced.
Education in Years: 10-16, 17-18, 19-22 or more.
Time Since Diagnosis, in days: 1-6, 7-12, 13-17.
Time Lapse Since First Symptoms, in weeks: 2-6, 7-11, 12 or more.
Source of Health Care: a cancer center, community oncologists, Health Maintenance Organization.
Type of Cancer: melanoma, other solid cancers, hematopoetic cancers.
Stage of Cancer: local, regional, disseminated cancer.
Type of Treatment: surgery, chemotherapy, radiation therapy.

Inferences regarding differences or no differences in information needs of groups compared cannot be made because other intervening variables were not controlled.

## Summary

The INA instrument was found to be valid, reliable, and comprehensive according to measures of acceptability. Recently diagnosed cancer patients expressed their needs for information about the existing harms, threats, and resources eminating from the diagnosis of cancer. These needs and their relative importance values were described within the four major categories of Disease, Personal, Family, and Social Concerns. The exploratory-comparative test results indicated few differences in information needs among patients stratified according to person or situation-related variables. It may be suggested that the sample may have been homogeneous in information needs, or that controlled studies are warranted to describe information needs differences in this population of patients.

# CHAPTER VI

# DISCUSSION

## Instruments

### Validity of Instruments and Categories

The content validity of the INA and the categories of analysis, as well as the comprehensiveness of both, are supported by 100% agreement among the judge panel members. The face validity and comprehensiveness of the DI is also supported by 100% agreement among the panel members.

### Reliability of INA Instrument and Coding

The reliability of the INA is supported by symmetry of test-retest response counts greater than the predicted acceptable ($p< .05$) significance, or larger than 80% agreement in counts smaller than the cells of the test, based on McNemar test results. The one significant difference ($p< .001$) was among the response counts of Prognosis and in relation to one item only. The reliability of the INA is also reflected in the lack of significant differences in the test-retest importance values, except for differences in test-retest scores of the categories Prognosis Concerns ($p< .03$) and Spouse Concerns ($p< .04$). Based on the interviewer notes, patients tended to become emotional while responding to these categories, which may have influenced their evaluation of the importance of such information in either test or retest (Table 7).

The overall high reliability of the INA instrument should be accepted. A potential limitation may be that the relatively short interval between test and retest may have contributed to the symmetry of response by recall on the part of the patient. However, this may not be likely in view of the multiplicity of the interview items, and the interviewer reports indicating the patients' serious attempts to accurately express and evaluate their information needs.

Intercoder reliability. Intercoder reliability is supported by the Derdiarian-Lewis binomial test of proportion of agreements, which reflects the precision, clarity, and mutual exclusiveness of the definition of the variables. This test increases the probability that agreement was not by chance but by evidence of agreement on the large variance of content analyzed. The reliability of the definition of the categories and subcategories also is demonstrated in the strong intracoder agreement values. This is an unusual but more direct technique to show intracoder reliability. The above findings indirectly reflect the attributes of content validity of the INA instrument, as reliability is a strong indirect measure of validity, although does not guarantee it (Kerlinger, 1973; Krippindorff, 1980).

## Information Needs

As determined by aggregate response counts, recently diagnosed cancer patients in this study indicate their information needs and their importance values in relation to their disease and to their personal, family, and social concerns. Information needs and their importance values were described in relation to harms, threats, and resources within the major categories of Disease, Personal, Family, and Social Concerns (Table 9).

### Nature of Information Needs

Information needs in the categories of Disease, Personal, Family, and Social Concerns indicate information needs in various magnitudes of counts. Their rank order by category aggregate counts, indicate a hierarchy of information needs within each major category as well as among the major categories themselves. The description of categories of information needs are discussed according to their rank in their respective major categories (Table 9).

Disease concerns. The Disease Concerns indicate the largest aggregate response counts of information needs among the four major categories. Patients wanted to know the goals, the intended and unintended outcomes of treatments, the facts and implications of prognosis, the nature, extent, and causes of their cancer, and the nature, results and consequences of the tests. In all categories, they wanted to know facts as well as the implied meanings, indicating that facts alone would be inadequate to help appraise the harms (existing damage), threats (potential or anticipated damage), or resources. Information needs in Disease Concerns were aimed at appraising harms related to the diagnosis and tests, threats related to treatments and prognosis, and resources related to harms and threats. Expected positive results of treatments, health care professionals, appropriate literature, and other patients were identified as resources (Table 9).

Personal concerns. The Personal Concerns indicate the second largest response counts of information needs among the four major categories. Patients wanted to know the implications of cancer and its treatment for their ability to maintain psychological well-being and function, maintain physical well-being and function, to work, and pursue plans and goals. Information needs were aimed at appraising mostly threats related to job/career and plans/goals, harms and threats related to physical and psychological well-being, and resources related to harms and threats. Health care professionals, appropriate literature, clergy, other patients, and support groups were identified as resources (Table 9).

Family concerns. The Family Concerns indicate the third highest response counts of information among the four major categories. Patients wanted to know the implications of cancer and its treatment for their ability to continue to perform in their spouse, parent, child, or sibling roles, for the physical, psychological, and social well-being of their family members, and for the family relationships. Accounts for strained communication and threats of disrupted communication or interaction with loved ones were pervasive. Information needs were aimed at wanting to know how to handle the existing harms such as physical and psychological disturbances sustained, primarily by the spouse, but also by other loved ones, such as Children, Parents and Siblings. Information needs were aimed at appraising harms, threats and resources related mostly to the spouse, but to the other family members as well. Health care professionals, appropriate literature, clergy, other patients, and support groups were identified as resources (Table 9).

Social concerns. The Social Concerns indicate the least response counts of information needs among the four major categories. These patients wanted to know whether the physical and psychological sequalae of cancer will disrupt existing relationships or deter building new ones. Strategies of communication and interaction to pervent such relational problems were consistently requested. Information related to the implications of cancer and its treatment for future intimate, less intimate, and contractual relationships, as to what, when, and how much to disclose of the facts of cancer to others, and how to prepare to handle adverse reactions from others were central to their social needs. Information needs were aimed at appraising threats and resources in relation to job/career, special interests, leisure, and future relationships. Health care professionals, other patients, and support groups were perceived as resources for learning how to confront the existing or potential problems of relationships (Table 9).

It is evident that patients indicate information needs in relation to all four major categories. The nature of these needs is described in terms of harms, threats, and resources. This finding supports Lazarus' (1966) postulation that appraisal aims at the configuration of harm, threat, and resources. It also supports White's (1974) formulation that information seeking is essential to the process of appraisal and coping. The findings imply support to the researcher's contention in the theoretical framework that information seeking may have a mediating relationship to appraisal, and it, as appraisal, aims at the configuration of harm, threat, and resources.

The findings show that information needs were expressed in varying amounts in relation to the categories and major categories. When rank ordered by response counts, the relative dominance of information needs are ranked as Disease, Personal, Family, and Social, indicating the dominance of information related to physical survival over the others. This observation may reflect the resemblance of this hierarchy to the hierarchy of needs described by Maslow (1954, 1973). Similar hierarchies of counts in relation to the categories reveal consistency with this observation as well (Tables 9, 9a, and 9b). These findings imply support to the contention in the theoretical framework that information needs may be determined by the hierarchy of needs. Since needs reflect lack, it may be suggested that the lack of information mediates information seeking as well, as contended in the theoretical framework. This notion is supported by Adler et al. (1979), that a need for information refers to that which is lacking, incomplete, faulty, or distorted, in situations needing decision making.

The findings are consistent with those of Rotter (1977) and Cassileth et al. (1980a), who reported that most patients in their studies wanted to know about their diagnosis and disease and benefited from such information. Similarly, the findings of Greenleigh (1979), Feldman (1978), Mages and Mendelsohn (1979), and Weisman et al. (1980) are supported, that cancer patients need information most, but not only, about the diagnosis, tests, treatments, prognosis, but also about their implications for their personal, family, and social lives would have been helpful if given as soon after the diagnosis as possible. The findings of this study, however, do not entirely support the findings reported by McIntosh (1977), that patients generally avoided information regarding the diagnosis or progression of their disease, although it is possible that patients in this study also avoided some information. This inconsistency can be attributed to differences in the patients sampled, particularly cultural differences, in the English sample studied by McIntosh, or to some other factors.

## Importance of Information Needs

The categories of information needs within the Disease, Personal, Family, and Social Concerns evaluated by the patients indicate a wide range of importance values. The rank-order by magnitude of importance values indicate a hierarchy of important information needs within each major category as well as within the universe of categories across the major categories (Tables 10 and 10a).

Disease concerns. Although categories of information needs related to the Disease Concerns did not achieve the highest importance values among the universe of categories, they were, however, evaluated as relatively high in importance by the largest number of patients (mean scores ranging 15.2 to 40.1, number of categories = 4). This indicates that their relative importance was most commonly evaluated by the patients. It is possible that since Treatments are most closely associated with the survival of the patient, information related to them was evaluated as the most important. The ranks of the remaining categories of information needs are those related to Prognosis, Diagnosis, and Tests (Table 10).

Personal concerns. Although the categories of information needs related to the Personal Concerns also did not achieve the highest importance values among the universe of categories, they too were evaluated as the next most important by the next largest number of patients (mean scores ranging 16.2 to 55.9, n = 4), indicating that their importance was next most commonly evaluated by the patients. Since Psychological Well-being is most closely associated with the psychological survival of the patient, information related to it was evaluated as the most important. The ranks of the remaining categories of information needs are those related to Job/Career, Physical Well-being, and Plans/Goals (Table 10).

Family concerns. The categories of information needs related to the Family Concerns achieved importance values comparable to those in Disease and Personal Concerns. They were evaluated as relatively highly important by the third largest number of patients, indicating that the importance of information needed related to this major category was the third most commonly evaluated by the patients. It is possible that because information needs related to the Spouse are most closely associated with the psychological, social, and relational survival of the patient, information related to it was evaluated as most important. The ranks of the remaining categories of information needs are children, parents, and siblings (Table 10).

Social concerns. The categories of Social Concerns achieved the highest importance values in this, as well as in the universe of categories. However, they were evaluated by the least number of patients, indicating that the importance of information related to Social Concerns was least commonly evaluated by the patients. As shown, information related to the Future Relationships, which are most closely related to the social survival of the patients, was evaluated as most important. The ranks of the remaining categories of information needs are those related to Job, Leisure, and Special Interest Relationships (Table 10).

These findings indicate two distinct and similar hierarchies of information needs: one within each major category, and another among the four major categories. In both, information needs more closely related to the physical survival of the patient dominate those less closely related.

For example, the hierarchial orders of information needs within each major category point to a distinct type of survival need. As demonstrated in the Disease Concerns, the dominance of information needs related to Treatments reflects the need for physical survival and its dominance in the rank order of the major categories. Likewise, the dominance of information needs related to Psychological Well-being reflects the need for psychological survival and its rank in the order of the major categories. Similarly, the relative dominances of information needs related to Spouse and Job/Career Relationships, respectively, reflect needs for social survival and their respective dominances in the order of the major categories (Tables 10 and 10a).

These findings imply support of Maslow's (1954, 1973) theory of hierarchy of needs which places physical survival needs in a dominant position, and of Lazarus' (1966) postulation that all threat may fall on a continuum of degree. These findings also imply support of the contention proposed in the theoretical framework that hierarchy of needs may have a determining role in motivating information seeking as well as in determining the nature of the information sought.

### Patterns in Information Needs and their Importance Values Within Major Categories

There are similarities in the rank orders by counts and importance values in placing the same category of information needs in the Disease and Personal Concerns, although this is not shown to be consistent in the Family and Social Concerns (Tables 9a and 10).

Disease concerns. It is noted that information needs related to Treatments elicited the highest aggregate counts and the highest importance values in this major category. The rank order by importance values of the remaining categories is Prognosis, Diagnosis, and Tests (Tables 9a and 10).

These findings imply some explanations. First, treatments imply definitive conditions directly related to physical survival needs of the patients. Second, treatments imply imminence and likelihood of events. Third, they are less likely than diagnosis and tests to be included in the physician-patient discussions, because they are more tentative as plans and realities, at the time of diagnosis, than are the other categories. Information received may, accordingly, be less than regarding the other categories. All these explanations may reflect relationships between these characteristics of physical survival and the dominance of information needs related to physical survival. These explanations are supported by the rank order of the remaining categories in this major category, as they are relatively less related to physical survival, less imminent and likely, and less discussed.

Based on these observations, some relationships between information needs and the nature of concerns may be discerned from the findings in relation to these observations to Treatment Concerns. There may be a relationship between information needs and (a) the hierarchy of survival needs (physical) of the patient, and (b) the amount, imminence, and likelihood of the anticipated harms, and (c) the amount of information already known about such harms.

Personal concerns. It is noted that information needs related to Psychological Well-being Concerns elicited the highest aggregate counts and importance values. The rank order by importance values of the remaining categories is Physical Function (a larger number of patients evaluated this category than Job/Career, which had a higher value), Job/Career, and Plans/Goals Concerns (Tables 9a and 10).

These findings imply some explanations. First, Psychological Well-being implies a closer association than the other categories with the psychological survival of the patients. Second, its disturbance is more imminent and likely than disturbance of the other categories. Third, it is unlikely that Psychological Well-being is included, to an adequate extent, in the physician-patient discussions at the time of diagnosis. Information received may, accordingly, be less than others. All these explanations may reflect relationships between these characteristics of treatments and the dominance of information needs related to treatments. These explanations are also supported by the rank order of the remaining categories, as they are relatively less associated with psychological survival, less imminent and likely, and less discussed.

Based on these observations, some relationships between information needs and the nature of concerns may be discerned from the findings in relation to Personal Concerns. There may be a relationship between information needs and (a) the survival (psychological) of the patient, and (b) the amount, imminence, and likelihood of the anticipated harm, and (c) the amount of information already known about such harms.

Family concerns. It is noted that the information needs related to Spouse eliected the highest response counts and the highest importance values. The rank order by importance value of the remaining categories is Children, Siblings and Parents Concerns (Tables 9a and 10).

These findings imply some explanations. First, Spouse Concerns imply a closer association with psychological and social survival than the other categories. Second, spouse concerns are more imminent and likely than the concerns of the other categories. Third, it is unlikely that spouse concerns were included in the physician-patient discussions, to an adequate extent, at the time of the diagnosis. All these explanations may reflect relationships between these characteristics of spouse concerns and the dominance of information needs related to it. These explanations are also supported by the rank order of the remaining categories, as they are less closely associated with social survival, less imminent and likely, and less discussed.

Based on these observations, several relationships between information needs and the nature of concerns may be discerned from the findings in relation to Family Concerns. There may be a relationship between information needs and (a) the survival (psychological, social) of the patient, (b) the amount, imminence, and likelihood of the anticipated harms, and (c) the amount of information already known about such harms.

Social concerns. It is noted that the information needs related to Job/Career Relationships elicited the highest response counts and the least importance values. The category of Future Relationships elicited the highest importance value in this and the other major categories. The rank order by importance values of the remaining categories is Leisure, Special Interest, and Job/Career Relationships Concerns.

These findings imply some explanations. First, Job/Career Relationships and Future Relationships Concerns imply a closer association with social survival than the other categories. Second, potential adjustments related to these relationships are more imminent and likely than those related to the other categories. Third, it is unlikely that such relationships were included in the physician-patient discussions, to an adequate extent, at the time of diagnosis. All these explanations may reflect relationships between these characteristics of Job/Career, and Future Relationships and the dominance of information needs related to them. These explanations are also supported by the rank order of the remaining categories, as they are less closely related to social survival, less imminent and likely, and less discussed.

Similar relationships may be discerned from the findings in this major category. There may be a relationship between information needs and (a) the survival (social) of the patient, (b) the amount, imminence, and likelihood of the anticipated harms, and (c) the amount of information already known about such harms.

In the above observations, it is shown that the most dominant categories of information needs in each of the major categories themselves represent a relative rank order of dominance, such as Treatment (reflecting physical survival), Psychological Well-being (reflecting psychological survival), Spouse Concerns (reflecting psychological and social survival), and Job/Career and Future Relationships (reflecting social survival). These observations imply that information needs may be related to (a) the hierarchy of physical, psychological, and social needs, (b) the amount, imminence, and likelihood of occurrence of harms, and (c) the amount of information known about harms (concerns).

These findings support Lazarus' (1966, p.43) postulation that (a) the degree of threat is primarily the function of the amount, imminence, and likelihood of the anticipated harm, and (b) all threat can be described as falling on a continuum of degree. The hierarchial order of information needed, by measures of response counts and importance values, reflected both imminence and likelihood of concerns, and a continuum of degree of threat. The third observed relationship between lack of information and information need, support the contention of this study, that lack of information may mediate information seeking, and that the relevance of information may be determined by its lack when concerns are important to the patients.

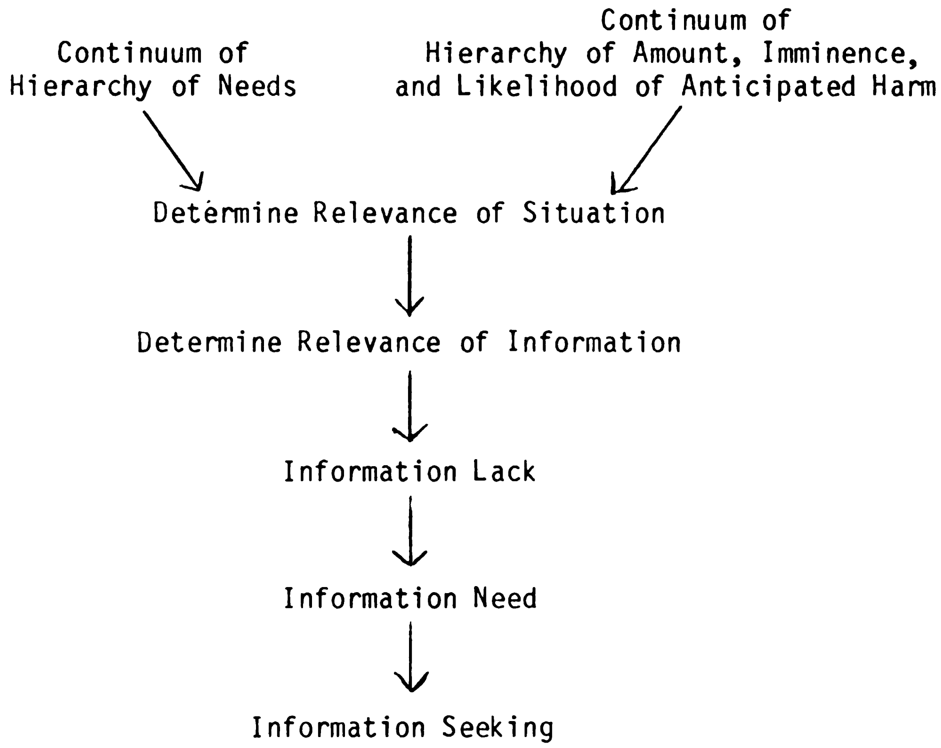
### Patterns of Information Needs and Their Importance Values Among the Major Categories

The rank order of the major categories by aggregate response counts is Disease, Personal, Family, and Social Concerns. This pattern indicates a continuum in the progressive decreases in information needs. This is similar to the rank order of the dominant categories Treatment, Spouse, Psychological, and Job/Career and Future Relationships.

This observation implies several plausible explanations for the patients' responses. First, Disease Concerns, being most closely associated with physical survival, elicited the most response counts and importance values. Second, Personal Concerns, being the next less closely associated with physical survival, elicited the next most response counts and importance values. Third, the Family Concerns, being third less closely associated with physical survival, elicited the third most response counts and importance values. Finally, the Social Concerns, being least closely associated with physical survival, elicited least response counts and least commonly evaluated importance values.

Based on these data, three implications can be made. First, a linear (coninuum of degree) relationship may exist between Disease Concerns (physical survival), and Personal Concerns, Family Concerns, and Social Concerns. The continuum of degree observation is supported in the degree of a gradually decreasing threat implied to physical survival from Disease to Social Concerns. Second, the continuum of degree is also supported in the degree of a gradually decreasing imminence and likelihood of anticipated harms. Therefore, a temporal (time sequence) relationship may exist between Disease Concerns and Personal Concerns, Family Concerns, and Social Concerns. For example, Disease Concerns are most imminent and likely to occur than are Personal, Family, and Social Concerns, therefore, information needs are most needed and most important, accordingly. Therefore, it may be suggested that information needs and their importance about a concern may be determined by the degree of imminence and likelihood of occurrence of that concern. These observations imply that the concerns and their related information needs may fall on continuii of degree of threat and/or degree of time/occurrence corresponding to the order of Disease, Personal, Family, and Social Concerns, as these pertain to the recently diagnosed cancer patient.

These observations pertaining to the information needs imply support of Lazarus' (1966) postulation that all threat may fall on a continuum of degree. They also imply support of Maslow's (1953, 1974) theory of hierarchy of needs. The implications are that these theories may be related as they pertain to information needs of recently diagnosed cancer patients examined in this study. Deriving from these theories and the findings, it may be suggested that there may be a relationship between the information needed and the nature of the noxious stimuli about which information is sought. This is expressed as, in the recently diagnosed cancer patient, information needs may be determined by the hierarchy of survival needs, and by the amount, imminence, and likelihood of anticipated harm. Together they determine relevance of information, which in turn determines the lack, and therefore the nature, of the need. Need, then, mediates information seeking. This scheme is shown below.



## Findings Pertaining to Differences in Information Needs and Importance Values Among Groups

The several comparisons of information needs counts and importance values between groups stratified according to situation-related variables (type of cancer, stage of cancer, type of treatment, time since diagnosis, times since first symptoms, and source of patient referral) indicated only one difference in information needs among patients with cancer at different stages. Of similar comparison of information needs and importance values between groups stratified by person-related variables (sex, age, marital status, education, having read about cancer since diagnosis), very few differences in information needs and importance values were indicated, as discussed below.

## Differences in Information Needs Among Patients According to Person-related Variables

Differences according to sex. The few differences in information needs between males and females indicate that females have a greater need than men for information in relation to prognosis, psychological well-being, sibling(s), and making new friends among patients. Males attached more importance value than females to information about diagnosis and physical well-being. Females attached more importance than males to information about spouse, siblings, and parents.

These observations may relfect reinforced cultural traits insofar as expression of concern and seeking succurance is reinforced by societal expectations in the upbringing of the female in this society from which the sample was drawn. Females recognized and expressed more readily than men their needs for information about these concerns. Also, role structure proscribes the care and relational responsibility of the family members more to the expressive role of the female. Therefore, females recognized and expressed more readily than men their concern and need for information in relation to family members. Likewise, males were more concerned than females about diagnosis and physical well-being, reflecting societal expectations of physical well-being and function, and stoicism.

The second explanation relates to the general similarity of information needs of recently diagnosed cancer patients evidenced in the absence of significant differences in the information need counts and in importance values in the several variables according to which males and females were compared. The third relates to the possible interaction of the variable of sex with other intervening variables which were not controlled. Thus, the variations may reflect the sex differences combined with those of age, type or stage of cancer, type of treatment, education, or other variables. Finally, the findings may reflect the validity and reliability of the instrument in discriminating some empirically expected differences based on the variable of sex, and possibly, in reflecting the homogeneity of the groups in the absence of differences in the variable of information need by these groups, if they were homogeneous. Inferences related to these interpretations cannot be made on the basis of the data, which indicate the need for research in larger samples and multivariate analytical designs to discern the relationship of information needs and the variable of sex.

Differences according to age. The few differences in information needs and importance values seen among the young adults, adults, and older adults, indicate that the young adults and adults tended to have greater need than older adults for information in relation to spouse, parents, siblings, and job/career relationships. Likewise, young adults and adults tended to attach greater importance than older adults to information in relation to spouse than older adults.

These differences are consistant with Newgarten's (1968a) theories as well as with empirical knowledge of the age-specific characteristics, as the older patients in the sample were mostly retired, widowed, separated from family, and had no living parents. However, inferences about such differences cannot be made because of a lack of control for several intervening variables. The lack of significant differences among the groups may reflect similarity of information needs despite the variable of age, and thus perhaps the findings reflect the validity and reliability of the instrument. These differences may reflect a rudimentary sensitivity of INA in the discrimination of the patients whose lack of information needs in relation to the particular concerns is compatible with their demographic characteristics. Some sensitivity of INA is also suspected in the lack of differences in information among patients stratified according to the person- or situation-related variables, thus, in the reflection of a possible homogeneity of information needs of the sample, if this was so. However, such inferences cannot be drawn from the data, because other intervening variables were not controlled.

## Differences in Information Needs Among Patients According to Situation-related Variables

Differences according to stage of cancer. Patients with local and regional cancer tended to indicate greater information needs than the patients with disseminated cancer regarding spouse concerns. There were no significant differences among the three groups stratified according to the person or situation-related variables in the importance values attached to information needs related to all of the categories in the major categories.

These observations should likewise be interpreted in view of the limitations cited regarding the comparative descriptions among groups stratified by sex and age. These observed differences, and their lack, in information needs among the groups stratified by person- or situation-related variables, indicate that relationship between information needs and these variables may or may not exist, and that further research is needed to explore and describe them.

## Summary

In this chapter it was demonstrated that the INA is a valid, reliable, and comprehensive instrument. The information needs and their importance values expressed by the recently diagnosed cancer patients in this study were described in terms of harms, threats, and resources within the major categories of Disease, Personal, Family, and Social Concerns. These findings support Lazarus' (1966) postulation that appraisal aims at configuring harm, threat, and resources in confronting noxious stimuli. They also imply support of the contention in the theoretical framework that information seeking aims at defining the harm, threat, and resources, and in so doing may mediate appraisal.

The rank order of information needs by aggregate response counts and importance values indicate dominances of information needs compatible with the hierarchy of needs. The dominant information needs within each major category are in relation to Treatments (Disease Concerns), Psychological Well-being (Personal Concerns), Spouse (Family Concerns), and Job/Career Relationships and Future Relationships (Social Concerns). Dominance of information needs among the major categories is indicated according to their rank order by aggregate response counts and importance values. The dominant information needs among the major categories are related to Disease, Personal, Family, and Social Concerns. This order of dominance of information needs also is compatible with the hierarchy of needs.

The hierarchial order of the dominances of information needs is compatible with the amount, imminence, and likelihood of anticipated events confronting the cancer patient after the diagnosis. Therefore, the hierarchy of dominances in information needs may be explained as being related to the order of the amount, imminence, and likelihood of such events as well. Therefore, it may be extrapolated that information needs may be related to both hierarchy of needs and the amount, likelihood, and imminence of events. These possible relationships are explained as that, in the recently diagnosed cancer patient, hierarchy of needs and amount, imminence, and likelihood of events, together, may determine the relevance of a situation, and therefore the relevance of information. Information, in turn, may (a) determine the need for information, and (b) mediate information seeking, as contended in the theoretical framework.

Differences in information need or their importance values among groups stratified by person- and situation-related variables were minimal. Information needs in the recently diagnosed cancer patients in this study may or may not be universal, and they may or may not be related to person- or situation-related variables. Further research to explore such relationships is indicated.

# CHAPTER VII

# CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

## Conclusions

### Conclusions Pertaining to the Methodological Findings

According to the methodological objective of the study, the INA is developed as a valid, reliable, and comprehensive instrument to describe information needs of recently diagnosed cancer patients. Although it was not intended to establish its sensitivity, some evidence of its rudimentary sensitivity is apparent, and data indicate research to establish this. As a by-product, the Derdiarian-Lewis binomial test of proportion of agreement is developed as a stronger measure of interrater reliability.

### Conclusions Pertaining to Information Needs Findings

According to the purpose of this study, information needs of 60 recently diagnosed cancer patients are described in relation to their disease and to their personal, family, and social concerns. These patients indicated their needs for information and their importance in relation to the major categories of Disease, Personal, Family, and Social Concerns. Information needs are also described in terms of harm, threats, and resources within these major categories. These findings support Lazarus' (1966) postulation that appraisal aims at configuring the harm, threat, and resources in confronting noxious stimulii. They also imply support to the contention in the theoretical framework of the study that information seeking may mediate appraisal.

There are dominances in information needs within the major categories as well as among them. The rank order by aggregate response counts and importance values of information needs within each major category indicate the dominant information needs as related to Treatments (Disease Concerns), Psychological Well-being (Personal Concerns), Spouse (Family Concerns), and Job/Career Relationships and Future Relationships (Social Concerns). Dominance of information needs among the major categories rank ordered by response counts and importance values as related to Disease, Personal, Family, and Social Concerns.

Rank orders of information needs related to the dominant categories and the major categories indicate hierarchies compatible with the hierarchy of needs (physical, psychological, social). This observation may imply a possible relationship between information need and the hierarchy of needs, and thus may imply support of the contention in the theoretical framework that hierarchy of needs may determine the information needs.

These rank orders of information needs indicate hierarchies compatible with the order of amount, imminence, and likelihood of events confronting the cancer patient after the diagnosis. Therefore, the hierarchies of information could be explained by the relative amount, imminence, and likelihood of events related to the disease, personal, family, and social concerns. This observation may imply a possible relationship between information need and the degree of amount, imminence, and likelihood of anticipated events. It implies support of Lazarus' (1966) postulations (a) that threat is primarily the function of the amount, imminence, and likelihood of anticipated harm, and (b) that all threat may fall on a continuum of degree.

Together, the hierarchy of need, and degree of amount, imminence, and likelihood, may determine relevance, which imply support of the contention in the theoretical framework of the study that relevance of need may determine information seeking.

Based on the observations derived from the data, it may be proposed that the hierarchy of needs and the degree of amount, imminence, and likelihood of anticipated harm may determine the lack of information. This lack may determine the need for information which may mediate (a) information seeking, and (b) the nature of information sought.

### Conclusions Pertaining to Exploratory-Comparison Findings

It was another objective of the study to explore whether there are differences in information needs among patients stratified according to person- or situation-related variables. Comparisons of information needs among patients stratified by person-related variables (sex, age, marital status, education, having or having not read about cancer since diagnosis) show few differences in information needs. Women needed more information than men in relation to prognosis, psychological well-being, and parents. Young adults and adults tended to need more information than older adults in relation to spouse, parents, siblings, and job/career relationships. Comparisons of importance values attached to informaiton needs among patients stratified by person-related variables show that males attached more importance than females to information related to diagnosis, physical well-being, and spouse. Comparisons of information needs of patients stratified by situation-related variables (type, stage, and treatment of cancer, time since diagnosis, and time since first symptom and source of patient referral) show one difference. Patients with local and regional cancer needed more information in relation to spouse. There are no other differences in information needs or importance values among patients stratified by person- or situation-related variables.

These findings are not sufficient to infer differences in information needs among patients compared. They merely mean such differences may or may not exist, and also that information needs may or may not be universal in the sample studied. Further explorations are needed to determine these.

## Implications

### Implications Pertaining to the Methodological Findings

It is recommended that the INA instrument be used as a research instrument in similar (or other designs) to describe information needs of recently diagnosed cancer patients. It is also suitable to be used to describe information needs of patients recently diagnosed with other long-term illnesses. (Recommendations pertaining to its use are provided below.) The Derdiarian-Lewis binomial test is suitable to be used to establish interrater reliability among judge panel members, intercoders, interobservers of behavior, or in estimating agreement in other binomial data.

The INA is suitable for clinical practice as well. Its particular implication for practice, based on its design, is for more accurate identification and description of the nature, amount, and importance of information needed. It can be used to assess information needs of recently diagnosed cancer patients as a basis of patient teaching, counseling, referring, or evaluating change (as a function of teaching, change of events, or other reasons) in patient information needs. Documentation of such data has wide implications for systematic practice and generation of data for clinical research. It has similar implications for practice in other cancer patient populations or in patients with other long-term illness.

## Implications Pertaining to Information Needs Findings

Implications of the findings pertaining to information needs and their importance values relate to research. Data are needed to describe the nature, amount, and importance values of information needs of other recently diagnosed cancer patients. Data are also needed to describe the information needs and their importance values in cancer patients in other stages of the disease, or those contending with critical events such as treatments, remission, or relapse. Findings imply replication of this study in patients with other long-term illnesses.

The findings pertaining to the hierarchy of information needs imply research to determine whether information needs of recently diagnosed cancer patients are related to (a) the hierarchy of needs, (b) the amount, imminence, and likelihood of anticipated harm, and (c) the amount of information known about concerns. These findings also imply research to determine whether such relationships exist in other recently diagnosed cancer patients, or in cancer patients in other stages of the disease.

Implications of the findings to the theories used include: providing empirical support to their respective postulations, discover-ing potential relationships among the theories of coping, appraisal, information seeking, information need and hierarchy of needs, and providing a potential framework of their interrelationships.

The implications of the findings also relate to practice. There is a need to examine the assumptions underlying patient information and counseling practices in view of the findings; recently diagnosed cancer patients need and are able to evaluate information in relation to their disease, personal, family, and social concerns. They need resources to contend with the existing physical and psychological harm as well as with such threats. Hierarchies of information needs can be determined to design judicious, essential, and economical patient teaching, counseling, and referral practices. Implications for health care facilities should examine the aggregate amount of time, facilitation, and professional skills assigned to meet the patient's as well as the family's information and counseling needs.

Implications are for evaluating whether provisions of time, place, and professional service should be designated to meet the patient's or the family's information and counseling needs following the diagnosis. Often patients are unable to discern the nature of their information needs, or anticipate them. Most importantly, the implications for nursing practice are that patients' information needs should be systematically assessed, intervened, and evaluated. Interventions should consider reassessments of priorities of information needs over time, as these may vary.

### Implications Pertaining to the Exploratory-Comparison Findings

Implications pertaining to the differences in information needs and their importance values for research are for further explorations to determine whether relationships between information needs and person- or situation-related variables exist, and to describe such relationships.

Implications pertaining to the differences in information needs and their importance values are to sensitize the health care professional that information needs and their importance may or may not be universal in recently diagnosed cancer patients, therefore, information needs should be assessed in light of possible commonality of such needs. At the same time, such needs should be assessed in light of the possible uniqueness of the patient on the basis of the demographic characteristics of the patient.

## Recommendations

### Recommendations Pertaining to the Methodological Findings

The INA should be used in research designs to describe information needs of other recently diagnosed cancer patients. It should be used to describe information needs in other patients recently diagnosed with other long-term illnesses. The necessary provisions for its use are methodological modifications in the items, content validity, reliability, and comprehensiveness, as appropriate for the population for study. Its sensitivity in eliciting information needs of recently diagnosed cancer patients should be determined in large samples using appropriate designs.

The Derdiarian-Lewis binomial test should be used as a stronger measure of intercoder reliability than measures of percent agreement often used in nursing and behavioral research. Its use is recommended in content analysis designs or other designs requiring measure of agreement in binomial data.

The INA is recommended for clinical practice to determine the information needs and their importance values of the recently diagnosed cancer patients. Modifications in its content and length are recommended as appropriate to the characteristics of the patients to be assessed.

## Recommendations Pertaining to Information Needs and Findings

The study should be replicated in other recently diagnosed cancer patients to determine stronger support in terms of the nature, scope, importance, and hierarchy of information needs described in this study. The study should be replicated in large cross-sectional samples in similar populations to determine the validity of the nature, scope, importance, and hierarchy of information needs in terms of recently diagnosed cancer patients. This objective can be met also in the replication of the design in longitudinal studies across illness events such as treatments, remission, and relapse, to discern whether changes in information needs occur according to changes in these events. Likewise, randomly selected populations are recommended to achieve similar aims if small samples are to be used. Multivariate analytical designs should be used in conjunction with these recommendations. Similar replications of the study are recommended to determine the relationship of information needs to (a) hierarchy of needs, (b) amount, imminence, and likelihood of anticipated harm, and (c) amount of information known about concerns.

Recommendations for practice are that recently diagnosed cancer patients' information needs and their importance values be assessed in terms of the harms, threats, and resources as perceived by them. Also, that the information needs of the family members, particularly those of the spouse, be assessed and intervened.

### Recommendations Pertaining to Exploratory-Comparison Findings

Data from large samples of recently diagnosed cancer patients should be used with multivariate analytical designs to determine whether differences in information needs and importance values exist among groups stratified by person- or situation-related variables. Also, smaller, randomly selected, recently diagnosed cancer patient samples, or samples homogeneous in these characteristics, can be studied in terms of information needs and importance values, because the recruitment of these patients to participate in such studies is extremely difficult and requires much financial resources and time.

## Summary

The purpose of the study is to describe the information needs of recently diagnosed cancer patients in relation to their disease as well as to their personal, family, and social concerns.

The theoretical framework is constructed from theories of coping, appraisal, information seeking, information needs, and hierarchy of needs. Categories of analysis are derived from the theories and findings of previous research.

Methodological, descriptive, and exploratory-comparative designs are simultaneously used. The INA (Information Need Assessment) instrument is developed as a valid, reliable, and comprehensive interview instrument which is used to gather the data. Data gathered from 60 recently diagnosed cancer patients are content analyzed by the researcher. The intracoder reliability is established by percent agreement among data coded and recoded at 6-8 week intervals, and by intercoder reliability using the Derdiarian-Lewis binomial test of proportion of agreements developed during this study.

According to the purpose of this study, information needs of 60 recently diagnosed cancer patients are described in relation to their disease and to their personal, family, and social concerns. These patients indicated their needs for information and their importance in relation to the major categories of Disease, Personal, Family, and Social Concerns. Information needs are also described in terms of harm, threats, and resources within these major categories. These findings support Lazarus' (1966) postulation that appraisal aims at configuring the harm, threat, and resources in confronting noxious stimulii. They also imply support to the contention in the theoretical framework of the study that information seeking may mediate appraisal.

There are dominances in information needs within the major categories as well as among them. The rank order by aggregate response counts and importance values of information needs within each major category indicate the dominant information needs as related to Treatments (Disease Concerns), Psychological Well-being (Personal Concerns), Spouse (Family Concerns), and Job/Career Relationships and Future Relationships (Social Concerns). Dominance of information needs among the major categories rank ordered by response counts and importance values as related to Disease, Personal, Family, and Social Concerns.

Rank orders of information needs related to the dominant categories and the major categories indicate hierarchies compatible with the hierarchy of needs (physical, psychological, social). This observation may imply a possible relationship between information need and the hierarchy of needs, and thus may imply support of the contention in the theoretical framework that hierarchy of needs may determine the information needs.

These rank orders of information needs indicate hierarchies compatible with the order of amount, imminence, and likelihood of events confronting the cancer patient after the diagnosis. Therefore, the hierarchies of information could be explained by the relative amount, imminence, and likelihood of events related to the disease, personal, family, and social concerns. This observation may imply a possible relationship between information need and the degree of amount, imminence, and likelihood of anticipated events. It implies support of Lazarus' (1966) postulations (a) that threat is primarily the function of the amount, imminence, and likelihood of anticipated harm, and (b) that all threat may fall on a continuum of degree. Together, the hierarchy of need, and degree of amount, imminence, and likelihood, may determine relevance, which imply support of the contention in the theoretical framework of the study that relevance of need may determine information seeking.

Based on the observations derived from the data, it may be proposed that the hierarchy of needs and the degree of amount, imminence, and likelihood of anticipated harm may determine the lack of information. This lack may determine the need for information which may mediate (a) information seeking, and (b) the nature of information sought.

It was another objective of the study to explore whether there are differences in information needs among patients stratified according to person- or situation-related variables. Comparisons of information needs among patients stratified by person-related variables (sex, age, marital status, education, having or having not read about cancer since diagnosis) show few differences in information needs. Women needed more information than men in relation to prognosis, psychological well-being, and parents. Young adults and adults tended to need more information than older adults in relation to spouse, parents, siblings, and job/career relationships. Comparisons of importance values attached to informaiton needs among patients stratified by person-related variables show that males attached more importance than females to information related to diagnosis, physical well-being, and spouse. Comparisons of information needs of patients stratified by situation-related variables (type, stage, and treatment of cancer, time since diagnosis, and time since first symptom and source of patient referral) show one difference. Patients with local and regional cancer needed more information in relation to spouse. There are no other differences in information needs or importance values among patients stratified by person- or situation-related variables.

These findings are not sufficient to infer differences in information needs among patients compared. They merely mean such differences may or may not exist, and also that information needs may or may not be universal in the sample studied. Further explorations are needed to determine these.

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# APPENDIX A

Table 1

Patients Classified by Sex, Age, Marital Status, Race, Education, Job/Career, and Reading About Cancer (N=60)

| Variable | N | % |
|---|---|---|
| **Sex** | | |
| Male | 31 | 52 |
| Female | 29 | 48 |
| **Age** | | |
| 18-35 (young adult) | 18 | 30 |
| 36-55 (adult) | 30 | 50 |
| 56-70 (older adult) | 12 | 20 |
| **Marital Status** | | |
| Married | 41 | 68 |
| Widow/Separated/Divorced | 9 | 15 |
| Single | 10 | 17 |
| **Education** | | |
| High School or equivalent (H.S.) | 17 | 28 |
| Junior College to College (A.A.-B.A.) | 26 | 44 |
| College to Graduate (B.A.-M.A.) | 11 | 18 |
| Graduate or Advanced Education (Ph.D) | 6 | 10 |
| **Race** | | |
| White | 58 | 97 |
| Hispanic | 2 | 3 |
| **Job or Career** | | |
| Employed | 48 | 80 |
| Unemployed | 2 | 3 |
| Retired | 10 | 17 |
| **Read About Cancer** | | |
| Read | 22 | 37 |
| Did not read | 38 | 63 |

Table 2

Patients Classified by Type of Cancer, Stage of Cancer, Type of Treatment, Time Since Diagnosis, Time Since Symptoms, Source of Patients (N=60)

| Variable | N | % |
|---|---|---|
| Type of Cancer | | |
| Melanoma | 29 | 48 |
| Other hard tumors | 24 | 40 |
| Hematopoetic | 7 | 8 |
| Stage of Cancer | | |
| Local disease | 23 | 38 |
| Regional disease | 23 | 38 |
| Metastatic/Generalized disease | 14 | 22 |
| Type of Initial Treatment | | |
| Surgery | 37 | 62 |
| Chemotherapy | 22 | 36 |
| Radiation Therapy | 1 | 2 |
| Time Since Diagnosis | | |
| 1-6 days | 24 | 40 |
| 7-12 days | 27 | 45 |
| 12-17 days | 9 | 15 |
| Time Since Symptoms | | |
| 1 week to 2 weeks | 13 | 22 |
| 2 weeks to 4 weeks | 9 | 12 |
| 4 weeks to 12 weeks | 5 | 8 |
| 12 weeks to 16 weeks | 13 | 22 |
| 16 weeks to 20 weeks | 0 | 0 |
| 20 weeks to 100 weeks | 20 | 33 |
| Source of Patients | | |
| One comprehensive cancer center | 50 | 83 |
| Other oncology medical groups | 8 | 13 |
| HMO (Health Maintenance Organization) | 2 | 3 |

Table 3

Patients Classified by Relationship With Spouse, Children, Parents, Siblings; Job/Career, Peers, Special Interest Groups, and Leisure Groups, and Importance of Religious Beliefs and Practices (N=60)

| Variable | N | % |
|---|---|---|
| <u>Family Relationships</u> | | |
| Spouse/Significant Other | 41 | 70 |
| Child/Children | 40 | 69 |
| Sibling(s) | 42 | 70 |
| Parent(s) | 38 | 63 |
| <u>Social Relationships</u> | | |
| Job/Career Relationships | 50 | 83 |
| Special Interest Group Relationships | 19 | 31 |
| Leisure Group Relationships | 26 | 43 |
| <u>Importance of Religious Beliefs and Practices</u> | | |
| Very important | 36 | 60 |
| Somewhat important | 13 | 22 |
| Not very important | 10 | 17 |
| Not at all important | 1 | 1 |

Table 4

Percent Agreement Values Among Three Members of Judge Panel Members on Items of Information Assessment Instrument by Category

| Category | Number of Items | Percent Agreement |
|---|---|---|
| Disease Concern | | |
| Diagnosis | 7 | 100 |
| Test(s) | 7 | 100 |
| Treatment(s) | 7 | 100 |
| Prognosis | 7 | 100 |
| Other | 1 | 100 |
| Importance Value | 1 | 100 |
| Personal Concern | | |
| Job/Career | 7 | 100 |
| Plans/Goals | 7 | 100 |
| Physical Wellbeing | 7 | 100 |
| Psychological Wellbeing | 7 | 100 |
| Other | 1 | 100 |
| Importance Value | 1 | 100 |
| Family Concern | | |
| Spouse | 7 | 100 |
| Children | 7 | 100 |
| Parent(s) | 7 | 100 |
| Sibling(s) | 7 | 100 |
| Other | 1 | 100 |
| Importance Value | 1 | 100 |
| Social Concern | | |
| Job/Career Relationships | 7 | 100 |
| Special Interest Relationships | 7 | 100 |
| Leisure Relationships | 7 | 100 |
| Future Relationships | 7 | 100 |
| Other | 1 | 100 |
| Importance Value | 1 | 100 |

Table 5

Percent Agreement Values Among Three Members of Judge Panel on Categories and Subcategories of Content Analysis by Major Category and Category (N=3)

| Category | Number of Categories | Number of Subcategories | Percent Agreement |
|---|---|---|---|
| Disease Concerns | | | |
| Diagnosis | 3 | 8 | 100 |
| Test(s) | 3 | 8 | 100 |
| Treatment(s) | 3 | 9 | 100 |
| Prognosis | 2 | 7 | 100 |
| Personal Concerns | | | |
| Job/Career | 2 | 5 | 100 |
| Plans/Goals | 2 | 6 | 100 |
| Physical Wellbeing | 3 | 7 | 100 |
| Psychological Wellbeing | 3 | 9 | 100 |
| Family Concerns | | | |
| Spouse | 6 | 9 | 100 |
| Children | 5 | 9 | 100 |
| Parents | 5 | 8 | 100 |
| Siblings | 5 | 7 | 100 |
| Social Concerns | | | |
| Job/Career Relationships | 3 | 5 | 100 |
| Special Interest Relationships | 3 | 5 | 100 |
| Leisure Relationships | 3 | 5 | 100 |
| Future Relationships | 3 | 7 | 100 |

Table 6

Summary of P-Values of Test Re-Test Reliability of Responses to the Information Needs Assessment Instrument Using the McNemar Test of Symmetry/Agreement by Categories

| Major Category | Total Number Of Items | Number of Items Compared | Number of Patients | Percent Agreement | P-Value (p< .05)* |
|---|---|---|---|---|---|
| Disease Concerns | 23 | 5 (22%) | 17 | 100 | 1.00 |
| | | 2 ( 9%) | 15 | 100 | 1.00 |
| | | 2 ( 9%) | 14 | 100 | 1.00 |
| | | 1 ( 4%) | 4 | 100 | 1.00 |
| | | 4 (17%) | 17 | 94 | 0.37 |
| | | 4 (17%) | 16 | 94 | 0.37 |
| | | 2 ( 9%) | 17 | 88 | 0.14 |
| | | 1 ( 4%) | 13 | 88 | 0.14 |
| | | 1 ( 4%) | 1 | 68 | 0.001 |
| | | 1 ( 4%) | 1 | NA | NA |
| Personal Concerns | 26 | 4 (15%) | 16 | 100 | 1.00 |
| | | 4 (15%) | 15 | 100 | 1.00 |
| | | 1 ( 4%) | 14 | 100 | 1.00 |
| | | 2 ( 7%) | 8 | 100 | 1.00 |
| | | 1 ( 4%) | 7 | 100 | 1.00 |
| | | 1 ( 4%) | 16 | 94 | 0.37 |
| | | 2 ( 7%) | 15 | 94 | 0.37 |
| | | 2 ( 7%) | 13 | 94 | 0.37 |
| | | 2 ( 7%) | 8 | 94 | 0.37 |
| | | 1 ( 4%) | 11 | 88 | 0.14 |
| | | 1 ( 4%) | 16 | 82 | 0.05 |
| | | 1 ( 4%) | 15 | 80 | 0.10 |
| | | 4 (15%) | 15 | NA | NA |
| Family Concerns | 35 | 2 ( 6%) | 9 | 100 | 1.00 |
| | | 10 (29%) | 8 | 100 | 1.00 |
| | | 3 ( 9%) | 6 | 100 | 1.00 |
| | | 4 (11%) | 5 | 100 | 1.00 |
| | | 1 ( 3%) | 7 | 100 | 1.00 |
| | | 1 ( 3%) | 4 | 100 | 1.00 |
| | | 2 ( 6%) | 9 | 94 | 0.37 |
| | | 4 (11%) | 8 | 94 | 0.37 |
| | | 1 ( 3%) | 5 | 94 | 0.37 |
| | | 1 ( 3%) | 6 | 88 | 0.14 |
| | | 1 ( 3%) | 5 | 88 | 0.14 |
| | | 5 (14%) | 11 | NA | NA |

Table 6, continued

| Major Category | Total Number Of Items | Number of Items Compared | Number of Patients | Percent Agreement | P-Value ($p < .05$) |
|---|---|---|---|---|---|
| Social Concerns | 20 | 11 (55%) | 13 | 100 | 1.00 |
| | | 1 ( 5%) | 10 | 100 | 1.00 |
| | | 1 ( 5%) | 4 | 100 | 1.00 |
| | | 4 (20%) | 13 | 94 | 0.37 |
| | | 1 ( 5%) | 13 | 88 | 0.14 |
| | | 1 ( 5%) | 10 | 88 | 0.14 |
| | | 1 ( 5%) | 8 | 88 | 0.14 |

*$p < .05$ minimum acceptable p-value of test-retest reliability (agreement).

Table 6a

Estimated Percent Values of Test-retest Agreement Reliability of Responses to the Information Needs Assessment Instrument

| Major Category | Total Number Of Items | Number of Items Compared | Number of Patients | Percent* Agreement |
|---|---|---|---|---|
| Disease Concerns | 23 | 1 ( 4%) | 1 | 100 |
| Personal Concerns | 26 | 2 ( 7%) | 2 | 100 |
| | | 1 ( 4%) | 5 | 88 |
| | | 1 ( 4%) | 7 | 86 |
| Family Concerns | 35 | 2 ( 6%) | 2 | 100 |
| | | 1 ( 3%) | 1 | 100 |
| | | 1 ( 3%) | 5 | 88 |
| | | 1 ( 3%) | 7 | 86 |
| Social Concerns | 20 | 1 ( 3%) | 1 | 100 |

*75% minimum acceptable percent value of test-retest reliability (agreement).

## Table 6b

## Differences in Test-Retest Mean Scores of Importance Value (1-100) Attached to Information Needed in Categories of Disease, Personal, Family, and Social Concerns, Using Paired T-test

| Importance of Information About | N | Mean | Min.-Max. | S.E.M. | T-value | P-value (p<.05) |
|---|---|---|---|---|---|---|
| Disease Concerns | | | | | | |
| Diagnosis | 12 | 1.67 | (0.0, 10) | 0.86 | 1.34 | 0.21 |
| Test | 9 | -6.55 | (-27, 0.0) | 3.63 | -1.80 | 0.11 |
| Treatment | 11 | 1.20 | (0.0, 5) | 0.61 | 1.92 | 0.08 |
| Prognosis | 14 | -10.3 | (-4.5, 0.0) | 4.23 | -2.43 | 0.03* |
| Personal Concerns | | | | | | |
| Job/Career | 9 | 0.0 | (0.0, 0.0) | 0.0 | 0.0 | 1.00 |
| Plans/Goals | 10 | 0.20 | (-5.0, -3.0) | 0.61 | 0.33 | 0.75 |
| Physical Wellbeing | 13 | -8.7 | (-45.0, 10.0) | 4.41 | -1.97 | 0.07 |
| Psychological Wellbeing | 12 | -9.41 | (-100, 0.0) | 9.14 | -1.03 | 0.32 |
| Family Concerns | | | | | | |
| Spouse | 11 | 1.81 | (0.0, 5.0) | 0.76 | 2.39 | 0.04** |
| Children | 8 | -15.4 | (-98, 0.0) | 12.0 | -1.28 | 0.24 |
| Parents | 3 | -1.67 | (-3.0, 0.0) | 0.88 | -1.9 | 0.19 |
| Siblings | 2 | -1.50 | (-3.0, 0.0) | 1.50 | -1.0 | 0.50 |
| Social Concerns | | | | | | |
| Job/Career Relationship | 7 | -22.4 | (-89.0, 5.0) | 12.7 | -1.6 | 0.16 |
| Special Interest Relationship | 4 | 0.0 | (0.0, 0.0) | 0.0 | 0.0 | 1.00 |
| Leisure Relationship | 5 | 3.0 | (0.0, 10.0) | 2.0 | 1.5 | 0.20 |
| Future Relationship | 7 | 0.0 | (0.0, 0.0) | 0.0 | 0.0 | 1.00 |

*p< 0.05 minimum acceptable p-value of reliability (no significant difference)

Table 7

Summary of Probability Values of Agreement Among Three Coders of Patient Responses Using Derdiarian-Lewis Binomial Test of Agreement by Categories of Disease, Personal, Family, and Social Concerns

| Category | Total Number of Items | Number of Items | Number of Patients | Percent Agreement | P-Value (p<.05)* |
|---|---|---|---|---|---|
| Disease Concerns | 56 | 40 (71%) | 6 | 100% | 0.000 |
| | | 18 (31%) | 6 | 83.3% | 0.004 |
| Personal Concerns | 56 | 35 (63%) | 6 | 100% | 0.000 |
| | | 6 (11%) | 5 | 100% | 0.001 |
| | | 11 (20%) | 6 | 83.3% | 0.004 |
| | | 3 ( 5%) | 5 | 80.0% | 0.015 |
| | | 1 ( 2%) | 6 | 66.7% | 0.037 |
| Family Concerns | 82 | 21 (26%) | 6 | 100% | 0.000 |
| | | 16 (20%) | 5 | 100% | 0.001 |
| | | 38 (46%) | 4 | 100% | 0.003 |
| | | 2 ( 2%) | 6 | 83.3% | 0.004 |
| | | 2 ( 2%) | 5 | 80.0% | 0.015 |
| | | 1 ( 1%) | 6 | 66.7% | 0.037 |
| | | 2 ( 2%) | 3 | 75% | 0.050 |
| Social Concerns | 57 | 51 (89%) | 6 | 100% | 0.000 |
| | | 5 (11%) | 6 | 83.3% | 0.004 |

*p<.05 minimum acceptable p-value of reliability (agreement).

## Table 8

## Percent Agreement in Coding Re-coding of Responses of Six (6) Patients by One Coder, by Major Categories

| Category | Subject # | Number of Items | Time 1 | Time 2 | Percent* Agreement |
|---|---|---|---|---|---|
| Disease Concerns | 1 | 8 | | | 100 |
| Personal Concerns | 1 | 11 | | | 100 |
| Family Concerns | 1 | 13 | | | 100 |
| Social Concerns | 1 | 7 | | | 100 |
| | | | | | 100 |
| Disease Concerns | 2 | 14 | | | 100 |
| Personal Concerns | 2 | 21 | | | 90 |
| Family Concerns | 2 | 9 | | | 100 |
| Social Concerns | 2 | 11 | | | 100 |
| | | | | | 97.5 |
| Disease Concerns | 3 | 16 | | | 100 |
| Personal Concerns | 3 | 18 | | | 100 |
| Family Concerns | 3 | 8 | | | 92 |
| Social Concerns | 3 | 6 | | | 100 |
| | | | | | 98 |
| Disease Concerns | 4 | 10 | | | 100 |
| Personal Concerns | 4 | 9 | | | 100 |
| Family Concerns | 4 | 15 | | | 100 |
| Social Concerns | 4 | 19 | | | 98 |
| | | | | | 99.5 |
| Disease Concerns | 5 | 11 | | | 96 |
| Personal Concerns | 5 | 7 | | | 100 |
| Family Concerns | 5 | 9 | | | 100 |
| Social Concerns | 5 | 10 | | | 100 |
| | | | | | 98.5 |
| Disease Concerns | 6 | 23 | | | 98 |
| Personal Concerns | 6 | 29 | | | 96 |
| Family Concerns | 6 | 6 | | | 100 |
| Social Concerns | 6 | 13 | | | 100 |
| | | | | | 98.5 |

Total Percent Agreement 6 = $\frac{5900}{6000}$ = 98.3%

*80% minimum percent agreement acceptable measure of content validity.

## Table 9

Information Needed by Patients in the Category of Disease Concerns, by Frequency Count and Percent of Responses (N=60)

| Content of Information Needed in the Category of Disease Concerns | Responses N | Responses % |
|---|---|---|
| Diagnosis | | |
| Information Needed Overall Responses | 48 | 80 |
| 1. Nature of the Cancer (Harm) | 39 | 65 |
| a. Type of the cancer | 22 | 37 |
| b. Site of the cancer | 9 | 15 |
| c. Arrestibility of the cancer | 27 | 45 |
| 2. Extent of the Cancer (Harm) | 38 | 63 |
| a. Stage (level of disease progress) | 24 | 40 |
| b. Meaning of stage (implications of and for spread) | 33 | 55 |
| 3. Etiology of the Cancer (in one's own case) (Harm) | 17 | 28 |
| a. Biological factors (hereditary) | 9 | 15 |
| b. Behavioral factors (habits) | 10 | 16 |
| c. Environmental factors (occupation and the like) | 6 | 10 |
| Test(s) | | |
| Information Needed Overall Responses | 33 | 55 |
| 1. Nature of Test(s) (Threat) | 25 | 42 |
| a. Type of test(s) | 19 | 32 |
| b. Purpose of test(s) | 18 | 30 |
| c. Procedure of test(s) | 16 | 27 |
| 2. Results of Test(s) (Threat) | 28 | 47 |
| a. Accuracy of tests and/or results | 13 | 22 |
| b. Meaning of results (implications) | 20 | 33 |
| 3. Consequences of Test(s) (unintended, adverse) (Threat) | 21 | 35 |
| a. Pain | 6 | 10 |
| b. Loss of tissue | 6 | 10 |
| c. Loss of physical and/or physiological function | 9 | 15 |

Table 9, continued

| Content of Information Needed in the Category of Disease Concerns | Responses | |
|---|---|---|
| | N | % |
| Treatment(s) | | |
| Information Needed Overall Responses | 54 | 90 |
| 1. Nature of Treatment(s) (Threat) | 37 | 62 |
| a. Type of treatment(s) | 20 | 33 |
| b. Purpose of treatment(s) (main goal(s) and/or mode of action) | 14 | 23 |
| c. Procedure of treatment(s) | 19 | 32 |
| d. Experimental treatments | 4 | 7 |
| e. Adjuvant treatments (possibility and/or purpose) | 24 | 40 |
| 2. Results (intended) (Resource) | 46 | 77 |
| a. Effectiveness of treatment(s) | 38 | 63 |
| b. Alternatives if primary treatment(s) fails | 22 | 37 |
| c. Symptom control (disease and/or treatment) | 14 | 23 |
| 3. Consequences (unintended, adverse) (Threat) | 54 | 90 |
| a. Physical | 39 | 65 |
| - symptoms | 35 | 58 |
| - appearance | 28 | 47 |
| - complications (risk factors) | 19 | 32 |
| - biological loss (such as gland function) | 10 | 17 |
| b. Function (activity level) | 34 | 57 |
| - strength (stamina) | 23 | 38 |
| - limitation on activity due to tissue loss | 27 | 45 |
| - time needed for treatment(s) | 18 | 30 |
| - time needed for recuperation | 27 | 45 |
| Prognosis | | |
| Information Needed Overall Responses | 54 | 90 |
| 1. Facts Related to the Prognosis (Threat) | 52 | 87 |
| a. Knowing of the prognosis | 10 | 17 |
| b. Morbidity rate | 36 | 60 |
| - recurrence following remission | 31 | 52 |
| - failure to control current disease | 31 | 52 |
| c. Mortality rate | 6 | 10 |

Table 9, continued

| Content of Information Needed in the Category of Disease Concerns | Responses | |
|---|---|---|
| | N | % |
| Prognosis, continued | | |
| 2. Implications of prognosis for self (Threat) | 45 | 75 |
| a. Survival | 30 | 50 |
| b. Type of events to expect | 25 | 42 |
| c. Time of events (timetable of events to expect) | 19 | 32 |
| d. Measures one must take in light of prognosis | 21 | 35 |

Table 9, continued

Information Needed by Patients in the Category of Personal Concerns, by Frequency Count and Percent of Responses (N=60)

| Content of Information Needed in the Category of Personal Concerns | Responses N | Responses % |
|---|---|---|
| Job/Career (n = 50) | | |
| Information Needed Overall Responses | 38 | 64 (76) |
| 1. Implications for Work Production (Threat) | 19 | 32 (38) |
| 2. Implications for Self (Threat) | 36 | 60 (72) |
| a. Physical disability (residual of disease) | 29 | 48 (58) |
| b. Physical disability (residual of treatment) | 25 | 42 (50) |
| c. Financial loss | 22 | 37 (44) |
| - reduction of earning | 9 | 15 (18) |
| - cost of treatment (how to manage) | 10 | 17 (20) |
| d. Loss or change of job (whether necessary) | 12 | 20 (24) |
| e. Loss of promotion, benefits | 16 | 27 (32) |
| Plans and Goals | | |
| Information Needed Overall Responses | 35 | 58 (70) |
| 1. Implications for Disruption of Plans/Goals (Threat) | 27 | 45 (54) |
| a. Cancellation of plans/goals | 21 | 35 (42) |
| b. Postponement of plans/goals | 17 | 28 (34) |
| 2. Implications for Modification of Plans/Goals (Threat) | 30 | 50 (60) |
| a. Physical ability to pursue plans/goals | 22 | 37 (44) |
| b. Potential recurrence of disease | 8 | 13 (16) |
| c. Time and schedule constraints of treatment(s) on plans/goals | 17 | 28 (34) |
| d. Threatened incentive value of goals | 13 | 22 (26) |

Table 9, continued

| Content of Information Needed in the Category of Personal Concerns | Responses | |
|---|---|---|
| | N | % |
| <u>Physical Wellbeing</u> | | |
| Information Needed Overall Responses | 44 | 73 |
| 1. Implications for Feeling Well (Threat) | 23 | 38 |
| a. Symptoms (potential) | 18 | 30 |
| - symptoms of cancer | 12 | 20 |
| - symptoms of treatment | 11 | 18 |
| b. Propensity to contract other diseases | 12 | 20 |
| 2. Implications for Physical Function (Threat) | 30 | 50 |
| a. Effects of cancer on function | 29 | 48 |
| b. Effect of treatments on function | 24 | 40 |
| 3. Attainment of Assistance to Maintain and Promote Physical Wellbeing (Resources) | 39 | 65 |
| a. Prevention (primary) of cancer | 24 | 40 |
| b. Prevention (secondary) of cancer | 26 | 43 |
| c. Prevention (primary) of other diseases | 24 | 40 |
| d. Symptom management modes | 20 | 33 |
| <u>Psychological Wellbeing</u> | | |
| Information Needed Overall Responses | 39 | 65 |
| 1. Emotional Disturbances (Harm) | 38 | 63 |
| a. Anxiety | 34 | 57 |
| b. Shock | 13 | 22 |
| c. Fear of losing control of emotions | 15 | 25 |
| 2. Cognitive Disturbances (Harm) | 20 | 33 |
| a. Constant awareness of cancer | 10 | 17 |
| b. Inability to concentrate | 14 | 23 |
| c. Fear of losing hope or positive attitude | 15 | 25 |
| d. Inability to make decisions | 7 | 12 |

Table 9, continued

| Content of Information Needed in the Category of Personal Concerns | Responses N | Responses % |
|---|---|---|
| **Psychological Wellbeing, continued** | | |
| 3. Attainment of Assistance (Resources) | 38 | 63 |
| a. Cognitive control through learning | 18 | 30 |
| b. Cognitive control based on facts | 17 | 28 |
| c. Maintenance of hope or positive attitude based on resources such as God, religious leader, or friends, health professionals' competence, and otherwise a relatively good health | 21 | 35 |
| Information Needed Overall Responses (Threat) | 32 | 53 |
| 1. Implications for Psychological Stability | 19 | 32 |
| a. Emotional disturbances | 15 | 25 |
| - inability to maintain a positive attitude | 13 | 22 |
| - fear of being depressed | 6 | 10 |
| b. Cognitive disturbances | 29 | 48 |
| - time of waiting in absence of total certainty | 10 | 17 |
| - diminished ability to function as usual in daily tasks | 21 | 35 |
| - feeling that one is not the same as before the diagnosis | 17 | 28 |
| 2. Attainment of Assistance (Resources) | 22 | 37 |
| a. Support of health professionals | 13 | 22 |
| b. Support of friends and relatives | 6 | 10 |
| c. Support of other patients and/or their families | 10 | 17 |

Table 9, continued

Information Needed by Patients in the Category of Family Life, by Frequency Count and Percent of Responses (N=60)

| Content of Information Needed in the Category of Family Life | Responses | |
|---|---|---|
| | N | % |
| Spouse (n = 41) | | |
| Information Needed Overall Responses | 29 | 48 (71) |
| 1. Impact of Diagnosis on Spouse (Harm) | 25 | 42 (61) |
| a. Psychological/emotional strain | 19 | 32 (46) |
| b. Physical strain | 11 | 18 (27) |
| 2. Impact of Diagnosis on the Relationship (Harm) | 22 | 41 (54) |
| a. Communicaiton (closed) | 17 | 28 (41) |
| - not knowing spouse's thoughts | 14 | 23 (34) |
| - not knowing whether spouse is coping | 13 | 22 (32) |
| b. Interaction | 18 | 30 (44) |
| - how to support spouse | 15 | 25 (37) |
| - how to help spouse support the patient | 11 | 18 (27) |
| 3. Attainment of Assistance (Resources) | 16 | 27 (39) |
| a. Support of health professional by answering spouse's questions | 13 | 22 (32) |
| b. Support of health professionals by counseling, being available, appropriate literature | 9 | 15 (22) |
| c. Support of other spouses whose mates have cancer | 11 | 18 (27) |
| d. Support of groups (self-help) | 7 | 12 (17) |
| Spouse (n = 41) | | |
| Information Needed Overall Response | 19 | 32 (46) |
| 1. Implications for Spouse/Significant Other (Threat) | 17 | 28 (41) |
| a. Potential psychological strain | 13 | 22 (32) |
| b. Potential physical strain | 12 | 20 (29) |
| c. Potential financial strain | 10 | 17 (24) |
| 2. Implications for the Relationship (Threat) | 12 | 20 (29) |
| a. Problems of closed communication | 6 | 10 (15) |
| b. Problems of interaction | 7 | 12 (17) |
| - inability to care for spouse | 10 | 17 (24) |
| - inability to support one another | 6 | 10 (15) |
| - inability to maintain the relationship | 6 | 10 (15) |

Table 9, continued

| Content of Information Needed in the Category of Family Life | Responses N | Responses % |
|---|---|---|
| **Spouse, continued** | | |
| 3. Attainment of Assistance (Resources) | 19 | 32 (46) |
| a. Support of health professionals by answering spouse's questions | 19 | 32 (46) |
| b. Support of professionals by counseling, being available, appropriate literature | 13 | 22 (32) |
| c. Support of other spouses whose mates have cancer | 20 | 33 (49) |
| d. Support of groups (self-help) | 10 | 17 (24) |
| **Children** (n = 40) | | |
| Information Needed Overall Responses | 23 | 38 (58) |
| 1. Impact of Diagnosis on Children (Harm) | 12 | 20 (30) |
| a. Psychological/emotional strain | 12 | 20 (30) |
| b. Physical strain | 6 | 10 (15) |
| 2. Impact of Diagnosis on the Relationship (Harm) | 15 | 25 (38) |
| a. Communication (closed) | 8 | 13 (20) |
| - not knowing children's thoughts | 6 | 10 (15) |
| - what to tell, how to tell | 6 | 10 (15) |
| - how to warn children to prevent cancer | 6 | 10 (15) |
| **Children** (n = 40) | | |
| Information Needed Overall Responses | 23 | 38 (58) |
| 1. Implications for Children (Threat) | 19 | 32 (48) |
| a. Potential psychological/emotional strain | 10 | 17 (25) |
| b. Potential physical strain | 4 | 7 (10) |
| c. Susceptibility to cancer | 7 | 12 (18) |
| 2. Implications for the Relationship (Threat) | 15 | 25 (38) |
| a. Problems of closed communication | 14 | 23 (35) |
| b. Problems of interaction | 18 | 30 (45) |
| - inability to parent children | 14 | 23 (35) |
| - inability to support children | 8 | 13 (20) |

Table 9, continued

| Content of Information Needed in the Category of Family Life | Responses | |
|---|---|---|
| | N | % |
| Children, continued | | |
| 3. Attainment of Assistance (Resources) | 17 | 28 (43) |
| a. Support of health professionals by answering children's questions | 15 | 25 (38) |
| b. Support of health professionals by counseling, being available, appropriate literature | 15 | 25 (38) |
| c. Support of other children who have parents with cancer | 4 | 7 (10) |
| Parents (n = 38) | | |
| Information Needed Overall Responses | 23 | 38 (61) |
| 1. Impact of Diagnosis of Parent(s) (Harm) | 22 | 37 (58) |
| a. Psychological/emotional strain | 20 | 33 (53) |
| b. Physical strain | 11 | 18 (29) |
| 2. Impact of Diagnosis on the Relationship (Harm) | 14 | 23 (37) |
| a. Communication (closed) | 13 | 22 (34) |
| - what to tell, how to tell | 10 | 17 (26) |
| - how to handle their reactions | 10 | 17 (26) |
| b. Interaction | 12 | 20 (32) |
| - how to support parents | 11 | 18 (29) |
| - how to help parents support the patient | 6 | 10 (16) |
| Parents (n = 38) | | |
| Information Needed Overall Responses | 8 | 13 (21) |
| 1. Implications for the Parent(s) (Threat) | 6 | 10 (16) |
| a. Potential psychological/emotional strain | 6 | 10 (16) |
| b. Potential physical strain | 6 | 10 (16) |
| 2. Implications for the Relationship (Threat) | 8 | 13 (21) |
| a. Problems of closed communication | 6 | 10 (16) |
| b. Problems of interaction | 7 | 12 (19) |
| - inability to care for parents | 6 | 10 (16) |
| - inability to support parents | 4 | 7 (11) |

Table 9, continued

| Content of Information Needed in the Category of Family Life | Responses N | % |
|---|---|---|
| **Parents, continued** | | |
| 3. Attainment of Assistance | 9 | 15 (24) |
| a. Providing information | 8 | 13 (21) |
| b. Counseling | 8 | 13 (21) |
| c. Referral to self help groups | 7 | 12 (19) |
| **Siblings** (n = 42) | | |
| Information Needed Overall Responses | 15 | 25 (36) |
| 1. Impact of Diagnosis on Siblings (Harm) | 12 | 20 (29) |
| a. Psychological/emotional strain | 9 | 15 (21) |
| 2. Impact of Diagnosis on the Relationship (Harm) | 12 | 20 (29) |
| a. Communication (closed) | 7 | 17 (17) |
| - what to tell, how to tell | 6 | 10 (14) |
| - how to warn siblings to prevent cancer | 6 | 10 (14) |
| b. Interaction | 10 | 17 (24) |
| - how to support siblings | 5 | 8 (12) |
| - how to help siblings support the patient | 6 | 16 (14) |
| **Siblings (Threat)** (n = 42) | | |
| Information Needed Overall Responses | 19 | 32 (45) |
| 1. Implications for Siblings (Threat | 9 | 15 (21) |
| a. Potential psychological/emotional strain | 6 | 10 (14) |
| b. Susceptibility to cancer | 7 | 17 (17) |
| 2. Implications for the Relationship (Threat) | 6 | 10 (14) |
| a. Problems of closed communication | 8 | 13 (19) |
| b. Problems of interaction | 6 | 10 (14) |
| - how to support one another | 4 | 7 (10) |
| - how to maintain the relationship | 3 | 1 ( 7) |
| 3. Attainment of Assistance (Resources) | 12 | 20 (29) |
| a. Support of health professional by answering sibling's questions | 12 | 20 (29) |
| b. Support of health professional by giving appropriate literature | 10 | 17 (24) |

Table 9, continued

Information Needed by Patients in the Category of Social Concerns, by Frequency Count and Percent of Responses (N=60)

| Content of Information Needed in the Category of Social Concerns | Responses N | Responses % |
|---|---|---|
| Job/Career, Relationships (n = 50) | | |
| Information Needed Overall Responses | 28 | 47 (56) |
| Implications for Relationships | 28 | 47 (56) |
| 1. Implications for Communication (Harm/Threat) | 23 | 38 (46) |
| a. Whether to disclose the diagnosis | 20 | 33 (40) |
| b. What to tell, how to tell | 19 | 32 (38) |
| c. How to handle others' curiosity | 18 | 30 (36) |
| 2. Implications for Interaction (Harm/Threat) | 19 | 32 (38) |
| a. Change in amount of interaction | 17 | 28 (34) |
| - reduced interaction due to diminished ability and time | 12 | 20 (24) |
| - avoidance behavior of peers | 9 | 15 (18) |
| - exaggerated interaction of peers (harm/threat) | 7 | 12 (14) |
| b. Change in quality of interaction | 18 | 30 (36) |
| - implications that the patient is different than others (offensive) | 17 | 28 (34) |
| - implications that the patient is different than before the diagnosis | 6 | 10 (12) |
| - implications that the patient is less capable than before the diagnosis | 11 | 18 (22) |
| 3. Attainment of Assistance (Resources) | 21 | 35 (42) |
| a. Support of health professionals by counseling and appropriate literature | 13 | 22 (26) |
| b. Support of other patients who have (have had) cancer | 11 | 18 (22) |

Table 9, continued

| Content of Information Needed in the Category of Social Concerns | Responses | |
|---|---|---|
| | N | % |
| Special Interest Group Relationships | | |
| Information Needed Overall Responses | 17 | 28 |
| Implications for Relationships (Harm/Threat) | 12 | 20 |
| 1. Implications for Communication (Harm/Threat) | 10 | 17 |
| a. Whether to disclose the diagnosis | 8 | 13 |
| b. What to tell, how to tell | 6 | 10 |
| c. How to handle others' curiosity | 10 | 17 |
| 2. Implications for Interaction (Harm/Threat) | 11 | 18 |
| a. Change in amount of interaction | 9 | 15 |
| - reduced interaction due to diminished ability and time | 5 | 8 |
| - avoidance behavior of peers | 7 | 12 |
| - exaggerated interacion of peers | 6 | 10 |
| b. Change in quality of interaction | 7 | 12 |
| - implications that the patient is different than others (offensive) | 6 | 10 |
| - implications that the patient is different than before the diagnosis | 6 | 10 |
| - implications that the patient is less capable than before the diagnosis | 7 | 12 |
| 3. Attainment of Assistance (Resources) | 5 | 8 |
| a. Support of health professionals by counseling, appropriate literature | 3 | 5 |
| b. Support of other patients who have (have had) cancer | 4 | 7 |
| Leisure Group Relationships | | |
| Information Needed Overall Responses | 17 | 28 |
| Implications for the Relationship | 16 | 27 |
| 1. Implications for Communication (Harm/Threat) | 13 | 22 |
| a. Whether to disclose the diagnosis | 8 | 13 |
| b. What to tell, how to tell | 6 | 10 |
| c. How to handle others' curiosity | 13 | 22 |

Table 9, continued

| Content of Information Needed in the Category of Social Concerns | Responses N | % |
|---|---|---|
| **Leisure Group Relationship, continued** | | |
| 2. Implications for Interaction (Harm/Threat) | 16 | 27 |
| a. Change in amount of interaction | 13 | 22 |
| - reduced interaction due to diminished ability and time | 11 | 18 |
| - avoidance behavior of peers | 6 | 10 |
| - overinteracting behavior of peers | 6 | 10 |
| b. Change in quality of interaction | 13 | 22 |
| - implications that the patient is different (offensive) | 6 | 10 |
| - implications that the patient is different than before the diagnosis | 7 | 12 |
| - implications that the patient is less capable than before the diagnosis | 6 | 10 |
| 3. Attainment of Assistance (Resources) | 15 | 25 |
| a. Support of professionals by counseling and literature | 13 | 22 |
| b. Support of other patients who have (have had) cancer | 9 | 15 |
| **Future Relationships** | | |
| Information Needed Overall Responses | 25 | 42 |
| Implications for Future Relationships | 25 | 42 |
| 1. Implications for Future Intimate Relationships (Threat) | 20 | 33 |
| a. Deferrant factors on the part of others | 8 | 13 |
| - physical (potential of recurrence, susceptibility of offspring) | 12 | 20 |
| - psychosocial stigma (offensive, contagious, doomed) | 10 | 17 |
| b. Strategies for communication | 18 | 30 |
| - whether and when to tell | 10 | 17 |
| - what to tell, how to tell | 8 | 13 |

Table 9, continued

| Content of Information Needed in the Category of Social Concerns | Responses N | % |
|---|---|---|
| **Future Relationships, continued** | | |
| 2. Implications for Future Less Intimate or Contractual Relationships (Threat) | 14 | 23 |
| a. Deterrant Factors | 10 | 17 |
| - physical (potential of recurrence, less able) | 6 | 10 |
| - psychosocial stigma (unspecific) | 7 | 12 |
| b. Strategies for communication | 12 | 20 |
| - whether and when to tell | 6 | 10 |
| - what to tell, how to tell | 4 | 7 |
| 3. Implications for Making New Lasting Friendships (Resources) | 23 | 38 |
| a. How to contact other patients | 22 | 37 |
| - to share experiences | 18 | 30 |
| - to learn from their experience | 13 | 22 |
| - to help others like them | 8 | 13 |
| b. How to help families contact other patients' families | 13 | 22 |
| - to share experiences | 9 | 15 |
| - to learn from their experience | 8 | 13 |
| - to help others like them | 7 | 12 |
| c. How to join support groups (self-help) | 13 | 22 |

Table 9a

Rank Order of Major Categories by Highest Aggregate Response Counts in the Categories and Subcategories (n = 60)

| Categories and Subcategories of Concern Related Information Needs | Aggregate Counts (Harm) N | % | Aggregate Counts (Threats) N | % |
|---|---|---|---|---|
| Major Category of Disease Concerns | | | | |
| Category of Treatment(s) | | | 54 | (90) |
| Category of Prognosis | | | 54 | (90) |
| Category of Diagnosis | 48 | (80) | | |
| Category of Test(s) | 33 | (55) | | |
| Major Category of Personal Concerns | | | | |
| Category of Psychological Wellbeing | 39 | (65) | 32 | (53) |
| Category of Physical Wellbeing | | | 44 | (73) |
| Category of Job/Career | | | 38 | (63) |
| Category of Plans and Goals | | | 35 | (58) |
| Major Category of Family Concerns | | | | |
| Category of Spouse | 29 | (48) | 19 | (32) |
| Category of Children | 23 | (38) | 23 | (38) |
| Category of Parent(s) | 23 | (38) | 8 | (13) |
| Category of Sibling(s) | 18 | (30) | 19 | (32) |
| Major Category of Social Concerns | | | | |
| Category of Job/Career Relationships | | | 28 | (47) |
| Category of Speical Interest Relationships | | | 25 | (42) |
| Category of Leisure Relationships | | | 17 | (28) |
| Category of Future Relationships | | | 16 | (27) |

Table 9b

Rank Order of Major Categories by Five Subcategories with Highest Aggregate Response Counts (n = 60)

| Categories and Subcategories of Concern Related Information | Aggregate Response Counts N | % |
|---|---|---|
| Major Category of Disease Concerns | | |
| Subcategory Consequences (unintended) of Treatments (Threat) | 54 | (90) |
| Subcategory Facts Related to Prognosis (Threat) | 52 | (87) |
| Subcategory Results (intended) of Treatments (Threat) | 46 | (77) |
| Subcategory Implications of Prognosis for Self (Threat) | 45 | (75) |
| Subcategory Nature of Diagnosis (Harm) | 39 | (65) |
| Major Category of Personal Concerns | | |
| Subcategory Attainment of Assistance (Psychological Wellbeing, Harm) (Resource) | 39 | (65) |
| Subcategory Emotional Disturbance (Harm) | 38 | (63) |
| Subcategory Attainment of Assistance (Psychological Wellbeing, Threat) (Resource) | 38 | (63) |
| Subcategory Job/Career Implications for Self (Threat) | 36 | (60) |
| Subcategory Modifications for Plans/Goals | 30 | (50) |
| Subcategory Implications for Physical Function | 30 | (50) |
| Major Category of Family Concerns | | |
| Subcategory Impact of Diagnosis on Spouse (Harm) | 25 | (42) |
| Subcategory Implications of Diagnosis for Marital Relationship (Threat) | 23 | (38) |
| Subcategory Impact of Diagnosis on Parent(s) (Harm) | 22 | (37) |
| Subcategory Attainment of Assistance for Spouse (Threat) (Resources) | 19 | (32) |
| Subcategory Implications of Diagnosis for Children (Threat) | 19 | (32) |
| Subcategory Attainment of Assistance for Children (Threat) (Resource) | 17 | (23) |
| Major Category of Social Concerns | | |
| Subcategory Implications for Communication, Job/Career Relationships (Threat) | 23 | (38) |
| Subcategory Making New Friends in Patients | 23 | (38) |
| Subcategory Attainment of Assistance, Job/Career (Resource) | 21 | (35) |

Table 9b, continued

| Categories and Subcategories of Concern Related Information | Aggregate Response Counts N | % |
|---|---|---|
| Social Concerns, continued | | |
| Subcategory Implications for Future Intimate Relationships (Threat) | 20 | (33) |
| Subcategory Implications for Interaction, Job/Career Relationships (Threat) | 19 | (32) |

Table 10

Importance Value (0-100) Attached to Information Needed in the Categories of Disease, Personal, Family, and Social Concerns by Number (N), Mean (X), Minimum, Maximum Value, and Standard Error of the Mean (S.E.M.) of Responses

| Category | Number | Mean | Minimum-Maximum | S.E.M. |
|---|---|---|---|---|
| Disease Concerns | | | | |
| Diagnosis | 37 | 31.2 | (10, 75) | 2.3 |
| Test(s) | 30 | 15.2 | (1, 50) | 2.6 |
| Treatment(s) | 46 | 40.1 | (10, 99) | 2.8 |
| Prognosis | 45 | 34.9 | (2, 99) | 4.4 |
| Personal Concerns | | | | |
| Job/Career | 27 | 35.1 | (10, 100) | 5.3 |
| Plans/Goals | 26 | 29.7 | (10, 100) | 3.8 |
| Physical Wellbeing | 40 | 28.5 | (1, 99) | 4.0 |
| Psychological Wellbeing | 38 | 49.2 | (3, 100) | 4.0 |
| Family Concerns | | | | |
| Spouse | 34 | 55.9 | (25, 100) | 4.0 |
| Children | 21 | 25.6 | (0, 100) | 5.4 |
| Siblings | 17 | 16.2 | (0, 50) | 3.3 |
| Parents | 22 | 30.3 | (5, 99) | 5.5 |
| Social Concerns | | | | |
| Job/Career Relationship | 20 | 40.1 | (2, 90) | 5.7 |
| Special Interest Relationship | 7 | 42.1 | (25, 100) | 6.0 |
| Leisure Relationship | 11 | 49.4 | (5, 99) | 8.0 |
| Future Relationship | 20 | 62.4 | (10, 100) | 7.2 |

# Table 10a

## Rank Order of Importance Value Mean Scores by Major Category and Category of Concerns (n = 60)

| Category | Major Category | Mean Scores | Number of Patients |
|---|---|---|---|
| Future Relationship | (Social Concerns) | 62.4 | 20 |
| Spouse | (Family Concerns) | 55.9 | 34 |
| Leisure Relationship | (Social Concerns) | 49.4 | 11 |
| Psychological Wellbeing | (Personal Concerns) | 49.2 | 38 |
| Special Interest Relationship | (Social Concerns) | 42.1 | 7 |
| Job/Career Relationship | (Social Concerns) | 40.1 | 20 |
| Treatments | (Disease Concerns) | 40.1 | 46 |
| Job/Career Concerns | (Personal Concerns) | 35.1 | 27 |
| Prognosis | (Disease Concerns) | 34.9 | 45 |
| Diagnosis | (Disease Concerns) | 31.2 | 37 |
| Parents | (Family Concerns) | 30.3 | 22 |
| Plans and Goals | (Personal Concerns) | 29.7 | 26 |
| Physical Wellbeing | (Personal Concerns) | 28.5 | 40 |
| Children | (Family Concerns) | 25.6 | 21 |
| Siblings | (Family Concerns) | 16.2 | 17 |
| Test(s) | (Disease Concerns) | 15.2 | 30 |

Table 11

Differences in Information Needs Aggregate Response Counts Between Males and Females, Using Fisher Exact (1-tail) Test (n = 60)

| Category Overall Response | Number of Patients | Sex | Percent of Response | Percent of No Response | P-Value (p<.05)* |
|---|---|---|---|---|---|
| Disease Concerns | | | | | |
| Diagnosis | 31 | Male | 43.3 | 6.7 | 0.25 |
| | 29 | Female | 38.3 | 11.7 | |
| Test(s) | 31 | Male | 29.3 | 22.7 | 0.60 |
| | 29 | Female | 27.3 | 20.7 | |
| Treatment(s) | 31 | Male | 43.3 | 6.7 | 0.65 |
| | 29 | Female | 42.3 | 5.7 | |
| Prognosis | 31 | Male | 41.0 | 11.0 | 0.01* |
| | 29 | Female | 49.0 | 0.0 | |
| Personal Concerns | | | | | |
| Job/Career | 31 | Male | 32.7 | 17.3 | 0.60 |
| | 29 | Female | 30.7 | 19.3 | |
| Plans/Goals | 31 | Male | 31.0 | 19.0 | 0.50 |
| | 29 | Female | 27.0 | 22.7 | |
| Physical Wellbeing | 31 | Male | 37.7 | 12.3 | 0.61 |
| | 29 | Female | 35.7 | 14.3 | |
| Psychological Wellbeing | 31 | Male | 21.0 | 29.0 | 0.0002* |
| | 29 | Female | 44.0 | 5.0 | |
| Family Concerns | | | | | |
| Spouse | 31 | Male | 25.0 | 25.0 | 0.50 |
| | 29 | Female | 23.3 | 26.7 | |
| Children | 31 | Male | 13.3 | 36.7 | 0.21 |
| | 29 | Female | 20.0 | 30.0 | |
| Parent(s) | 31 | Male | 15.0 | 35.0 | 0.14 |
| | 29 | Female | 23.3 | 26.7 | |
| Sibling(s) | 31 | Male | 6.7 | 43.3 | |
| | 29 | Female | 18.3 | 31.7 | 0.04* |

Table 11, continued

| Category Overall Response | Number of Patients | Sex | Percent of Response | Percent of No Response | P-Value (p<.05)* |
|---|---|---|---|---|---|
| **Social Concerns** | | | | | |
| Job/Career Relationships | 31 | Male | 18.3 | 31.7 | 0.15 |
| | 29 | Female | 26.7 | 23.3 | |
| Special Interest Relationships | 31 | Male | 8.3 | 41.7 | 0.37 |
| | 29 | Female | 11.7 | 38.3 | |
| Leisure Relationships | 31 | Male | 13.3 | 36.7 | 0.50 |
| | 29 | Female | 15.0 | 36.0 | |
| Future Relationships | 31 | Male | 15.0 | 35.0 | 0.21 |
| | 29 | Female | 21.7 | 28.3 | |

*p<.05 minimum acceptable p-value for difference.

Table 12

Differences in Information Needs Aggregate Response Counts Among Age Groups 18-35, 36-55, 56-70, Using Pearson Chi Square Test (n = 60)

| Category Overall Response | Number of Patients | Age | Percent of Response | Percent of No Response | Pearson Chi Square | P-Value ($p<.05$)* |
|---|---|---|---|---|---|---|
| Disease Concerns | | | | | | |
| Diagnosis | 16 | 18-35 | 21.7 | 5.0 | 1.10 | 0.58 |
| | 32 | 36-55 | 41.7 | 11.7 | | |
| | 12 | 56-70 | 18.3 | 1.7 | | |
| Test | 16 | 18-35 | 16.7 | 10.0 | 0.34 | 0.82 |
| | 32 | 36-55 | 28.3 | 25.0 | | |
| | 12 | 56-70 | 11.7 | 8.3 | | |
| Treatment(s) | 16 | 18-35 | 23.3 | 3.3 | 0.42 | 0.81 |
| | 32 | 36-55 | 45.0 | 8.3 | | |
| | 12 | 56-70 | 18.3 | 1.7 | | |
| Prognosis | 16 | 18-35 | 23.3 | 3.3 | 0.16 | 0.92 |
| | 32 | 36-55 | 48.3 | 5.0 | | |
| | 12 | 56-70 | 18.3 | 1.7 | | |
| Personal Concerns | | | | | | |
| Job/Career | 16 | 18-35 | 20.0 | 6.7 | 3.44 | 0.18 |
| | 32 | 36-55 | 35.0 | 18.3 | | |
| | 12 | 56-70 | 8.3 | 11.7 | | |
| Plans/Goals | 16 | 18-35 | 9.0 | 7.0 | 0.04 | 0.98 |
| | 32 | 36-55 | 19.0 | 13.0 | | |
| | 12 | 56-70 | 7.0 | 5.0 | | |
| Physical Wellbeing | 16 | 18-35 | 21.7 | 5.0 | 2.0 | 0.35 |
| | 32 | 36-55 | 35.0 | 18.3 | | |
| | 12 | 56-70 | 16.7 | 3.3 | | |
| Psychological Wellbeing | 16 | 18-35 | 16.7 | 10.0 | 0.48 | 0.79 |
| | 32 | 36-55 | 36.7 | 16.7 | | |
| | 12 | 56-70 | 11.7 | 8.3 | | |

Table 12, continued

| Category Overall Response | Number of Patients | Age | Percent of Response | Percent of No Response | Pearson Chi Square | P-Value (p<.05)* |
|---|---|---|---|---|---|---|
| **Family Concerns** | | | | | | |
| Spouse | 16 | 18-35 | 20.0 | 6.7 | 6.4 | 0.04* |
| | 32 | 36-55 | 21.7 | 31.7 | | |
| | 12 | 56-70 | 6.7 | 13.3 | | |
| Children | 16 | 18-35 | 10.0 | 16.7 | 0.9 | 0.64 |
| | 32 | 36-55 | 15.0 | 38.3 | | |
| | 12 | 56-70 | 8.3 | 11.7 | | |
| Parents | 16 | 18-35 | 16.7 | 10.0 | 8.53 | 0.01* |
| | 32 | 36-55 | 20.0 | 33.3 | | |
| | 12 | 56-70 | 1.7 | 18.3 | | |
| Siblings | 16 | 18-35 | 13.3 | 13.3 | 8.0 | 0.02* |
| | 32 | 36-55 | 6.7 | 46.7 | | |
| | 12 | 56-70 | 5.0 | 15.0 | | |
| **Social Concerns** | | | | | | |
| Job/Career Relationships | 16 | 18-35 | 16.7 | 10.0 | 5.92 | 0.05* |
| | 32 | 36-55 | 25.0 | 28.3 | | |
| | 12 | 56-70 | 3.3 | 16.7 | | |
| Special Interest Relationships | 16 | 18-35 | 8.3 | 18.3 | 4.86 | 0.09 |
| | 32 | 36-55 | 5.0 | 48.3 | | |
| | 12 | 56-70 | 6.7 | 13.3 | | |
| Leisure Relationships | 16 | 18-35 | 10.0 | 16.7 | 1.47 | 0.48 |
| | 32 | 36-55 | 11.7 | 41.7 | | |
| | 12 | 56-70 | 6.7 | 13.3 | | |
| Future Relationships | 16 | 18-35 | 11.7 | 26.7 | 2.63 | 0.27 |
| | 32 | 36-55 | 21.7 | 53.3 | | |
| | 12 | 56-70 | 3.3 | 20.0 | | |

*p<.05 minimum acceptable p-value for difference.

## Table 13

## Differences in Information Needs Aggregate Response Counts Among Patients with Local, Regional, Disseminated Cancer, Using Pearson Chi Square Test (n = 60)

| Category Overall Response | Number of Patients | Stage of Cancer | Percent of Responses | Percent of No Response | Pearson Chi Square | P-Value (p<.05)* |
|---|---|---|---|---|---|---|
| Disease Concerns | | | | | | |
| Diagnosis | 23 | Local | 26.7 | 11.7 | 3.83 | 0.15 |
| | 23 | Regional | 35.0 | 3.3 | | |
| | 14 | Disseminated | 20.0 | 3.3 | | |
| Test(s) | 23 | Local | 16.7 | 21.7 | 4.69 | 0.10 |
| | 23 | Regional | 28.3 | 10.0 | | |
| | 14 | Disseminated | 11.7 | 11.7 | | |
| Treatment(s) | 23 | Local | 31.7 | 6.7 | 0.77 | 0.68 |
| | 23 | Regional | 35.0 | 3.3 | | |
| | 14 | Disseminated | 20.0 | 3.3 | | |
| Prognosis | 23 | Local | 35.0 | 3.3 | 0.41 | 0.82 |
| | 23 | Regional | 33.3 | 5.0 | | |
| | 14 | Disseminated | 21.7 | 1.7 | | |
| Personal Concerns | | | | | | |
| Job/Career | 23 | Local | 25.0 | 13.3 | 1.49 | 0.47 |
| | 23 | Regional | 26.7 | 11.7 | | |
| | 14 | Disseminated | 11.7 | 11.7 | | |
| Plans/Goals | 23 | Local | 18.3 | 20.0 | 2.25 | 0.32 |
| | 23 | Regional | 26.7 | 11.7 | | |
| | 14 | Disseminated | 13.3 | 10.0 | | |
| Physical Wellbeing | 23 | Local | 26.7 | 11.7 | 1.76 | 0.41 |
| | 23 | Regional | 31.7 | 6.7 | | |
| | 14 | Disseminated | 15.0 | 8.3 | | |
| Psychological Wellbeing | 23 | Local | 23.3 | 15.0 | 1.47 | 0.48 |
| | 23 | Regional | 23.3 | 15.0 | | |
| | 14 | Disseminated | 18.3 | 5.0 | | |

Table 13, continued

| Category Overall Response | Number of Patients | Stage of Cancer | Percent of Responses | Percent of No Response | Pearson Chi Square | P-Value (p<.05)* |
|---|---|---|---|---|---|---|
| Family Concerns | | | | | | |
| Spouse | 23 | Local | 23.3 | 15.0 | 8.56 | 0.01* |
| | 23 | Regional | 21.7 | 16.7 | | |
| | 14 | Disseminated | 3.3 | 20.0 | | |
| Children | 23 | Local | 13.3 | 25.0 | 1.14 | 0.57 |
| | 23 | Regional | 10.0 | 28.3 | | |
| | 14 | Disseminated | 10.0 | 13.3 | | |
| Parent(s) | 23 | Local | 15.0 | 23.3 | 0.05 | 0.97 |
| | 23 | Regional | 15.0 | 23.3 | | |
| | 14 | Disseminated | 8.3 | 15.0 | | |
| Sibling(s) | 23 | Local | 11.7 | 26.7 | 0.58 | 0.75 |
| | 23 | Regional | 8.3 | 30.0 | | |
| | 14 | Disseminated | 5.0 | 18.3 | | |
| Social Concerns | | | | | | |
| Job/Career Relationships | 23 | Local | 16.7 | 21.7 | 0.12 | 0.94 |
| | 23 | Regional | 18.3 | 20.0 | | |
| | 14 | Disseminated | 10.0 | 13.3 | | |
| Special Interest Relationships | 23 | Local | 10.0 | 28.3 | 2.02 | 0.36 |
| | 23 | Regional | 8.3 | 30.0 | | |
| | 14 | Disseminated | 1.7 | 21.7 | | |
| Leisure Relationships | 23 | Local | 11.7 | 26.7 | 0.43 | 0.81 |
| | 23 | Regional | 11.7 | 26.7 | | |
| | 14 | Disseminated | 5.0 | 18.3 | | |
| Future Relationships | 23 | Local | 13.3 | 25.0 | 0.10 | 0.95 |
| | 23 | Regional | 15.0 | 23.3 | | |
| | 14 | Disseminated | 8.3 | 15.0 | | |

*p<.05 minimum acceptable p-value for difference.

Table 14

Differences in Information Needs Aggregate Response Counts Among Patients with Different Types of Cancer, Using Pearson Chi Square Test (n = 60)

| Category Overall Response | Number of Patients | Type of Cancer | Percent of Response | Percent of No Response | Pearson Chi Square | P-Value (p<.05)* |
|---|---|---|---|---|---|---|
| Disease Concerns | | | | | | |
| Diagnosis | 29 | Melanoma | 36.7 | 11.7 | 2.75 | 0.25 |
| | 24 | Hard Tumors | 36.7 | 3.3 | | |
| | 7 | Hematoetic | 8.3 | 3.3 | | |
| Test(s) | 29 | Melanoma | 28.3 | 20.0 | 0.11 | 0.95 |
| | 24 | Hard Tumors | 21.7 | 18.3 | | |
| | 7 | Hematoetic | 6.7 | 5.0 | | |
| Treatment(s) | 29 | Melanoma | 38.3 | 10.0 | 3.11 | 0.21 |
| | 24 | Hard Tumors | 38.3 | 1.7 | | |
| | 7 | Hematoetic | 10.0 | 1.7 | | |
| Prognosis | 29 | Melanoma | 41.7 | 6.7 | 1.51 | 0.47 |
| | 24 | Hard Tumors | 38.3 | 1.7 | | |
| | 7 | Hematoetic | 10.0 | 1.7 | | |
| Personal Concerns | | | | | | |
| Job/Career | 29 | Melanoma | 28.3 | 20.0 | 1.80 | 0.41 |
| | 24 | Hard Tumors | 25.0 | 15.0 | | |
| | 7 | Hematoetic | 10.0 | 1.7 | | |
| Plans/Goals | 29 | Melanoma | 25.0 | 23.3 | 2.69 | 0.26 |
| | 24 | Hard Tumors | 23.3 | 16.7 | | |
| | 7 | Hematoetic | 10.0 | 1.7 | | |
| Physical Wellbeing | 29 | Melanoma | 33.3 | 15.0 | 2.45 | 0.29 |
| | 24 | Hard Tumors | 33.3 | 6.7 | | |
| | 7 | Hematoetic | 6.7 | 5.0 | | |
| Psychological Wellbeing | 29 | Melanoma | 30.0 | 18.3 | 0.27 | 0.87 |
| | 24 | Hard Tumors | 26.7 | 13.3 | | |
| | 7 | Hematoetic | 8.3 | 3.3 | | |

Table 14, continued

| Category Overall Response | Number of Patients | Type of Cancer | Percent of Response | Percent of No Response | Pearson Chi Square | P-Value (p<.05)* |
|---|---|---|---|---|---|---|
| **Family Concerns** | | | | | | |
| Spouse | 29 | Melanoma | 26.7 | 21.7 | 1.89 | 0.39 |
| | 24 | Hard Tumors | 15.0 | 25.0 | | |
| | 7 | Hematoetic | 6.7 | 5.0 | | |
| Children | 29 | Melanoma | 13.3 | 35.0 | 1.25 | 0.53 |
| | 24 | Hard Tumors | 16.7 | 23.3 | | |
| | 7 | Hematoetic | 3.3 | 8.3 | | |
| Parent(s) | 29 | Melanoma | 18.3 | 30.0 | 0.70 | 0.96 |
| | 24 | Hard Tumors | 15.0 | 25.0 | | |
| | 7 | Hematoetic | 5.0 | 6.7 | | |
| Sibling(s) | 29 | Melanoma | 8.3 | 40.0 | 0.23 | 0.89 |
| | 24 | Hard Tumors | 5.0 | 35.0 | | |
| | 7 | Hematoetic | 1.7 | 10.0 | | |
| **Social Concerns** | | | | | | |
| Job/Career Relationships | 29 | Melanoma | 26.7 | 21.7 | 2.54 | 0.28 |
| | 24 | Hard Tumors | 13.3 | 26.7 | | |
| | 7 | Hematoetic | 5.0 | 6.7 | | |
| Special Interest Relationships | 29 | Melanoma | 6.7 | 41.7 | 2.99 | 0.22 |
| | 24 | Hard Tumors | 8.3 | 31.7 | | |
| | 7 | Hematoetic | 5.0 | 6.7 | | |
| Leisure Relationships | 29 | Melanoma | 11.7 | 36.7 | 0.58 | 0.77 |
| | 24 | Hard Tumors | 13.3 | 26.7 | | |
| | 7 | Hematoetic | 3.3 | 8.3 | | |
| Future Relationships | 29 | Melanoma | 16.7 | 31.7 | 2.44 | 0.30 |
| | 24 | Hard Tumors | 18.3 | 21.7 | | |
| | 7 | Hematoetic | 1.7 | 10.0 | | |

*p<.05 minimum acceptable p-value for difference.

# APPENDIX B

## Design of the INA Instrument

Sequencing of the interview questions was deemed vital to produce candid, thought-through, reliable responses from the patient. It was therefore designed so that the patient be asked to respond to the least sensitive questions first and last. Responding to the Demographic Information instrument would help the patient deal with factual and ordinary aspects of a professional interview. After that the patient was asked to respond to the more central, concrete, and immediate questions related to the category of Disease Concerns. The next two major categories, the Personal and Family Concerns, were thought to be more sensitive and difficult to discuss, and thus preceded the less concrete and less immediately experienced final category of Social Concerns. The same considerations guided the sequencing of subcategories within each major category. For example, the questions concerning the diagnosis and tests preceded the questions concerning the treatments and prognosis in the Disease Concerns category. Similarly, the questions concerning job and plans preceded the more sensitive and immediate questions of physical and psychological wellbeing in the Personal Concerns category. In the Family Concerns category, the more sensitive and relevant questions pertaining to the spouse, the significant other, and children preceded the less sensitive and more peripheral questions pertaining to siblings and parents, thus reversing the flow from more intense content to less. This flow continued into the final category of Social Concerns, through which the patient would have the opportunity to regain emotional stability (composure) before the retesting and departure from the interview. These considerations of scheduling the instrument on the item and category level intended to minimize patients' emotional discomfort and thus maximize their responses to be most representative of their true experiences. The researcher believed that such considerations are related to the validity and reliability of the data, and that to ignore them would impose confounding influences upon the data.

## Information Needs Assessment Instrument for Recently Diagnosed Cancer Patients

Card # ________

| | |
|---|---|
| Date ________ | Time begun _______ |
| Place Code # ________ | Time finished _______ |
| Interviewer Code # _______ | Patient Code # _______ |

Thank you very much for helping us in our attempt to understand the patient's experience. I would like to ask you some questions about yourself, your disease, and your thoughts about your experience at this time. There are no right or wrong answers to those questions. The correct answer is when your answer describes your thought. The nursing research team is grateful for your participation in this study which is aiming at providing a more comprehensive nursing care to patients at this stage of their disease.

## Disease Concerns

The following group of questions relate to your disease.

### Diagnosis

1. Have you been told about your diagnosis?
   yes_____no_____not applicable_____.
2. Was the information adequate?
   yes_____no_____not applicable_____.
3. Do you have a main concern about your diagnosis?
   yes_____no_____ (if yes)
4. What is your main concern about your diagnosis?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

### Tests

1. Have you been told about tests you may need to have such as blood works, x-rays, and the like?
   yes_____no_____not applicable._____
2. Was the information adequate?
   yes_____no_____not applicable_____.
3. Do you have a main concern about the test(s)?
   yes_____no_____ (if yes)
4. What is your main concern about the test(s)?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

### Treatment(s)

1. Have you been told about the treatment(s) you may receive?
   yes_____no_____not applicable_____
2. Was the information adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about the treatment(s)?
   yes_____no_____ (if yes)
4. What is your main concern about the treatment(s)?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

### Prognosis

1. Have you been told about the prognosis of your disease?
   yes_____no_____not applicable_____
2. Was the information adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about the prognosis?
   yes_____no_____ (if yes)

Prognosis (continued)

4. What is your main concern about the prognosis?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

Other Aspects of the Disease

1. Is there another aspect of your disease that you are concerned about?
   yes_____no_____ (if yes)
2. Can you tell me about such a concern?
3. Would you like to have information about this concern?
   yes_____no_____ (if yes)
4. What would you like to know about this concern?
5. From whom or where would you want this information?

You identified your need for information with regard to the diagnosis, tests, treatments, and prognosis (other). If you were to have one hundred dollars to spend on each of these areas what value would you place on the following in terms of importance?

the diagnosis ______________
the tests ______________
the treatment(s) ______________
the prognosis ______________
other(s) ______________

Personal Life Concerns

The following group of questions relate to your personal life concerns.

Job or Career

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your job or career in light of your disease?
   yes_____no_____not applicable_____
2. Was the informaton adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your job or career?
   yes_____no_____ (if yes)
4. What is your main concern about your job or career?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you like to have this information?

### Plans and Goals

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your plans and goals in light of your disease?
   yes_____no_____not applicable_____
2. Was the information adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your plans and goals?
   yes_____no_____ (if yes)
4. What is your main concern about your plans and goals?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

### Physical Wellbeing

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your general physical wellbeing in light of your disease.
   yes_____no_____not applicable_____
2. Was the information adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your physical wellbeing?
   yes_____no_____ (if yes)
4. What is your main concern about your physical wellbeing?
5. Would you like to have information about this concern?
   yes_____no_____not applicable_____
6. What would you like to know about this concern?
7. From whom or where would you want this information?

### Psychological Wellbeing

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your general psychological wellbeing in light of your disease?
   yes_____no_____not applicable_____
2. Was this information adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your psychological wellbeing?
   yes_____no_____ (if yes)
4. What is your main concern about your psychological wellbeing?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

Other Aspects of Personal Life

1. Is there another aspect of your personal life that you are concerned about?
   yes_____no_____ (if yes)
2. Can you tell me about this aspect and your concern?
3. Would you like to have information about this concern?
   yes_____no_____ (if yes)
4. What would you like to know about this concern?
5. From whom or where would you want this information?

You identified your need for information with regard to your job, plans and goals, physical, and psychological wellbeing, (other). If you were to have one hundred dollars to spend on each of these areas, what value would you place on the following in terms of importance?

Your job or career _______________
Your plans or goals _______________
Your physical wellbeing _______________
Your psychological wellbeing _______________
Other(s) _______________

Family Life Concerns

The following group of questions relate to your family life concerns.

Spouse (husband/wife, or the significant other)

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your spouse (significant other if not married) in light of your illness?
   yes_____no_____not applicable_____
2. Was the discussion adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your spouse?
   yes_____no_____ (if yes)
4. What is your main concern about your spouse?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you like to have this information?

Children

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your child (children) in light of your disease?
   yes_____no_____not applicable_____
2. Was this discussion adequate?
   yes_____no_____not applicable_____

Children (continued)

3. Do you have a main concern about your child (children)?
   yes_____no_____ (if yes)
4. What is your main concern about your child (children)?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you like to have this information?

Parents

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your parent(s) in light of your disease?
   yes_____no_____not applicable_____
2. Was this discussion adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your parents?
   yes_____no_____ (if yes)
4. What is your main concern about your parents?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want to have this information?

Siblings

1. At the time of the diagnosis or since then, did someone of the health care team duscuss with you your sibling(s) in light of your disease?
   yes_____no_____not applicable_____
2. Was the information adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your sibling(S)?
   yes_____no_____ ( if yes)
4. What is your main concern about your sibling(s)?
5. Would you like to have information about your concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

Other Aspects of Family Life

1. Is there another aspect of your family life that you are concerned about?
   yes_____no_____(if yes)
4. What would you like to know about this concern?
5. From whom or where would you want this information?

You identified your need for information with regard to your spouse (significant other), children, parents, siblings, (others). If you were to have one hundred dollars to spend on each of these areas, what value would you place on the following in terms of importance?

Spouse/significant other _______________
Children _______________
Parents _______________
Siblings _______________
Other(s) _______________

Social Life Concerns

The following group of questions relate to your social life concerns.

Relationships (job or career)

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your relationship with your peers (job or career) in light of your illness?
   yes_____no_____not applicable_____
2. Was this discussion adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your relationships with your peers in your job or career?
   yes_____no_____ (if yes)
4. What is your main concern about your relationships with your peers in your job or career?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

Relationships (leisure related group members or friends)

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your relationship with your peers (leisure groups or friends) in light of your illness?
   yes_____no_____not applicable_____
2. Was this discussion adequate?
   yes_____no_____not applicable_____
3. Do you have a main concern about your such group members or friends?
   yes_____no_____ (if yes)
4. What is your main concern about your such group members or friends?
5. Would you like to have information about this concern?
   yes_____no_____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

Need for New Affiliations

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you the possibility of future relationships such as new friendships, business or casual contacts in light of your disease?
   yes____no____not applicable____
2. Was this discussion adequate?
   yes____no____not applicable____
3. Do you have a main concern about such group memberships or contacts?
   yes____no____ (if yes)
4. What is your main concern about such groups memberships or contacts?
5. Would you like to have information about this concern?
   yes____no____ (if yes)
6. What would you like to know about this concern?
7. From whom or where would you want this information?

Relationships (special interest group members or friends)

1. At the time of the diagnosis or since then, did someone of the health care team discuss with you your relationship with your peers (special interest group) in light of your disease?
   yes____no____not applicable____
2. Was this discussion adequate?
   yes____no____not applicable____
3. Do you have a main concern about your such group members or friends?
   yes____no____ (if yes)
4. What is your main concern about your such group members or friends?
5. Would you like to have information about this concern?
   yes____no____ (if yes)
6. What would you like to know about this information?
7. From whom or where would you want this information?

Other Aspect(s) of Social Life)

1. Is there another aspect of your social life that you are concerned about?
   yes____no____ (if yes)
2. Can your tell me about this aspect and concern?
3. Would you like to have information about this concern?
   yes____no____ (if yes)
4. What would you like to know about this concern?
5. From whom or where would you want this information?

You identified your need for information with regard to your relationships at your job, with interest groups, leisure groups, new relationships, (others). If you were to have one hundred dollars to spend on each of these areas, what value would you put on the following in terms of importance?

Job or career relationships ________________
Special interest group relationships ________________
Leisure relationships ________________
Future relationships ________________
Other(s) ________________

This concludes the interview. I appreciate your time and participation in this study.

## Face Sheet Information

1. Sex______
2. Age______, day______ Month______ year______
3. Diagnosis:
   a. Stage______ b. First time: yes______ no______
   c. Confirmed: yes______ no______
4. Marital Status:
   a. married______ b. separated______ c. widowed______
   d. single______
5. Children: yes______ no______
   a. how many______ b. living at home_____ (how many?)
   c. not living at home______ (how many?)
6. Currently, are you working at a paid job?
   yes______ no______
   a. unemployed______ b. retired______
7. Are your parent(s) living? yes______ no______
8. Do you have sibling(s)? yes______ no______
9. How many years of regular school (including college did you finish?)
   no degree or diploma ______ High school diploma _____
   Associate (A.A,) ______ Bachelors (BA. or B.S.) _____
   Masters (M.A., M.S. MSA etc.) ______
   Professional (MD. Ph.D. Law degree etc.) ______
10. What is your racial or ethnic group?
    white (not of Hispanic origin) ______ Asian ______
    Black ______ Hispanic ______ American Indian ______
11. How important are religious or spiritual beliefs in helping you deal with problems?
    very important ______ somewhat important ______
    not very important _____ not at all important ______
12. At this time, are you receiving any medication or treatments for your illness, what are they?
13. How would you rate your health at this time?
    excellent ______ good ______ fair ______ poor _____
14. When did you suspect that something was wrong?
    days ______ weeks ______ months ______ years ______
15. How long ago did you see a doctor for this problem?
    weeks ______ months ______ years ______
16. When were you told about the diagnosis?
17. Did you talk about it to someone? yes _____ no _____
18. To whom did you talk to?
    family member ______ friend _____
    physician or a health professional ______
19. Did you read about it? yes ______ no______

# APPENDIX C

## Derdiarian-Lewis Technique of Intercoder Reliability

According to Krippindorff (1980), the term reliability covers at least three distinct types of reliability. Stability reflects the degree to which a process is unchanging over time manifested under test-test conditions, and it is the weakest of the types. Stability is also known as intra-observer reliability. Reproducibility is the degree to which a process can be recreated under varying conditions such as different times, locations, and employing different coders. Reproducibility is obtained when two or more coders apply the same coding instructions independently on the same sets of data. Disagreements between the coding of these individuals reflect both intracoder and intercoder inconsistencies in the manner of application of instructions for analysis. Disagreements between coders also reflect the clarity of definition of the variables, mutual exclusiveness of the variables defined, and clarity of the instructions. Reproducibility is the stronger of these two techniques. The strongest type is accuracy, which reflects the degree to which a process is nonvariant from a standard process. It is obtained when the performance of one coder is compared with a known correct (standard) performance. In the absence of such known standard coding, the reprodubility approach to intra- and intercoder reliability was employed.

It was proposed by the researcher that the agreement among the coders could be subject to doubt in the absence of a known standard. It could be subject to doubt also that the observed agreement could be by chance or by a collective deviation from a norm on the part of the coders. Therefore, a statistical measure stronger than percent agreement should be applied to the ratings of the coders to estimate the degree of probability that the observed agreement is not the function of chance. Therefore, following the principles underlying Bernouli's (1977) trials, a statistical design could be devised to estimate the reliability of the data produced by three coders in terms of reproducibility independent of chance.

The proposal was made and a statistical design was produced by Lewis (1983) which was named the Derdiarian-Lewis binomial test of proportion of agreement, and it is described below.

The three coders were asked to code each of k items of an interview transcript as belonging to one of the categories. For convenience the categories were labelled as 1 for belonging and 2 for not belonging. For each item the raters' assessment would be one of eight possible outcomes, 111, 112, 121, 211, 122, 212, 221, and 222. For the outcomes 111 and 222, complete (100%) agreement among coders was accepted, while for all other outcomes there would be agreement between only two raters. For the k items combined, the percent of outcomes for which there was complete agreement was defined as the measure of intercoder k = 6 agreement. For example, if there were k = 6 items and the coders' assessments were 111, 111, 121, 111, 111, 222, then the measure of intercoder agreement would be 5 out of 6 or 83.3%. In addition to the measure of agreement, the likelihood of observing at least that degree of agreement under the null hypothesis that the raters were randomly assigned to rate all the transcribed items according to codes as 1 or 2 was calculated. In other words, the hypothesis was tested that the level of agreement occurred by chance alone. Thus, under the null hypothesis, each of the eight outcomes (111, 112, etc.) would occur with probability 1/8. Therefore, the event, "complete agreement," would occur with probability 1/8 + 1/8 = 1/4, corresponding to the sum of the probabilities for outcomes 111 and 222. It follows that the number of "complete agreement" out of k trials can be modeled as a binomial variable with n = k and p = 0.25. The p-value for testing the hypothesis that the percent agreement occurred by chance was calculated as the upper tail probability of the appropriate binomial distribution.

# APPENDIX D

PROTECTION COMMITTEES
CLINICS 116

TO: Jeanne Hallburg, Ph.D./Anayis Derdiarian
N 405 Y/3440 Alana Dr., Sherman Oaks, CA 91403

RE: Informational Needs Perceived by Recently Diagnosed Adult Cancer Patients

The UCSF Committee on Human Research (an IRB holding DHHS assurance G0155) approved the above request to involve humans as research subjects.

APPROVAL NUMBER: 932109-01* This number is a UCSF CHR number which should be used on all consent forms, correspondence and patient charts.

APPROVAL DATE: July 12, 1982 Full review ____
Expedited review XX

EXPIRATION DATE: July 12, 1983 If the project is to continue it must be renewed by the expiration date. If the number has an asterisk, the renewal will be expedited.

SUBMISSION ADDENDA: No ____ or Yes XX. A yes indicates that there was correspondence between the Committee and the investigator during review of this submission; it does not stand unaltered.

CONDITIONS:

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within five working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

LEGAL NOTICE: The University will defend and indemnify a principal investigator in legal actions arising from research activities involving humans if the activities had current CHR approval.

QUESTIONS: Please contact the Human and Environmental Protection Committees office (Erica Heath or Louise Tipton) at (415) 666-1814, room Clinics 116.

Sincerely,

Neal L Benowitz MD for

Richard C. Maurer, M.D.
Chairman
Committee on Human Research

CC: Contract and Grants
Drug Info and Analysis Service
___ VAMC Research Office

Enc: extra copies of protocol

UNIVERSITY OF CALIFORNIA (Letterhead for interdepartmental use)