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**DEVELOPMENT AND EVALUATION OF A DECISION AID FOR PATIENTS CONSIDERING
TREATMENT OPTIONS FOR STAGE IV NON-SMALL CELL LUNG CANCER**

By

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Thesis submitted to the School of Graduate Studies and Research
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Abstract

A decision whether to receive chemotherapy for stage IV non-small cell lung cancer (NSCLC) is one in which the benefits and risks of the treatment and the personal values of the patient must be considered. An evidence-based practice guideline has been produced regarding chemotherapy for the management of stage IV NSCLC. Treatment options include supportive care, which may involve palliative radiation therapy, or supportive care in addition to chemotherapy. Currently, there are no structured methods to support patients making the decision about these treatment options.

This study was guided by O'Connor's Decision Support Framework, which asserts that decision support interventions increase comprehension of treatment alternatives, benefits and risks and decrease the decisional conflict experienced by the patient. Objectives of the study were to develop and conduct a preliminary evaluation of a decision aid for patients making the decision about chemotherapy for stage IV NSCLC. In particular, this study: 1) evaluated the effect of the decision aid on the patient's comprehension of the treatment alternatives, benefits and risks; 2) evaluated the effect of the decision aid on the decisional conflict experienced by the patient; and 3) evaluated the decision aid's acceptability to patients and practitioners.

The decision aid was developed by Valerie Fiset, Dr Annette O'Connor, Dr Bill Evans, Dr Jo Logan and Cathy DeGrasse. It includes information describing advanced lung cancer, its effects and what people may do to cope with those effects. As well, the decision aid describes supportive care, radiation therapy, and chemotherapy, discussing in detail the benefits and risks of chemotherapy. The last part of the decision aid is an exercise in values clarification, which

helps the patient to think about what is most important to them in making the decision about chemotherapy.

The decision aid was evaluated in two phases. In phase 1, its acceptability was determined with a group of patients who had already made the decision. Phase 2 was a before / after study of patients actually facing the decision. Study participants were recruited from the Ottawa Regional Cancer Centre. They completed a baseline questionnaire eliciting their comprehension of treatment alternatives, benefits and risks; importance ratings; tentative decision regarding chemotherapy; and the degree of decisional conflict experienced. Participants used the decision aid at home, and at a return visit completed another questionnaire eliciting the same variables as in the pre-test plus the acceptability of the decision aid.

Of the 20 patients who were offered the decision aid, 14 used the decision aid, and 12 users were available for follow-up. The Wilcoxon matched pairs signed ranks test was used to determine that there was a significant difference in the pre- and post- test comprehension and decisional conflict scores. In those who used the decision aid, there was a statistically significant improvement in comprehension of treatment alternatives, benefits and risks ($p=0.004$). There was also a significant decline in decisional conflict ($p=0.006$). The decision aid was found to be acceptable to patients and among practitioners who see it as their role to counsel patients making this decision.

The preliminary results of this evaluation are promising, and further evaluation is required to establish the generalizability of these results. If positive results are found, the decision aid has great clinical relevance in that high demands on the health care system have resulted in practice situations where time is limited for personal counseling. Moreover, patient recall of verbal information during such

a stressful time is poor. A structured decision aid which the client and family can use on their own may provide a useful adjunct to counseling. This study also contributes to the growing body of research examining optimal methods of providing decision support to patients in a variety of clinical settings.

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Chapter One

Introduction

This chapter provides an introduction to the issues surrounding treatment decision making for stage IV non-small cell lung cancer and provides the rationale for the development of a decision aid for this patient population.

Organization of Thesis

This thesis is divided into six chapters. Chapter Two provides an extensive review of the research relevant to the provision of decision support and a description of the conceptual framework on which this thesis is based. It concludes with a summary of the study objectives and hypotheses. Chapter Three describes the development and pilot testing of the decision aid intervention and Chapter Four describes the design of the study. The results of the evaluation of the decision aid are presented in Chapter Five, and a discussion of the results of the study is found in Chapter Six.

Problem and Purposes

In 1996, lung cancer was the leading cause of cancer deaths for Canadian men and women (1). There is a relatively low overall five-year survival rate (15%) for lung cancer as compared with other cancers (2,3). In stage IV non-small cell lung cancer (NSCLC), which accounts for 25-30% of presenting patients, the five year survival rate is particularly poor at 3% (3,4). Given the current fiscal environment in health care and the introduction of new, expensive systemic therapies, treatment guidelines have been developed by the Ontario Cancer Treatment Practice Guidelines Initiative (5,6). Specifically, a practice guideline has been produced for the management of stage IV (metastatic) NSCLC (7). Treatment options include supportive care,

which may include palliative radiation therapy, or supportive care in addition to chemotherapy.

A decision whether or not to receive chemotherapy for stage IV NSCLC is one in which the benefits and risks of the treatment and the personal values of the patient must be considered. The marginal improvement in survival needs to be weighed against the side effects and inconvenience of treatment, and all patients may not agree that the benefits outweigh the risks. Patients are likely to experience some difficulty in making such a decision, and thus may experience decisional conflict (8). Providing for ethical, quality patient care necessitates that health care practitioners intervene in order to help patients make informed decisions consistent with personal values.

It is essential that patients and their families be provided with information, and be assisted to identify what is most important to them in making this decision. Research by Slevin and colleagues (9), showed that patients with cancer are much more likely to choose radical treatment with minimal chance of benefit than people who do not have cancer, including health care practitioners. It is therefore necessary to elicit the patient's personal preferences, and not assume that their values are the same or similar to those providing care.

Participation in treatment decisions has also been identified as a strategy for empowering cancer patients (10,11). Hack, Degner and Dyck maintain: "Two important ways by which cancer patients may gain a sense of control over their illness include: a) acquiring information about their illness and its treatment, and b) playing a more active role in treatment decision making." Other benefits of participation in decision making include decreased anxiety and depression (12,13), increased satisfaction with decisions taken and the care received (14), and a higher degree of hope (15).

Decision aids provide a structured method of decision support for patients and their families to assist them in making difficult decisions. Generally, decision aids provide a description of choices and their probable outcomes based on research evidence. Decision aids assist in clarifying values or the desirability of each of the expected outcomes (16). The efficacy of decision aids has not been well established, but preliminary evidence suggests that they reduce uncertainty about what to do, improve comprehension, clarify values and promote decisions considered effective by the patient (8). There have been no decision aids for patients with stage IV NSCLC deciding between supportive care alone and chemotherapy in addition to supportive care. Therefore, the objective of this thesis is to develop and evaluate a decision aid for patients considering chemotherapy for the treatment of Stage IV NSCLC.

The provision of decision support has great significance for nursing practice. Nurses are in a position to provide decision support to clients and their families deciding about treatment options (17-20). For example, Neufeld et al (18), describe a collaborative model for physicians and nurses to enhance involvement of patients in their treatment decision making. It is essential that clients who want to participate in decisions about their care make the decision to accept or refuse chemotherapy based on a consideration of the potential benefits and risks and the value they place on each of these. High demands on the health care system have resulted in practice situations where physicians and nurses may not always have a great deal of time to provide education and unstructured decision support. Time limitations also reduce the opportunity for participatory decision-making (21). A structured decision aid which the client and family can use on their own may provide a solution to this challenge. Guided by the Decision

Support Framework (DSF) (22), this study involved the development and initial evaluation of such an intervention for patients with stage IV NSCLC.

Chapter Two

Review of Previous Research and Theory

This chapter briefly describes the search methods used, followed by a summary of the research regarding patient's desire for information and participation in decision making and the types and efficacy of decision support interventions. The conceptual framework of the study is discussed, concluding with an outline of the study objectives and hypotheses.

Searching the Evidence

The strategy for searching the evidence on shared decision making and decision support interventions was to use a published annotated bibliography of the research from 1974-1995 and updated in 1997 using the same search methods (23). The following database index terms were searched: decision making, choice behaviour, informed consent, decision support techniques, patient advocacy, patient education, treatment refusal, patient participation, patient dropouts, patient compliance, consumer satisfaction, consent, decision support, consumer participation, health education, patients, participation, advocacy, consumer, satisfaction and acceptance of health care. The databases searched include Medline, Cinahl and PsycLit. In addition, a hand search was carried out by examining reference lists of the relevant published material.

Patient's Desire for Information and Shared Decision Making

Over the years, there has been an increased emphasis on consumerism in health care. This has been accompanied by greater articulation of patient rights and autonomy, which often is in conflict with the ethical principle of beneficence, on which many health care decisions are based (24). This conflict often is played out between the practitioner and the patient as treatment decisions are being made.

This section will briefly examine the literature regarding the patient's desire for information and involvement in treatment decisions.

In 1974, McIntosh (25), carried out a review of the literature examining the structure and organization of communication, information seeking and control associated with malignant disease. Since that time, a considerable number of descriptive studies have been conducted examining the information needs of cancer patients as well as the degree to which patients wish to be involved in decisions about their care. The results of a number of these studies are included in Appendix A, and the variables which correlate with preferences for information and participation in decision making are shown in Appendix B.

In terms of patients' informational needs, the majority of studies show that patients want detailed information about their diagnosis, possible treatment, and outcomes (12,15,26,27,29,30,32-35). This was also reflected in a review conducted by Deber in 1994 (24). Sociodemographic characteristics that were most strongly related to increased desire for information include younger age and higher level of education (15,29). The reported degree to which patients wish to participate in treatment decisions was more variable, ranging from 12% (28) to 69% (27). Degner and Sloan found that sociodemographic variables accounted for only 15% of variance in preferences for participation in decision making. Generally, the stronger preferences for participation were seen in patients who are young, well-educated and female (15,26-28,31). Cassileth, Zupkis, Sutton-Smith, and March reported that patients with a favourable diagnosis preferred a more active role in decision making, while Blanchard, Labreque, Ruckdeschel, and Blanchard reported that patients with a poorer prognosis were more

active (15,27).

Preferences for participation range from those who wish to take a very active role in decision making to those who prefer to leave the decision up to the practitioner (31). The variability of these studies could, in large part, be related to the difference in measures used to determine the degree of patient participation desired. In earlier studies, (15,27) two-item indicators of role preference were used. Others, (26,29,30,31,34) used a multiplicity of role descriptions. Differences may also be accounted for by the variability in the populations studied and the treatment decisions they are asked to consider.

The variability in study results calls for an increased sensitivity on the part of the practitioner to assess the degree to which patients wish to participate in decision making about their care. In all studies, (15,26-35) it is emphasized that practitioners must assess and take into consideration the patient's preferences for information and participation in decisions. Two issues that are not addressed in sufficient detail in the literature are the assessment of decision making preferences among individuals from different cultures, and the role of the family in the determination of patient preferences.

Decision support interventions

A number of approaches have been developed to provide information and decision support to individuals faced with making health care decisions. A summary of decision support intervention studies is outlined in Appendix C.

Four studies have looked at the use of a decision board to help elicit patient preferences for treatment (36-39). The decision board is a visual aid designed to provide information about a patient's choices for treatment, the outcomes associated with each alternative,

and the probabilities of the outcomes. The quality of life associated with the outcomes is detailed. The practitioner reviews the information on the board, and patients may keep a summarized version to refer to at home. The advantages of the decision board are its portability and low cost in development and updating. The decision boards that have been evaluated have dealt with treatment decisions for breast cancer, chronic myeloid leukemia and advanced ovarian cancer (36-39). Two of the studies were descriptive in nature using healthy volunteers (36,38). These studies demonstrated that the decision board was both reliable and valid, and acceptable to the subjects. Another study in patients with breast cancer (37) used a nonrandomized sequential design, demonstrating the decision board's acceptability and efficacy in facilitating shared decision making. Most recently, Elit and colleagues found a decision board for women with advanced ovarian cancer to be reliable, valid, acceptable and helpful to women in comprehending treatment alternatives, benefits and risks. They evaluated this decision board in healthy volunteers, patients who had previously made the decision and in patients actually at the point of decision making (39).

Advance directives (56,57) have also been evaluated as a type of decision aid. They provide individuals with information about life-sustaining treatments given varying health situations. They are used independently by patients and their families, and practitioners are informed of preferences. Patients are guided to indicate what kind of interventions they would want if they were very ill or nearing death. Evaluation of advance directives has been carried out using a randomized crossover trial in hemodialysis patients (56) and a cross sectional survey in medical outpatients (57). Evaluation of advanced directives has shown them to be generally acceptable, however, it is

suggested that patients should be allowed to choose the advanced directive most appropriate for them, whether disease-specific or generic (57).

A decision aid using a booklet and audiotape for women deciding about long-term hormone replacement therapy has also been described in the literature (22,40). It provides information about treatment alternatives, individualized risks and benefits of the alternatives and an exercise in values clarification which helps the user weigh the personal importance of the benefits and risks. Similar to the decision board, the booklet and audiotape are portable and inexpensive to develop and update. Other advantages include self-administration and increasing the opportunity for active learning for the woman. A descriptive pilot study of the decision aid has been carried out in women aged 45-75, showing it to be acceptable to women as well as reliable and valid (40). Other studies evaluated the decision aid using a before / after design (22) followed by a randomized control trial of a decision aid versus a pamphlet (41). The before / after study showed the decision aid reduced decisional conflict, increased comprehension, and created realistic expectations. Compared to the pamphlet, the decision aid was better at reducing decisional conflict, creating realistic expectations, and was more acceptable.

Another decision support intervention has been evaluated via a trial (42) in perimenopausal women. Three decision support strategies were compared: a brochure; lecture and discussion; and active decision support. All three interventions increased knowledge, satisfaction with provider, certainty with regard to the decision about hormone replacement therapy and self-efficacy. Active decision support was found to increase a person's willingness to make a decision and to develop a better understanding of the complexity of the decision.

An interactive video disk program has been developed and evaluated for men with benign prostatic hyperplasia (43,44) and in patients making decisions about treatment for ischemic heart disease (45). It has been demonstrated that this technology is acceptable to patients (43,45) and may affect treatment choices made (44,45). Several other video programs have been evaluated for other conditions including breast cancer and AIDS (46,47) and treatment options such as clinical trial entry (48). Using interactive videodisc technology, patients are provided with information about treatment options and the potential benefits and risks of each. The interactive component of the program allows tailoring to meet the user's need for information. These programs do not include exercises to allow the patient to weigh benefits and risks. There is also quite a high cost involved in their development and implementation and their use is limited to facilities having the space and resources to purchase video disk technology.

Another group of decision aids uses either formal, structured decision analysis or informal decision analysis (49-55). This process involves the use of complex procedures to quantify the subjective probabilities and utilities of outcomes, and combine them, with the goal of determining the alternative with the highest expected utility. This method is strong theoretically and analytically in its quantification of patient preferences, but in three studies, (49,50,55) the provision of information was not a coherent part of the decision making process. Many people find decision analysis complex to use in a situation when making health-related decisions that invoke a great deal of anxiety. Pauker and Pauker reported on the evaluation of a decision analysis model to help couples make the decision to have amniocentesis (60). They established that some participants tired during the process of utility elicitation, and that others refused to deal with the

numbers used in decision analysis. Lastly, there is poor correspondence between decisions derived from decision analysis and those made intuitively (61). Evaluation of decision analysis has been carried out in a variety of settings using a variety of research designs. It has been shown: to be acceptable to healthy volunteers (49) and in patients with benign prostatic hyperplasia (55); to have an effect on the treatment chosen (51-54); and to be helpful in making a decision and improve psychological adaptation following decision making (50).

A last group of interventions has been described in which patients were provided guidance by a nurse or clinical assistant prior to their appointment with their physician (18,58,59). Specifically, patients would be encouraged to identify questions to ask of their physician, would identify the degree to which they wanted to participate in treatment decision making, and would receive support and information. The two latter strategies were evaluated using randomized control trials, and were shown to increase the degree to which patients were involved in treatment decision making, improve functional and physical status, and change patient behaviours.

The primary problem in examining the literature on existing decision support interventions is that there has been very little evaluation done using experimental designs. The majority of the published literature is essentially not generalizable as results are from studies of healthy volunteers, or from studies with small sample sizes. It would be preferable for these interventions to be evaluated in a randomized trial with multiple outcome measures.

Conclusion

In summary, the literature demonstrates that patients do indeed want more information about their illness and treatment options.

Although the degree to which patients want to participate in decisions about their care is more variable, it has been shown that some patients do want to actively participate in this process. It remains an ethical practice imperative in health care that patients have the opportunity to provide informed consent which is based on their personal values. Decision support interventions have been developed, but they have not been evaluated completely with randomized control trials and none have examined the decisions facing individuals with lung cancer. There are no decision aids designed to help people make decisions about palliative treatment, a decision in which the client's values should be paramount in the decision making process. Guidelines on the use of chemotherapy for patients with incurable malignancy include recommendations that the patient be well informed and have assessed risks versus benefits (62). It is essential that practitioners become aware of methods to support patients making such decisions, and that evaluation of these supportive measures be carried out (63). This work will contribute to the growing body of research addressing the development and testing of decision aids, and through its conceptual base help to contribute to the identification of explicit theory for clinicians and researchers introducing decision aids into practice.

Conceptual Framework

Overview

The conceptual framework for this study is the Decision Support Framework (DSF), developed by O'Connor (22) (see Figure 1). The DSF summarizes the key variables in assessing determinants of decisions, providing decision support, and evaluating the quality of the decision making process, the decision and the outcomes of the decision (22). The theoretical underpinnings of the DSF include the expectancy value decision theories in economics (64), psychology (65) and social

psychology (66), the conflict model of decision making developed by Janis and Mann (67), Orem's self-care framework (68), and Norbeck's construct of social support (69).

Rationale for choice

The DSF was developed for health decisions that: 1) are stimulated by a new circumstance, diagnosis, or developmental transition; 2) require careful deliberation because of the uncertain and/or value-sensitive nature of the benefits and risks; and 3) need relatively more effort during the deliberation phase than the implementation phase. These criteria accurately reflect the nature of the decision regarding chemotherapy for Stage IV NSCLC.

The DSF describes a process of decision support in detail, by specifically addressing: 1) the determinants of the decision; 2) decision support interventions which can modify the determinants and consequently affect the decisions and outcomes; and 3) evaluation of decision support including the quality of the decision making process, the actual decision and the outcomes of the decision (22).

1. Assess Client & Practitioner Determinants of Decisions	2. Provide Decision Support Practitioner & Client for DM; Structure Follow-up Interaction	3a. Evaluate Quality of Decision and Decision Making Process	3b. Evaluate Client Outcomes of Decision
Sociodemographic & Clinical Characteristics	Tailor to participants' characteristics	Satisfaction with decision support	Improved health related quality of life
Perception of the Decision Knowledge Expectations Values Decisional conflict	Provide access to information Clarify/Modify expectations Clarify values Tailor support to factors contributing to decisional conflict	Improved knowledge Realistic expectations Improved clarity of values & value congruence with decision Reduced decisional conflict Reduced decision delay Satisfaction with decision	Reduced distress from consequences Reduced regret Appropriate persistence with decision
Perception of Important Others Norms Pressure Support Decision participation roles	Clarify/modify perceived norms Clarify pressure; Facilitate self-help skills handling pressure Facilitate access to support Tailor support to decision participation preferences	Realistic perception of norms and pressure Satisfaction with decision support	Appropriate persistence with decision
Resources to Make & Implement Decision Personal resources experience self-efficacy skills motivation other resources External resources	Enhance self-help skills preparing for, making, and implementing decisions and coping with consequences Facilitate access to resources	Improved self-efficacy Improved decision making skills Decision implementation	Reduced distress from consequences Appropriate persistence with decision Appropriate and efficient use of resources Satisfaction with care

Figure 1. Decision Support Framework (DSF)

Determinants. The DSF extensively describes the inputs into decisions including the practitioner's and the client's: demographic, clinical and practice characteristics; perceptions of the decision; perceptions of important others involved in the decision; and personal and external resources to make and implement a choice. The determinants are defined in greater detail in Figure 2.

According to the DSF, the relationship between determinants and the decision to accept chemotherapy for stage IV NSCLC may be described using the DSF. A person may decide to accept chemotherapy because 1) the patient's expectation is that it will lead to valued outcomes (e.g. survival or symptom relief); 2) others whose opinions are valued by the patient (e.g. family members, physicians) also think it is a desirable option; and 3) the patient has the necessary personal and instrumental resources and self-care agency to make the decision and implement it. Individuals with different clinical and demographic characteristics may make different decisions.

In the present study, the determinants measured include sociodemographic characteristics; knowledge of the clinical problem, treatment alternatives, benefits and risks; perceived likelihood of benefits and risks; the personal importance of the benefits and risks; and decisional conflict.

1. **Client's and Practitioner's Sociodemographic and Clinical Characteristics**
Client: age, gender, education, ethnicity, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social)
Practitioners: age, gender, ethnicity, clinical education and speciality, practice locale, years of experience
2. **Client's and Practitioners Perception of the Decision**
 - Knowledge→ Cognisance of the clinical problem, alternatives & rationale, consequences (benefits, risks).
 - Expectations→ Perceived likelihood or probability of benefits and risks.
 - Values→ Desirability or personal importance of benefits and risks; under conditions of uncertainty, utilities become values which incorporate not only desirability but also attitude toward risk.
 - Decisional→ Uncertainty about course of action to take arising from factors inherent in the decision (uncertainty of outcomes, or the need to make values trade-offs between benefits and risks) and modifiable factors (inadequate knowledge, unrealistic expectations, unclear values, social pressure, inadequate social support).
 - Conflict
3. **Client's and Practitioner's Perceptions of Important Others Regarding the Decision**
 - Norms→ Perceptions of what important others think is the appropriate choice. For the client, important others may include their spouse, family, peers and practitioner(s). For the practitioner, it may include the client, professional peers and personal network.
 - Pressure→ Perception of persuasion, influence, coercion from important others to select one alternative.
 - Support→ Informational, emotional and tangible help provided by one's social network (spouse, family, friends, peers) and professional network to bolster and sustain decision-making.
 - Roles→ Actual practice and preferences for participation in decision making (client controlled, shared with practitioner, practitioner controlled, other controlled).
4. **Resources to make the decision**
 - Personal Resources
 - Experience→ Previous exposure to the clinical problem, alternatives, consequences, decision making process.
 - Self-efficacy→ Confidence in one's abilities in decision making, including shared decision making.
 - Motivation→ Readiness and interest in decision making, including shared decision-making.
 - Skills→ Abilities in making and implementing a decision.
 - Other→ Instrumental and financial capabilities to implement choices.
 - External resources Assets from others that are required to make and implement the decision:
 - Type: access to information, advice, emotional support, instrumental help, financial assistance, and health and social services.
 - Source: social networks, professional networks, support groups, voluntary agencies and the formal health care, education and social sectors.

Figure 2. Definitions of determinants of decisions in the Decision Support Framework

Decision Support. The goal of decision support is to enhance the quality of decision making by addressing those determinants which can be modified such as: inadequate knowledge, unrealistic expectations, unclear values, unclear norms, unwanted pressure, inadequate support, and inadequate personal and external resources to make the decision. By addressing these determinants, decisional conflict may in turn be diminished (16). Specific decision support interventions include: providing information tailored to the patient's situation, clarifying values and norms and increasing self-help skills in decision making and implementation. These interventions may be provided as individual counseling (decision therapy) or as structured decision aids (22).

Structured decision aids include information about the problem, alternatives, benefits and risks to improve knowledge required to make the decision. Realistic expectations are promoted by presenting probabilities of outcomes that are tailored to the specific decision. Decision aids also serve to clarify values by asking individuals to consider the personal importance they place on each benefit and risk. This is intended to result in better congruence between a person's values and their choice.

Guiding patients through steps in decision making and illustrating how others have used these steps enhance skills and self-efficacy in decision making. The presentation of others' decisions also clarifies norms and demonstrates how personal health histories and personal values influence decisions.

One purpose of a structured decision aid for patients considering treatment options for stage IV NSCLC is to provide information regarding treatment alternatives and their associated benefits and risks. Providing this information may create more realistic expectations as to the benefits or risks of treatment. The decision

aid also provides a venue for values clarification by asking the patient to rate benefits and risks according to their relative desirability (16). Subjective norms may be clarified by indicating the degree of variability in opinions about preferences by other patients. This decision support intervention may also enhance resources for both decision making and implementation by providing information on how to access other resources.

Evaluation. The DSF describes decision outcomes in terms of the quality of the decision including: reduced decisional conflict; improved comprehension of alternatives, benefits and risks; more realistic expectations of consequences; improved value congruence with the decision; improved decision self-efficacy; and satisfaction with the decision or care. The quality of the decision is distinguished from the quality of the outcomes. Outcomes include long-term decision commitment; regret; treatment symptom distress; anxiety and depression; quality of life; ability to handle future decisions; use of health services; morbidity; and mortality (22).

In the present study, the evaluation criteria centred on the quality of the decision and decision-making process. Specifically, knowledge, expectations, decisional conflict, values congruence and satisfaction with the decision and decision support were measured.

Previous use of the framework

The DSF brings together the numerous factors that have been identified in the process of patient decision making. The DSF has been utilized in four studies (40,70-72), and is still in development. In one application to hormone replacement therapy in post-menopausal women, the DSF was validated in that key determinants such as knowledge, expectations and decisional conflict were modified in appropriate directions through the provision of a structured decision

aid. Moreover, the decision aid promoted value congruence with the decision and was considered acceptable by the women (22). The DSF has not been validated empirically for patients with stage IV NSCLC. This study will contribute information about its validity in a population who are seriously ill and are facing a life-threatening illness.

Study Objectives and Hypotheses

Purpose. The purpose of this study is to develop and evaluate the effectiveness of a decision aid for patients making the decision about chemotherapy for stage IV NSCLC. The specific study objectives are to:

1. Develop a decision aid based on treatment guidelines;
2. Evaluate the effect of the decision aid on the patient's comprehension of the treatment alternatives, benefits and risks;
3. Evaluate the effect of the decision aid on the decisional conflict experienced by the patient; and
4. Evaluate the acceptability of the decision aid to patients and practitioners.

Hypotheses. According to the DSF,

1. Patients using a structured decision aid will demonstrate improved comprehension of treatment alternatives, benefits and risks; and
2. Patients using a structured decision aid will experience decreased decisional conflict.

Chapter Three

Development and Pre-test of the Decision Aid

This chapter describes the approach used to develop the decision aid and the results of the pre-test in patients who had already made the decision.

The Process of Decision Aid Development

A decision aid entitled "Making Choices: Treatment of Stage IV Non-Small Cell Lung Cancer" was developed, operationalizing constructs in the Decision Support Framework (22) and based on practice guidelines regarding the use of chemotherapy for stage IV NSCLC (7). The process of decision aid development consisted of four stages: 1) prototype development, 2) validation by expert panels, 3) pre-testing with patients who had previously made the decision, and 4) revision.

Prototype development. The content of the decision aid was based on studies describing the quality of life for patients with lung cancer, the Ontario Cancer Treatment and Research Foundation (OCTRF) Supportive Care Framework (73), the evidence describing the role of chemotherapy in patients with stage IV NSCLC, and the OCTRF practice guidelines based on this body of evidence (7). The practice guideline describes the use of chemotherapy for patients with advanced lung cancer, in terms of both its effects on survival and quality of life. This evidence provided the basis for the "pros" and "cons" section of the decision aid.

In addition to the use of empirical literature, patient teaching materials that are currently being used at the Cancer Centre and the Canadian Cancer Society were consulted to ensure that the decision aid content complemented current patient education materials.

The format of the decision aid was modeled after the decision aid for women deciding about long-term hormone replacement therapy (22).

Inherent in this model are three "types" of intervention designed to facilitate decision making according to the Decision Support Framework. The first component is the provision of information, which is essential for patients undertaking this difficult decision. Davidson and Brundage examined the question "What type of information should be provided to patients with lung cancer making treatment decisions?" (74). They found that in order to make treatment choices, individuals believe it is important to know about the treatment regimen, side effects, survival and also about treatment effects on several aspects of quality of life. Information provided in the decision aid includes a description of cancer, non-small cell lung cancer, the staging process, how lung cancer can effect the patient and how to cope with these effects. As well, the decision aid discusses the treatment options of supportive care, radiation therapy and chemotherapy. The pros and cons of chemotherapy are described in a general sense, that is, they are not described specifically regarding a particular drug or treatment regime.

The second part of the intervention guides the patient through the steps in making a decision and provides examples of how other patients used these steps to make their decision. The third part of the decision aid involves values clarification using a "weigh scale" exercise to assist patients to identify the personal importance they place on the positive and negative consequences of accepting chemotherapy for stage IV NSCLC. The decision aid booklet is included in Appendix D.

Doak, Doak and Meade (75) published a compilation of strategies to improve cancer education materials, a number of which were incorporated in to the decision aid development. The reading level of the decision aid is at grade seven using the Flesch-Kincaid grade level

score. As recommended by the authors, understanding of the text portion of the decision aid is enhanced by the use of graphics and verbal instructions. The participative component of the decision aid also enhances the likelihood that learning will take place. The decision aid appeals to the claim that people are most interested in information that will help solve their immediate problems. The information contained in the decision aid is a concise summary of the information that patients need to solve their problem of treatment decision making. Lastly, the authors outline five critical writing elements which were applied to the decision aid: writing in active voice and conversational style, using common words as much as possible, using subject headings as advance organizers, providing examples, and using a readable type style and text arrangement.

Once the decision aid booklet content was determined, the text for the accompanying audiocassette was developed. The audio portion of the intervention guides the patient through the booklet, expanding upon key points in the written text.

Validation by an Expert Panel. Each draft of the booklet content was reviewed to ascertain face and content validity by the following expert panel: Dr Bill Evans (a medical oncologist and Chair of the Lung Disease Site Group of the Ontario Cancer Treatment Practice Guidelines Initiative), Dr Diane Logan (a medical oncologist), Dr Annette O'Connor (a specialist in decision making) and by Cathy DeGrasse (a clinical nurse specialist with extensive oncology nursing experience). Once this initial panel was satisfied with the overall presentation of the material, a second consultation process took place. Medical and radiation oncologists at the ORCC caring for lung cancer patients were asked to comment on the face and content validity of the decision aid and to ensure that the information in the decision aid reflected actual

practice. After incorporating many valuable suggestions from these practitioners, the decision aid was once again submitted to them for review prior to the pre-test.

Pre-test of the Decision Aid with Patients

A pre-test was carried out to determine the content validity and acceptability of the decision aid in patients who had already made the decision about chemotherapy.

Sample. A convenience sample of 6 individuals was recruited. Inclusion criteria were: English speaking men or women with a diagnosis of stage IV NSCLC; being followed at the Ottawa Regional Cancer Centre; who had already made the decision whether or not to accept chemotherapy for stage IV NSCLC; and had provided informed consent to participate in the study. Exclusion criteria were patients with metastases to the brain causing significant cognitive impairment; the inability to speak or read English; or patients judged unsuitable to participate by ORCC staff due to physical/ mental impairment or emotional distress. The investigator ensured that patients who declined chemotherapy were included in the sample.

Procedure. Patients who had decided to accept chemotherapy were recruited at follow-up appointments with their medical oncologist. After providing informed consent, they were provided with the decision aid to review at their convenience. At another follow-up or treatment appointment, patients completed an acceptability questionnaire. Palliative care physicians who had clinics at the ORCC were consulted and referred appropriate patients who decided not to take chemotherapy. One such patient was interviewed twice at the Cancer Centre, and the other was interviewed at home.

Measures. Demographic characteristics elicited included: gender, age, marital status, language most frequently spoken, and highest level

of education completed. Clinical characteristics collected included: cancer cell type, the location of the cancer, the location and number of metastases, and the performance status of the patient. (See Appendix E)

Acceptability of the decision aid was assessed using both open-ended questions and closed-ended questions with ordered choices (See Appendix F). The closed-ended questions had been used in another study assessing the acceptability of a shared decision making program (43).

Findings. Table 1 summarizes the demographic and clinical characteristics of the sample, and the choice they had made regarding chemotherapy. Four of the six participants had chosen to accept chemotherapy. The sample was predominantly male, married, English speaking, with a median age of 61 years. The education level of the majority of participants was high school diploma or less. In terms of clinical characteristics, the most frequent tumor type was large cell carcinoma, located in the right upper lung. Most common metastatic sites were bone, liver and lymph nodes. Lastly, performance status ranged from fully active to limited self-care.

The acceptability data are reported in Table 2. Generally, participants judged there was the right amount of information in the decision aid, the length and clarity were acceptable, and that it was appropriate and helpful for other patients making the same decision. The items that showed less agreement were the degree to which the decision aid was upsetting, and the balance of the decision aid. The participants who found the decision aid a little or somewhat upsetting were all taking chemotherapy. The information on survival rates is what participants found most upsetting. Two participants felt that the survival information should be removed, because it would be very upsetting for patients to get this information if they hadn't already

heard it from their physician. The information on survival may have been upsetting for these participants because they had unrealistic expectations of the benefits of chemotherapy. Three of the participants who indicated that the balance of the decision aid was slanted toward chemotherapy were taking chemotherapy and the other was not. One participant commented that they thought the decision aid was clearly slanted toward taking chemotherapy because the other options were not discussed in as much depth. The item on the questionnaire regarding balance was difficult for some of the participants to understand.

When asked what the participants liked most about the decision aid, they commented that it was very informative, straightforward, and easy to use, using simple terms. One participant felt that the decision aid reflected what people do experience with lung cancer and another said that the decision aid did give a good idea of what to expect in terms of survival and side effects. In responding to what the participants liked least about the decision aid, all those who commented felt that the survival rates were "pessimistic" and may take away hope.

Participants were asked what information they would add and what information they would remove. Additional information that respondents said would be useful included more information regarding side effects, the future or what to expect and information on complementary or alternative therapies. One respondent said that no information should be removed saying "You've got to know everything". Other comments included: "The decision aid reinforced everything that I have experienced over the past year and a half." And, "I had been through all this before in making the decision not to take chemotherapy."

Language was an issue for some of the respondents, which impacted

on their perception of the clarity of the decision aid. When asked to comment on the clarity of the decision aid, one respondent said that it should have been in French. Another francophone respondent found the survival information difficult to understand.

Table 1

Demographic and Clinical Characteristics of Pre-test Sample (n=6)

Variable	(n)	Median	Range
Gender:			
Male	5		
Female	1		
Age		61	49-78
Marital Status:			
Married, common-law	4		
Widowed	1		
Divorced / Separated	1		
Language Spoken:			
English	4		
French	2		
Other	1 (Polish / Croatian)		
Education:			
Less than grade 9	2		
Some high school	1		
High school diploma	1		
Trade certificate	1		
Some university	1		
Cancer Cell Type:			
Adenocarcinoma	2		
Large Cell Carcinoma	3		
Squamous Cell Carcinoma	1		
Primary Tumor :			
RUL	3		
LUL	2		
LLL	1		
Metastatic Sites:			
Bone	2		
Liver	2		
Lymph Nodes	3		
Adrenal Glands	1		
Other	1 (contralateral lung)		
Performance Status:			
0-fully active	3		
2-no work but self care	1		
3-limited self care	2		
Treatment Choice:			
Chemotherapy	4		
No Chemotherapy	2		

Table 2

Acceptability of the Decision Aid - Phase 1 (n=6)

<u>Criterion</u>	<u>Frequency</u>
1. Amount of information	
About the right amount of information	6
2. Was decision aid upsetting?	
Not at all upsetting	3
A little upsetting	1
Somewhat upsetting	2
3. Length	
About right	4
Little too long	1
Should have been a little longer	1
4. Clarity	
Everything was clear	4
Most things are clear	1
Some things are unclear	1
5. Balance	
Slightly slanted to chemotherapy	3
Clearly slanted to chemotherapy	1
Completely balanced	2
6. How helpful	
Very helpful	3
Somewhat helpful	3
7. Recommend to others making decision	
Would definitely recommend it	5
Would probably recommend it	1

In terms of how helpful the participants found the decision aid, one patient remarked that the decision aid reinforced what the doctor told him. In the final section of the questionnaire asking for other comments or suggestions for improving the tape and workbook, one respondent replied that the decision aid would need more information on how chemotherapy works and how much it helps. Another said that the decision aid was quite comprehensive and would not require revision unless new evidence regarding treatment comes up.

Revision of the Decision Aid

The decision aid was slightly modified prior to the next phase of evaluation. In the discussion of the benefits of chemotherapy, the written text was changed to emphasize that the range of benefit from chemotherapy was wide. Previously, this had only been stated in the

audiocassette accompanying the booklet. Patients must be aware of the benefits and risks of treatment to make informed treatment decisions. It was therefore decided that it would be impossible to alter the presentation of this information, despite the participants' reservations about including these data. Another change made to the decision aid was in the discussion regarding the side effects of chemotherapy. This information was re-ordered to ensure better flow and comprehension of the information. No additional information regarding side effects, what to expect, and alternative therapies were added to the decision aid at that time because of concerns regarding the decision aid's length.

Chapter Four

Methods of Evaluating the Decision Aid

This chapter describes the methods used to conduct a preliminary evaluation of the decision aid with patients at the point of making the decision and with practitioners. The research design, the study population, recruitment and data collection procedures are described.

Research Design

The study design is illustrated in Figure 3. Two groups evaluated the decision aid: patients at the point of making the decision and practitioners who may be supporting patients making the decision.

Group 1 n=12 Patients with Stage IV NSCLC at the point of making the decision about chemotherapy	Group 2 n=22 Practitioners (Family Doctors, Oncology Nurses, Other physicians)
Time 1 Baseline Questionnaire Demographics and clinical data Comprehension test Importance ratings Tentative decision Decisional conflict Decision aid given to review at home ⇓ Time 2 Post-test Questionnaire Comprehension test Importance ratings Decision Decisional conflict Acceptability	Time 1 Practice Guideline plus Decision Aid Distributed Acceptability Questionnaire on Postcard

Figure 3. Research design

Patient study

Design. As shown in Figure 3, a before/after study design was used to evaluate the decision aid. Patients were interviewed at baseline and after using the decision aid.

Sample. A convenience sample was recruited from both the General and Civic divisions of the Ottawa Regional Cancer Centre (ORCC). Inclusion criteria were: a) ability to read and speak English; b) diagnosed with stage IV NSCLC; c) being followed at the ORCC; d) making the decision regarding chemotherapy for stage IV NSCLC; and e) providing informed consent to participate in the study. Exclusion criteria were: a) patients having metastases to the brain causing significant cognitive impairment; and/or b) being judged unsuitable to participate by ORCC staff due to physical / mental impairment or emotional distress.

Procedures. Potential participants were identified by the medical oncologists caring for them at the ORCC. Following the history and physical examination, eligibility was confirmed. The medical oncologist introduced and explained the treatment options, and asked if the patient would be interested in participating in the study. The researcher then obtained informed consent and administered the baseline questionnaire. The use of the decision aid was explained to the patient and family. The patient was provided with the booklet and audiotape, and a cassette recorder was loaned to them if they did not have one at home.

On return to the Cancer Centre, the patient completed the post-test questionnaire. They then visited with the physician to ask any further questions they may have identified, and to make a decision regarding treatment. Some patients did not actually visit with their physician in follow-up, but instead informed them of their decision over the telephone. In this case, the researcher would arrange the completion of the post-test questionnaire at a time and location convenient for the patient.

Measures. The same demographic and clinical data that were

collected in the pre-test were gathered from this group of participants (Appendix E). A baseline questionnaire elicited the following data: comprehension of treatment alternatives, benefits and risks; importance ratings; tentative decision regarding chemotherapy; and the degree of decisional conflict experienced (Appendix G). The post-test questionnaire (Appendix H) assessed the same variables plus the acceptability of the decision aid. All questionnaires were reviewed for face validity by a panel consisting of: Dr Annette O'Connor, Dr Bill Evans, Dr Jo Logan, and Cathy DeGrasse.

Comprehension of treatment alternatives, benefits and risks was assessed using a knowledge test with a true / false / unsure format. Patients were assessed for their understanding of relevant information regarding their disease and treatment options, including their understanding regarding survival benefit with chemotherapy and the side effects of chemotherapy. Items in the questionnaire were based on information in the decision aid. This approach has been used by other authors to assess comprehension of information provided in decision aids (37,40,41).

Patients' *importance ratings* were elicited for the following benefits and risks of supportive care plus chemotherapy: the possibility of living longer; the possible reduction of symptoms; the side effects of chemotherapy; and the inconvenience of coming in for treatment and follow-up. Two methods of eliciting importance ratings were used. First, patients were asked in the decision aid to indicate how important the benefits and risks of chemotherapy were to them by shading boxes situated on a weigh scale to the height that best represented their opinion: (completely shaded in = extremely important; not shaded in = not at all important). Secondly, the pre- and post-test questionnaire used an 11 point rating scale ranging from 0 (not at

all important to me), to 10 (extremely important to me) to rate each benefit and risk. In a pilot study of a similar approach to measuring importance ratings for long-term hormone replacement therapy (40), the test-retest reliability coefficient of each rating ranged from $r = 0.79$ to 0.89.

The decision patients were likely to make was elicited using an 11 point rating scale anchored by "supportive care/radiation therapy plus chemotherapy" and "supportive care/radiation therapy", with "unsure" situated in the centre of the scale. The test-retest reliability coefficient for this question in a hormone replacement therapy study was 0.91(40).

Decisional conflict was assessed using a 12 item, 5 point Likert scale with responses ranging from "strongly agree" to "strongly disagree". The scale is divided into three subscales, which elicit the following: individuals' uncertainty in making a health-related decision; the factors that contribute to the uncertainty; and the individual's perceived effective decision making. The scale has been evaluated in 909 individuals deciding about influenza immunization or breast cancer screening (16). The test-retest reliability coefficient was 0.81, and internal consistency coefficients ranged from 0.78 to 0.92. The scale discriminated between those who delayed and made a decision either for or against a preventive health action. Similar results have been reported for decisions about hormone replacement therapy (22).

Acceptability of the decision aid was assessed in the same manner as the pre-test, however the questionnaire was shortened, using fewer open-ended questions.

Ethical Considerations. Potential subjects were identified by oncologists caring for patients with stage IV NSCLC. On the day of

their appointment with the oncologist, the researcher requested that the oncologist discuss possible participation in the study. If the patient agreed, the researcher explained the purpose of the study, and the nature of the participant's involvement. The patient was also told that the information would be kept confidential and would be kept secured in a locked filing cabinet. The right to refuse to participate or to withdraw was made clear, and time to consider participating was made available. The participant's signature on the informed consent form (Appendix I) signified their voluntary participation in the study and their agreement with the use of the data.

There were no known risks to the participants. The participants may have found some of the material in the decision aid upsetting if they had not yet come to terms with their diagnosis. If a patient or their family member had become unduly upset by use of the decision aid, arrangements would have been made for them to see their physician, nurse or social worker, if they wished. The researcher who administered the questionnaires is an oncology nurse, with experience dealing with patients with lung cancer, and so was able to provide support to the patient and family as well. The possible benefit of the study was to receive additional support to make this difficult decision about treatment options.

Joint ethical approval for the conduct of this study was obtained from the Ottawa Civic Hospital Research Ethics Committee, followed by approval from the Clinical Research and Evaluation Committee of the ORCC. As well, ethical approval was obtained from the Ottawa Civic Hospital Nursing Research Committee. Administrative support of the Chief Executive Officer and the Nurse Manager of the ORCC was given.

Data Analysis Plan. Data were entered, reduced and analyzed using the Statistical Package for the Social Sciences (SPSS-PC).

Quantitative data were coded numerically and entered on to the data file using the editor program of SPSS. Verification of data entry was performed by visually comparing the numbers printed on a printout of the data file with the data from the original questionnaires.

Descriptive statistics were used to describe the demographic characteristics of the patient sample. Gender, education, and marital status were described as a function of the total sample. The median and range was used to report age. Descriptive statistics were used to describe the acceptability of the decision aid.

The statistical approach used to test the hypothesized difference in comprehension and decisional conflict was the Wilcoxon matched pairs signed ranks test because the assumptions underlying parametric t-tests were not satisfied. The median was used to report scores on the knowledge test and the decisional conflict scale in both the baseline and the post-test questionnaire.

Sample size and power. The primary outcomes examined in this part of the study were patient comprehension and decisional conflict. In the study of women exposed to a decision aid about long-term hormone replacement therapy, the effect size ranged from 0.92 to 1.12 (40). Conservatively using an effect size 0.82 for this study and $\alpha = 0.05$ (right-tailed t-test for paired samples) and $\beta = 0.20$, no more than 25 patients would have been required to detect a significant difference. An effect size of 0.82 is defined as large by Cohen (76). It corresponds to a change of 16% in a knowledge score (scaled from 0 to 100%) using the 20% standard deviation reported in a previous study (40). Similarly, a shift in 0.5 on the decisional conflict scale (scaled from 1 to 5) could be detected using the standard deviation of 0.63 previously reported (40).

Practitioner study

Design. Two groups of practitioners were surveyed to determine the acceptability of the decision aid: family practitioners and nurses.

Sample. The family physicians were surveyed as part of another study examining the impact of the dissemination of lung cancer practice guidelines and a decision aid for lung cancer (Evans, Graham, O'Connor, Logan and Fiset, 1997). Family physicians were in the ORCC catchment area bordered by Cornwall, Barry's Bay, Hawkesbury, and Petawawa, Ontario. A number of mailing lists were used to ensure as complete an original list of family physicians as possible. These names were then grouped by area using the address postal code, avoiding contamination by ensuring that physicians from similar geographical locations received the same package. These groups were then group-randomized to receive only practice guidelines or the practice guidelines plus a decision aid. Only those provided with a decision aid were analyzed for this study.

The oncology nurses who participated were obtained by convenience sampling through the ORCC.

Procedures. Family physicians were sent the practice guidelines plus the decision aid along with a cover letter from Dr Evans. An evaluation postcard for each practice guideline and decision aid also accompanied the package. Oncology nurses were approached during their staff meetings and asked to volunteer to review the decision aid and complete the evaluation post card.

Measures. The postcard evaluation (Appendix J) asked the recipients to comment on the extent to which they agreed that the decision aid: is suitable for their patients; will complement their usual approach, is easy to use, will save time, will improve decision making, and will streamline counseling with patients. Agreement was

indicated on a Likert type scale ranging from strongly agree to strongly disagree. As well, respondents were asked to indicate how likely they were to use the decision aid in their practice, and to provide suggestions and / or other comments.

Descriptive statistics were used to describe practitioners' opinion of the acceptability of the decision aid, and to describe their specific practice setting.

Chapter Five

Results of Decision Aid Evaluation

This chapter presents the results of the evaluation of the decision aid with both patients and practitioners. The chapter begins with a description of the demographic and clinical characteristics of the patient sample, followed by the presentation of the effects of the decision aid on comprehension and decisional conflict. Next, the practitioners surveyed will be described, and their responses to the post-card questionnaire presented.

Responses of Patients to the Decision Aid

Participants were recruited for this phase of the study from May 20, 1997 to September 30, 1997. The accrual and completion rates are shown in Figure 4. Of 20 patients approached by an oncologist to participate in the study, 19 agreed and 12 used the decision aid and completed both the baseline and post-test questionnaires.

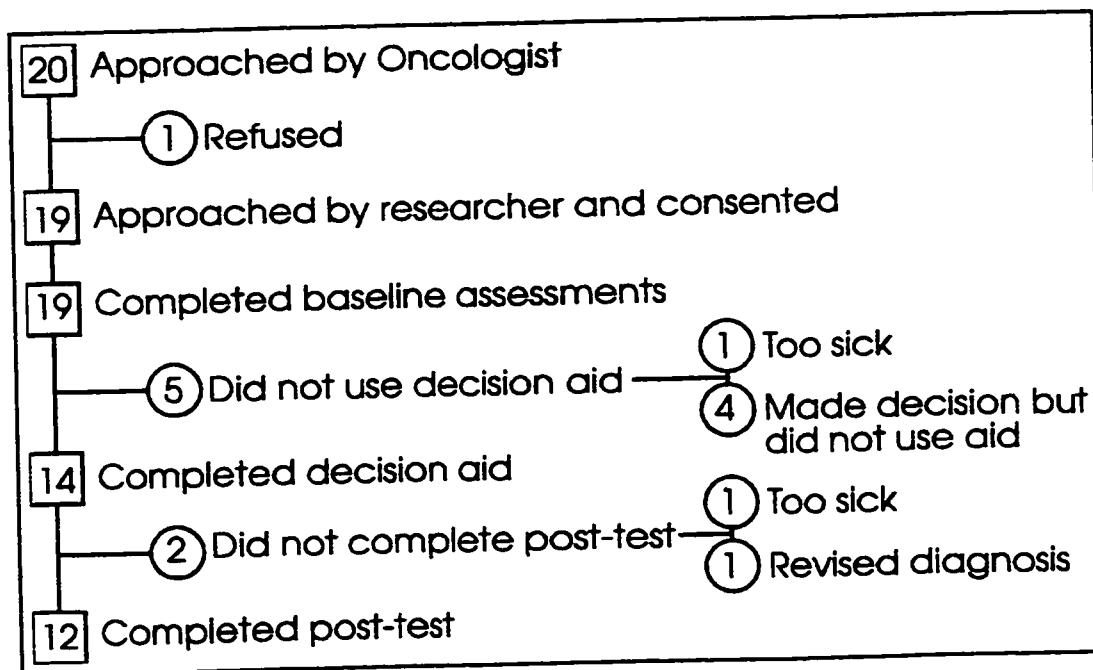


Figure 4. Accrual and completion rates

Clinical and demographic data. The demographic and clinical status of the participants is shown in Table 3. Of the participants who used the decision aid and completed the post-test, there was an equal number of men and women, with the typical participant being 61 years of age, married, English speaking, with an education level ranging from some grade school to some university education. Clinically, the typical patient was diagnosed with large-cell lung cancer, in the right middle lobe, with distant spread to the bone. The performance status ranged from fully active to limited self care. All but two participants decided to take chemotherapy.

The patients who did not complete the study, either by not using the decision aid or by not completing the post-test did not differ appreciably from those who did complete the study with the possible exceptions of performance status and treatment choice. There was a trend in those not using the decision aid to have a higher proportion in the "limited self care" category and to be more likely to decline chemotherapy.

Table 3

Demographic and Clinical Characteristics by Completion Status

Variable	Used decision aid completed post- test N=12	Did not use decision aid n=5	Used decision aid no post-test n=2
Gender:			
Male	6	1	2
Female	6	4	
Age	Md.=61 Range=38- 77	Md.=61 Range=55- 78	Range=65- 81
Marital Status:			
Married, common-law	9	4	1
Widowed	1	1	1
Single	2		
Language Spoken:			
English	11	5	2
French	1		
Education:			
Less than grade 9	1		1
Some high school	3	1	
High school diploma	3	1	
Trade certificate/diploma			
Some college	3		1
College diploma	1	2	
Some university	1	1	
Cancer Cell Type:			
Adenocarcinoma	3	2	
Large Cell Carcinoma	7	3	1 ^a
Squamous Cell Carcinoma	2		
Primary Tumor:			
RUL	2	2	
RML	3		
LUL	3	2	1 ^a
LLL	1		
R Hilum	1		
L Hilum	2	1	
Metastatic Sites^b:			
Bone	5	3	1 ^a
Brain	1		
Liver	1	1	
Lymph Nodes	3	1	
Adrenal Glands	2	1	
Other	1 (contralateral lung)	1 (contralateral lung)	
Performance Status:			
0-fully active	5	2	1
1-symptoms but ambulatory	1		1
2-no work but self care	2		
3-limited self-care	3 (1 missing)	3	
Treatment Choice:			
Chemotherapy	10	2	
No Chemotherapy	2	3	1 ^a

^a One patient did not have lung cancer.^b May have more than one metastatic site.

Effect of decision aid on comprehension. The frequency of correct items and median score before and after the use of the decision aid is presented in Table 4. There were improvements in 14 of 16 items after using the decision aid. The median scores significantly ($p=0.004$) improved from 72% to 94%, thereby supporting hypothesis 1. Particular items where a change was noted included the participants' understanding of the number of blood tests per week, the pros of chemotherapy in terms of improved survival and improved symptoms, and their knowledge of the degree to which chemotherapy improved chances of survival. Improvements in the number of correct items were the result of substantial reductions in both the incorrect and the unsure response categories.

Effect of decision aid on decisional conflict. Table 5 shows the responses of the participants to the specific items on the decisional conflict scale. The pattern of change in the decisional conflict scores is shown in Figure 5. As hypothesized, there was a statistically significant decline in decisional conflict ($p=0.006$). There were improvements in all but 2 items. Improvements were most pronounced in the items of feeling sure what to do, knowing the alternatives and the pros and cons of chemotherapy, being clear about what is most important, and having enough advice. All participants said that they were making the decision without pressure from others both before and after the decision aid. As well, before using the decision aid, all participants felt they had the right amount of support for making the decision, and in the post-test all but one felt the same.

Table 4

Changes in Comprehension Test Results (n=12)

Variable	Frequency					
	Pre		Post			
Total Number of Correct Items						
0-7	0		0			
8-10	2		0			
11-13	9		2			
14-16	1		10			
Knowledge test item	Correct		Incorrect		Unsure	
	Pre	Post	Pre	Post	Pre	Post
1. Stage IV NSCLC - spread	8	11	2		2	1
2. Stage IV NSCLC - weight loss	10	9	1	2	2	1
3. Stage IV NSCLC - symptoms	9	10	1		2	2
4. Supportive care - for all patients	12	12				
5. Supportive care - includes radiation	8	10	3		1	2
6. Supportive care - with chemotherapy	11	12	1			
7. Chemotherapy - many blood tests	4	9	1		7	3
8. Chemotherapy - drugs to control cancer	11	12			1	
9. Chemotherapy - treatment for months	9	12	2		1	
10. Pros - improved survival	7	12			5	
11. Pros - improved symptoms	7	11	1		4	1
12. Cons - permanent hair loss	10	11	1	1	1	
13. Cons - less energy	9	12	1		2	
14. Cons - infections	11	12			1	
15. Cons - frequent trips	10	12			2	
16. Survival at one year	4	11	7	1	1	
Total	140	178	21	2	32	10
Median Score						
Pre	72%	$z=2.92^a$		$p=0.004$		
Post	94%					

^a z-score of Wilcoxon matched pairs signed ranks test

Table 5

Responses to Items on Decisional Conflict Scale

<u>Subscale</u>	<u>Item</u>	<u>Strongly Agree / Agree</u>	<u>Neither Agree nor Disagree</u>	<u>Disagree / Strongly disagree</u>
Certainty	Easy choice			
	Pre	7	3	2
	Post	9	0	3
	Sure what to do			
	Pre	5	5	2
	Post	10	0	2
	Clear best choice			
	Pre	9	2	1
Informed	Post	11	1	0
	Know alternatives			
	Pre	9	0	3
	Post	12	0	3
	Know pros chemotherapy			
	Pre	8	2	2
	Post	12	0	0
	Know cons chemotherapy			
	Pre	7	1	4
	Post	11	1	0
Clear re: values	Aware importance of pros			
	Pre	9	1	2
	Post	11	0	1
	Aware importance of cons			
	Pre	9	1	2
	Post	11	0	1
	Sure which more important			
	Pre	7	3	2
	Post	11	0	1
Support	Have enough advice			
	Pre	8	2	2
	Post	11	0	1
	No pressure from others			
	Pre	12	0	0
	Post	12	0	0
	Have enough support			
	Pre	12	0	0
	Post	11	0	1

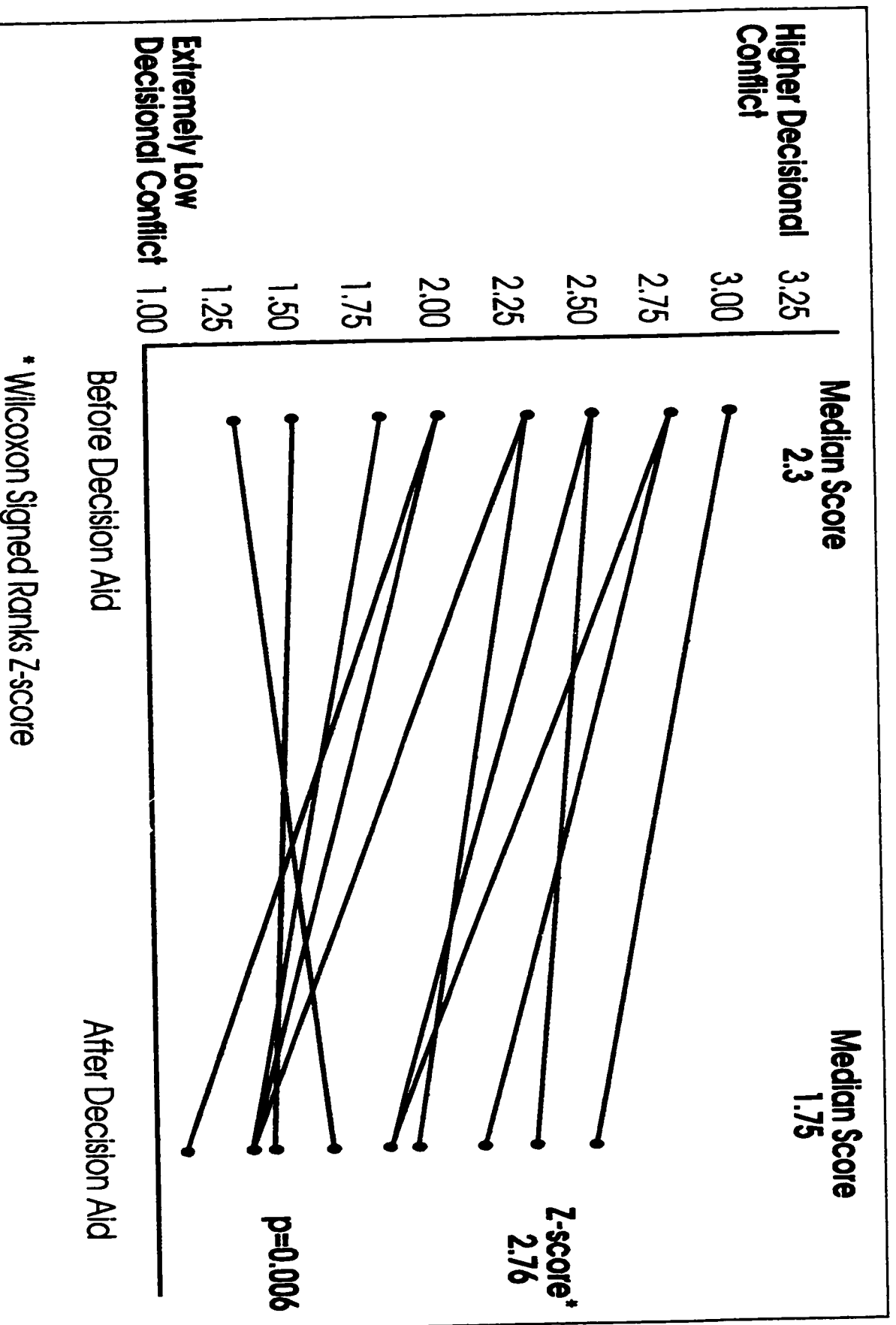


Figure 5. Distribution of decisional conflict scores before and after decision aid n=12

Importance ratings given to the pros and cons of chemotherapy.

Table 6 shows the importance ratings participants assigned to the pros and cons of chemotherapy before and after using the decision aid. There were no differences after using the decision aid. Participants generally rated the potential for improved chances of survival and potential for improved symptoms as extremely important to them in this decision, and rated the side effects and inconvenience of treatment and follow-up as less important.

Table 6

Importance Ratings Given to the Pros and Cons of Chemotherapy

Pros & Cons of Chemotherapy	Before Decision Aid	After Decision Aid
	Median (Range) of Importance Ratings	Median (Range) of Importance Ratings
Increasing chance of survival	10 (5-10)	10 (5-10)
Improving symptoms	10 (6-10)	10 (4-10)
Side effects of chemotherapy	5 (0-10)	5 (0-10)
Inconvenience of treatment and follow-up	0 (0-9)	2 (0-10)

Changes in predisposition before and after decision aid. The changes in leaning for the decision whether or not to accept chemotherapy are shown in Table 7. With the decision aid, 5 participants did not change their leaning, and 5 participants moved away from taking chemotherapy, 4 of whom still decided to take chemotherapy. Two moved toward taking chemotherapy, although ratings for one of these participants only changed from 5 to 4.

Table 7

Changes in Predisposition Before and After Decision Aid

	Leaning before D.A. ^a	Leaning post D.A. ^a	Number (n=12)	Unchanged	Moving away from chemo	Moving toward chemo
Took Chemotherapy	Definitely chemo	Definitely chemo	4	4		
	Definitely chemo	Probably chemo	4		4	
	Unsure	Definitely chemo	1			1
	Unsure	Unsure	1			1
No chemotherapy	Probably chemo	Probably no chemo	1		1	
	Definitely no chemo	Definitely no chemo	1	1		

^aLeanings were classified as follows: Definitely chemo=1; Probably chemo=2-3; Unsure=4-8; Probably no chemo=9-10; Definitely no chemo=11.

Acceptability of the decision aid. As shown in Table 8, the decision aid was viewed favourably by the participants. All participants were satisfied with the length, clarity and amount of information in the decision aid. There was less consensus on the items dealing with whether the decision aid was upsetting and whether it was balanced. Eight of the participants said that the information in the decision aid was not at all upsetting, while two indicated that it was a little upsetting and two indicated that it was somewhat upsetting. Nine participants felt that the decision aid was completely balanced and three felt it was slightly slanted toward chemotherapy. Most participants felt that the decision aid was very or somewhat helpful, and would recommend it to others making the same decision.

Table 8

Acceptability of Decision Aid - Phase 2 (n=12)

<u>Criterion</u>	<u>Frequency</u>
1. Amount of information	10
About the right amount of information	1
Much less than I needed	1
A little more information than I needed	1
2. Was decision aid upsetting?	8
Not at all upsetting	2
A little upsetting	2
Somewhat upsetting	2
3. Length	11
About right	1
Little too long	1
4. Clarity	9
Everything was clear	3
Most things are clear	3
5. Balance	9
Completely balanced	3
Slightly slanted to chemotherapy	3
6. How helpful	7
Very helpful	4
Somewhat helpful	1
A little helpful	1
7. Recommend to others making decision	9
Would definitely recommend it	3
Would probably recommend it	3

When asked what participants liked the most about the decision aid, participants frequently commented that the decision aid was very informative. One participant said the decision aid "asked a lot of questions that I would have never thought of asking...it helped me to make my decision." Participants also mentioned the clarity and ease of understanding. Some participants commented that the decision aid was user friendly and easy to use. As well, many said that they liked the combination of the tape and workbook, and that the narrator's voice and speed of presentation were appropriate.

A number of participants remarked on the fact that the decision aid made them recognize the gravity of their situation: "It made me realize the truth...It was a little frightening...You never think that anyone could be that sick (with metastases)...It was a bit depressing...I

found it a shock." Other comments on what participants liked the least about the decision aid included: regretting having to spend the time using it, that it was not in French, that there was not much room to write on the personal worksheet, and one participant felt that one of the examples used in the decision aid was not realistic.

When participants were probed on whether the decision aid was upsetting, one patient who did not find the decision aid upsetting said that they had already been given the information and had previously discussed it with their physician. One who found it a little upsetting said that the information in the decision aid made them sad, and that the information regarding all the cons of chemotherapy was upsetting. One participant said that their family members found the information on survival upsetting.

In terms of other comments, one respondent said that they appreciated having the opportunity to have the decision aid at home to help make her decision. Another commented that the information was presented in a way that wasn't "scary" and that the decision aid gave them the information they wanted to make a decision. Lastly, one participant commented on the timing of using the decision aid, that it was helpful to have it early on in considering her decision.

Patient's desire to participate in decision making. On the personal worksheet, participants were asked to indicate to what degree they wanted to participate in treatment decision making. Five participants indicated that they felt that they should decide after considering the opinions of others, and six said that they felt that they and their doctor should decide together. One participant did not indicate which he/she felt most comfortable with. No participants indicated that they felt that their physician should make the decision for them.

Responses of practitioners to the Decision Aid

Eighteen physicians of 438 returned survey cards after receiving the decision aid. Four nurses returned the survey cards. The frequencies of the various practice settings are described in Table 9. The majority of respondents were family physicians. The next most prominent group of respondents was nurses.

Table 9

Description of Practitioners

Type of practitioner	Frequency n=22
Physician	
Family physician	13
Respirologist	1
Thoracic surgeon	1
Plastic surgeon	1
Nurses	4
Other	
Psychotherapist	1
Plastic surgeon	1

Acceptability of decision aid. Practitioners' responses to the survey are shown in Table 10. Two of the respondents did not respond to the survey questions regarding the decision aid, both because it was not applicable for their practice. Generally, practitioners felt that the decision aid was suitable for their patients, complemented their usual approach, and would be easy to use in practice and streamline their counseling. Respondents were more divided as to whether they thought the decision aid would save them time. Most respondents agreed that the decision aid would improve decision making about treatment.

Table 10

Practitioners' Responses to Acceptability Survey (n=20)

Item	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Is suitable for my patients	7	9	2	2	
Complements my usual approach	5	10	3	2	
Will be easy to use in my practice	5	8	5		2
Will save time	3	5	6	4	2
Will improve decision making about treatment	13	4	1		2
Will streamline my counseling	4	10	4		2

Respondents were asked to indicate how likely they would be to use the decision aid in their practice. Seven said they were very unlikely to use the decision aid, one said it was unlikely, three responded somewhat likely, six said very likely and one said they did not know if they would use the decision aid in their practice. Four practitioners did not respond to this question.

Space was provided in the questionnaire for respondents to provide suggestions or comments. Four respondents did not feel it was appropriate for them to be included in the study as counselling cancer patients was rarely or never part of their practice. One practitioner felt the decision aid was an excellent tool, but would not be likely to keep it for further use because of the low probability that it would be necessary. This practitioner felt that it would be most useful to merely inform practitioners of the decision aid's existence and how to access it. Similarly, another family physician said that the decision

aid would be infrequently used, therefore likely to be misplaced. Accessibility to information on an ongoing basis was what this practitioner would find useful.

One practitioner commented on the actual content of the decision aid, saying that the risks of chemotherapy and radiation therapy were lightly dealt with, and are far more serious than discussed. Another practitioner found the voice of the narrator very clinical and monotone and that the decision aid needed to provide more hope and relate to patients that they are not alone.

Positive comments included that the decision aid would help patients to understand their disease and treatment, and that the decision aid was straightforward and easy to understand. The decision aid was seen by two respondents as a tool to help patients to take charge of their care and be involved in decision making. Lastly, one practitioner commented that the decision aid was balanced by giving equal emphasis to both the positive and negative aspects of treatment.

Chapter 6

Discussion

This final chapter begins with a brief summary of the results of the study and is followed by interpretation of the findings, study limitations, and the implications for practice and further research.

Summary of results

In this study, a team of clinicians and researchers developed a decision aid regarding chemotherapy for stage IV NSCLC. The aid was acceptable to patients who had previously made the decision and to practitioners. In a group of 20 new patients approached to participate in the study, 12 used the decision aid and found it acceptable. As hypothesized, those who used the decision aid had statistically significant improvements in comprehension ($p=0.004$) and decline in decisional conflict ($p=0.006$).

Sample Characteristics

The median age of the participants in this phase of the study was 61, which is in line with the age range of patients with lung cancer at the Ottawa Regional Cancer Centre. During the fiscal year 95/96, 67% of lung cancer patients fell within the age range of 60-79 years. The higher proportion of female participants differs from data reported in the Canadian Cancer Statistics (1), but is reflective of the increasing number of women being diagnosed with lung cancer. The frequencies of anatomic location and histology of the sample were similar to those in the National Cancer Data Base Report on Lung Cancer (3). The performance status of the participants was quite good considering their advanced disease. However, this may reflect a referral bias in that the patients with better function are referred to medical oncologists for discussion of chemotherapy.

Effect of Decision Aid on Comprehension

There was improvement in comprehension of treatment alternatives, benefits and risks among the participants, supporting the study hypotheses. This is quite remarkable given the small sample size and the fact that the information had already been provided by their oncologist. The result is consistent with other studies showing that reinforcement of verbal information with written material that the patient can review at home may enhance patients' comprehension (77,78).

It is difficult, however to tease out maturation effects from the effects of the intervention. This improved knowledge may be a function of the use of the decision aid, but also may be related to other information and support that participants accessed, or may be because patients had a better understanding of the information that was provided by their physician during their first meeting. As well, the participants had been sensitized to the questions in the post-test by completing the pre-test, which may have influenced their performance.

Nonetheless, these results do support the validity of the DSF in the lung cancer population, who are generally sicker, less educated and experiencing a more life-threatening illness than in previous decision aid studies (22,36-38,40-42). By intervening to address the perception of the decision, specifically, the cognizance of the clinical problem, alternatives, rationale and consequences, the quality of the decision and decision making process is influenced by improving knowledge and enhancing realistic expectations of treatment benefit.

Effect of Decision Aid on Decisional Conflict

The study hypothesis regarding reduced decisional conflict after using the decision aid was supported. Participants felt more certain about what to do, felt informed about their decision, and clearer regarding their values. The median scores after using the decision aid

fell in the range associated with reduced delay in decision making.

Maturation effects may have also influenced these results, and it is again difficult to distinguish the effects of the intervention from other effects. Participants had up to a week or more to make their decision, allowing them time to explore the value trade-offs involved in the decision, seek more information, and elicit the perceptions of significant others. These other co-interventions may have also contributed to the decline in decisional conflict.

The DSF is supported by these results, by demonstrating again the effect of decision support intervention upon the determinants of the decision to produce reduced decisional conflict. These results also contribute to the further evaluation of the decisional conflict scale in assessing its responsiveness to change. O'Connor hypothesized that decisional conflict scores should improve following interventions that provide information, clarify values, and augment self-help decision-implementation skills (16). These results support her hypothesis.

Importance Ratings Given to the Pros and Cons of Chemotherapy

It is not surprising that the majority of participants place a high value on increasing chances of survival and the chance of improving symptoms. Less important to the participants were the side effects of chemotherapy and the inconvenience of treatment and follow-up. These results are in keeping with the fact that the majority of participants chose to accept chemotherapy, so therefore would rate the "pros" of chemotherapy as more important than the cons.

These importance ratings and the decision that participants took are in line with the results of Slevin, Stubbs, Plant, Wilson, Gregory, Armes and Downer, who found that most patients were willing to accept intensive chemotherapy for a very small chance of survival benefit (9). These authors showed that people's attitudes to treatment change

radically when they are actually diagnosed with cancer, and survival becomes extremely important for most.

Changes in Predisposition Before and After Decision Aid

The predisposition of participants with extremely polarized predispositions did not change. For the remainder, there was movement in both directions, suggesting that the decision aid was not producing a bias in one direction. The majority of the shifts in predisposition were small. The two participants who experienced greater shifts in decision predisposition also had shifts in their realistic expectations of treatment benefit. Only one of the participants actually changed his decision after using the decision aid.

The intent of providing decision support is not to actually change patients' decisions, but rather to improve knowledge of treatment alternatives, benefits and risks, enhance realistic expectations of treatment benefits and risks, clarify values and reduce decisional conflict. These results support the role of using the decision aid intervention to support patients in making their decision.

Acceptability of the Decision Aid

Generally, the decision aid was acceptable to the participants. However, the fact that five participants who initially enrolled in the study and then subsequently decided not to use the decision aid suggests that a decision aid is not for everyone facing the decision about chemotherapy for stage IV NSCLC. As was found in this study, there are patients who do not want to spend the time using it, are too sick to use it, or feel that they were already quite certain regarding their decision and so do not need to use it.

Participant feedback may be useful in revising the decision aid in the future. Some specific suggestions that could be easily incorporated include: translating the decision aid into French,

enlarging the personal worksheet, and changing one of the examples used to demonstrate the decision making process. One of the participants did not feel that the example of the patient wanting to go on a cruise realistic, this could be changed to reflect the patient's desire to travel to visit family. As well, the fact that some of the participants found the decision aid upsetting points to the importance of combining the use of the decision aid with decision support provided by a health care practitioner.

Patient's Desire to Participate in Decision Making

- Study participants preferred an active or shared role in terms of participation in treatment decisions. This may be by virtue of the fact that those patients likely to consent to participate in the study had a greater desire for information and participation in treatment decisions. As well, the younger age and equal distribution of men and women in the sample may have contributed to this result, because younger patients and women are more likely to want to take a more active role in decision making (15,26-28,31). This degree of participation is also consistent with the study of Blanchard, Labreque, Ruckdeschel and Blanchard (27), who found that those preferring to participate in their care were significantly more likely to have been given a prognosis of less than 3 months. Interestingly, however, these authors also found that of all the diagnostic groups, those with lung cancer were less likely to want to take an active role in treatment decisions.

Acceptability to Practitioners

There was a very poor response rate on behalf of the family practitioners that were sent practice guidelines and decision aids. This may be because this group of practitioners does not provide a great deal of support to patients making decisions about cancer

treatment: they instead see that as the role of cancer or respiratory specialists. This would be supported by the fact that many of those who did respond to the questionnaire indicated that they would not be likely to use the decision aid in their practice. However, those who did respond to the questionnaire did find the decision aid generally acceptable. Comments from practitioners that may be taken into account in future revisions of the decision aid include: providing more in-depth information regarding the risks of treatment, providing information that is more specific to the specific drug(s) being offered, attempting to relate more hope for patients and relating to patients that they are not alone.

Implications for Further Research

This decision aid requires further evaluation with a larger sample size and a randomized controlled design, to improve the internal and external validity of the results. As well, with a larger sample size, inferences could be made about demographic and clinical factors that influence treatment decisions, and other outcome variables.

Other important research to be done with this population is to look at the role that family plays in treatment decision making and find ways to best support families as a whole to make treatment decisions. All study participants were accompanied by family members at their appointment with the oncologist. Results from the decisional conflict scale indicate that participants felt that they were making the decision without pressure from others and had the right amount of support from others in making the decision. In clinical practice, this is often not the case, and some families experience a great deal of stress over differing opinions regarding treatment decisions. As well, family members often make treatment decisions on behalf of the patient. It would therefore be of value to study the decision support needs of

families facing decisions about cancer treatments.

Another important area of research that remains is to ascertain how best to disseminate the decision aid. It would be of value to evaluate the acceptability of the decision aid with a large group of oncologists and oncology nurses, as they are most likely to be those who will be supporting patients making the decision about chemotherapy for stage IV NSCLC. The one drawback to this research would be that there is considerable practice variation in terms of the treatment of stage IV NSCLC. Another group of practitioners that should be accessed for evaluation includes thoracic surgeons and respirologists who refer many patients to medical oncologists.

The last implication of this study for further research is the recognition of the obstacles of conducting research with this population. Viola (79) conducted a survey of palliative care journal articles and summarized some of the obstacles. The primary obstacle that Viola identified, that was also present in this study, was the poor and unstable condition of the participants. This in turn affected recruitment to the study, the patient's ability to receive the intervention, the patient's ability to be a source of information, the quality of the data collected from the patient and the patient's ability to remain in the study. As well, Viola identified ethical concerns regarding the patient's participation in research. Although support was provided to participants in this study, some of the information in the decision aid was upsetting to them. As well, although participation in the study evaluating the decision aid was completely voluntary, some participants may have felt that the time spent using the decision aid and completing the evaluation testing could have been better spent, given their limited prognosis and very poor health.

Implications for Nursing

The results of the pre-test indicate that participants experienced decisional conflict and did not all have a comprehensive understanding of the treatment alternatives, benefits and risks at the point of making the decision. This indicates that this is indeed a difficult decision for patients to make, and that decision support and patient education, whether through a structured decision aid or through personal counseling is extremely important. While decision aids are one method of decision support, the study shows that decision aids are not for all patients. Nonetheless, all patients do require some form of support. Nurses have a great role to play in supporting patients and their family members as they make difficult treatment decisions, and must be aware of the role that they can play. McGrath (17) describes the essential role that nurses play in fostering informed consent to chemotherapy by virtue of their understanding of the difficulties patients face in coping with stressful treatment regimens. Framing is described by Pawlik Plank (19) as a nursing intervention which can enhance informed consent. Lastly, provision of information is described by Alvino (20) as a component of caring that allows clients and their families to make responsible, ethical and desirable decisions. Nurses must recognize opportunities to provide decision support and be skilled in doing so.

Nurses in advanced practice roles also have a great part to play in the provision of decision support to patients and families. In addition, through the consultative and education roles, nurses in advanced practice can facilitate the provision of decision support through other health care providers. Through the research role, the nurse in advanced practice can determine what are some of the difficult decisions that people living with cancer face, and develop and evaluate

decision support interventions.

Limitations

The limitations of this study are mainly related to problems with its internal validity and poor generalizability. Problems with the internal validity of the study include the effects of co-intervention, maturation and the effect of testing. Co-intervention could limit internal validity because patients may be accessing information and support in addition to using the decision aid that could in turn impact the outcomes of comprehension and decisional conflict. Maturation could in particular have had an effect on decisional conflict, because as time passed between the pre-test and the post-test participants may have become more comfortable with their decision and therefore experience less decisional conflict. The last threat to internal validity is the effect of taking a pre-test on the post-test scores. These three threats to internal validity provide alternate explanations to the study results that the decision aid intervention improved comprehension scores and reduced decisional conflict.

Three factors contribute to the limited generalizability of the results of the study. The first is the small sample size that may not be representative of the population of patients making the decision about treatment for stage IV NSCLC. Another limitation to the study generalizability is that by conducting the study at the ORCC, the sample may have been biased toward deciding to accept treatment. This may be addressed by conducting a similar evaluation in thoracic surgery or respiratory clinics after patients have received their initial diagnosis, but before they are seen at a cancer treatment centre. The last factor which may influence the external validity of the results is that the performance or responses of the participants may have been influenced by the researcher, and these effects may not be replicated

if the decision aid is used in another situation

Conclusion

Despite these limitations, this study has been an important first step in the evaluation of an intervention supporting patients deciding about chemotherapy for stage IV NSCLC. Specifically, the study has shown that the intervention is acceptable to patients and practitioners, and may improve comprehension and reduce decisional conflict. The results of this study also support the DSF, in that by affecting the determinants of a decision through decision support intervention, the quality of the decision may be impacted. This study contributes to the ever-expanding body of research that is examining the best way to support patients in making decisions about their health care, and provides an initial examination of a decision support intervention for patients with advanced disease.

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Appendix A
Summary of Results Examining Preferences for Information and
Participation in Decision Making

Appendix A
Summary of Results of Studies Examining Preferences for Information and Participation in Decision Making

Study	Sample Description and Size	Design	% Preferring Information	% Preferring Active Participation in Decision
■ Cassileth et. al. (1980) ■ Reference #15	■ Hematology-Oncology & Radiation Therapy Outpatients ■ N=256	■ Descriptive correlational design with interviews and questionnaires.	■ 83% in all age groups wanted all information-good and bad.	■ 63% in all age groups preferred to participate in decisions.
■ Strull et. al. (1984) ■ Reference #26	■ Outpatients with hypertension. ■ N=210	■ Descriptive correlational design with interviews and questionnaires.	■ 41% preferred to receive more information than they had actually received.	■ 22% wished to make joint decisions with the clinicians.
■ Blanchard et. al. (1988) ■ Reference #27	■ Hospitalized adult cancer patients. ■ N=439	■ Descriptive correlational design with interviews.	■ 92% wanted all information-good and bad.	■ 69% preferred to participate in decisions about their care.
■ Degner & Russell (1988) ■ Reference #28	■ Oncology outpatients, theoretical sampling. ■ N=60	■ Descriptive design with questionnaires.		■ Most patients preferred pattern of shared control.
■ Sutherland et. al. (1989) ■ Reference #29	■ Oncology outpatients receiving chemotherapy or radiation. ■ N=52	■ Descriptive correlational design with questionnaires.	■ Using Information Seeking Questionnaire, patients scored highly on desire for details on scale from 0-100 (mean=88.9)	■ 37% preferred to participate in decisions about their care.
■ Ende et. al. (1989) ■ Reference #30	■ General medicine patients. ■ N=312	■ Descriptive correlational design with questionnaires.	■ Mean score for information seeking from 0-100 was 79.5.	■ Mean score for participation in decision making from 0-100 was 33.2.
■ Degner & Sloan (1992) ■ Reference #31	■ Newly diagnosed cancer patients. ■ N=436 ■ General public. ■ N=482	■ Descriptive correlational survey design.		■ 12% of newly diagnosed cancer patients preferred active role. ■ 64% of general public preferred active role.
■ Hack et. al. (1990) ■ Reference #11	■ Women 2-6 mos. Post-diagnosis with Stage I & II breast cancer. ■ N=35	■ Descriptive correlational survey design. ■ Qualitative interviews.		■ 23% preferred active role ■ 57% preferred collaborative role. ■ 20% preferred passive role.

Appendix A
Summary of Results of Studies Examining Preferences for Information and Participation in Decision Making

Study	Sample Description and Size	Design	% Preferring Information	% Preferring Active Participation in Decision
- Centeno-Cortes & Nunez-Olarte (1994) - Reference #32	- Patients with advanced malignant disease. - N=97	Descriptive correlational with interviews.	1/3 of uninformed patients did want to know more. 42% of uninformed patients did not want to know more.	
- Arraras et. al. (1995) - Reference #33	- Advanced cancer patients. - N=89 - General public. - N= 78	Descriptive correlational with interviews.	- Patients' preferences not assessed). 90% of general public sample would want complete or partial knowledge.	
- Davison et. al. (1995) - Reference #34	- Men with prostate cancer. - N=57	Descriptive correlational survey design.	>50% want a little bit to almost no information about effect of treatment on sexual activity. >50% wanted a fair bit to almost everything on 8 other categories of information.	19% preferred active role. 23% preferred collaborative role. 58% preferred passive role.
- Fallowfield et. al. (1995) - Reference #35	Newly referred medical oncology patients.	Descriptive correlational design with questionnaires.	94% preferred as much information as possible.	

Appendix B
Correlates of Preferences for Information and Participation in Decision
Making

Appendix B
Correlates of Preferences for Information and Participation in Decision Making (Numbers indicate reference number of study)

Variable	Preferences for detailed information			Preferences for increased participation in decision making		
	Positive correlation	Negative correlation	No correlation	Positive correlation	Negative correlation	No correlation
Age		15, 30, 32, 35			15, 27, 30, 31	
Sex-male		32			27, 31, 34	
Education	30			11, 15, 26, 30, 31, 34		
Caucasian	15			26		
Prognosis less than 3 months		35		27		
Prognosis greater than 1 year	32			27		
Time since Dx		15		34		
Degree of hope				15		
Type and Severity of Disease			15	26	30	15, 31
Functional Status				27		
Rural Residence					31	
Marital Status					27, 34 (married), 30 (separated / divorced)	
Physician Behavior				27		

Appendix C
Summary of Decision Support Intervention Studies

Appendix C
Summary of Decision Support Evaluation Studies

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Outcomes evaluated	Study (Numbers indicate reference number of study)						
	#36	#37	#38	#39	#40	#41	#42
Amount of information	n/a	n/a	+	+	+	+	n/a
Length of intervention	n/a	+	+	n/a	+	+	n/a
Clarity of intervention	+	+	+	n/a	+	+	n/a
Balance of intervention	n/a	n/a	n/a	n/a	+	+	n/a
Intervention helpful in making decision	+	+	n/a	+	+	+	+
Intervention helpful in thinking of questions to ask	+	+	n/a	n/a	n/a	n/a	n/a
Intervention helpful in explaining information to others	+	+	n/a	n/a	n/a	n/a	n/a
Comprehension of information	n/a	+	n/a	+	n/a	+	+
Acceptability to patient	n/a	+	n/a	+	+	+	n/a
Acceptability to clinician	n/a	+	n/a	n/a	n/a	n/a	n/a
Increased perception of choice	n/a	+	n/a	n/a	n/a	n/a	n/a
Effect on treatment selection	n/a	+	+	+	+	+	+
Decreased decisional conflict	n/a	n/a	n/a	n/a	+	+	+
Psychological adaptation	n/a	n/a	n/a	+	n/a	n/a	n/a

n/a= not assessed

Appendix C
Summary of Decision Support Evaluation Studies

78

Outcomes evaluated	Study (Numbers indicate reference number of study)					
	#43	#44	#45	#46	#47	#48
Amount of information	+	n/a	n/a	+	+	n/a
Length of intervention	+	n/a	n/a	n/a	n/a	n/a
Clarity of intervention	+	n/a	n/a	+	n/a	n/a
Balance of intervention	+	n/a	n/a	n/a	n/a	n/a
Intervention helpful in making decision	+	n/a	n/a	+	+	n/a
Intervention helpful in thinking of questions to ask	n/a	n/a	n/a	n/a	+	n/a
Intervention helpful in explaining information to others	n/a	n/a	n/a	n/a	n/a	n/a
Comprehension of information	n/a	n/a	n/a	n/a	n/a	+
Acceptability to patient	+	n/a	n/a	+	+	n/a
Acceptability to clinician	n/a	n/a	n/a	n/a	n/a	n/a
Increased perception of choice	n/a	n/a	n/a	n/a	n/a	n/a
Effect on treatment chosen	+	+	+	n/a	n/a	+
Decreased decisional conflict / increased confidence	n/a	n/a	+	n/a	n/a	n/a
Psychological adaptation	n/a	n/a	n/a	+	n/a	n/a

n/a= not assessed

Appendix C
Summary of Decision Support Evaluation Studies

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Outcomes evaluated	Study (Numbers indicate reference number of study)						
	#49	#50	#51	#52	#53	#54	#55
Amount of information	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Length of intervention	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Clarity of intervention	n/a	n/a	n/a	n/a	n/a	+	+
Balance of intervention	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Intervention helpful in making decision	+	+	n/a	n/a	n/a	n/a	n/a
Intervention helpful in thinking of questions to ask	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Intervention helpful in explaining information to others	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Comprehension of information	n/a	n/a	n/a	n/a	n/a	n/a	+
Acceptability to patient	+	n/a	n/a	n/a	n/a	+	n/a
Acceptability to clinician	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Increased perception of choice	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Effect on treatment chosen	n/a	n/a	+	+	+	+	+
Decreased decisional conflict	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Psychological adaptation	n/a	n/a	n/a	+	n/a	n/a	n/a

n/a= not assessed

Appendix C
Summary of Decision Support Evaluation Studies

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Outcomes evaluated	Study (Numbers indicate reference number of study)			
	#56	#57	#58	#59
Amount of information	n/a	n/a	n/a	n/a
Length of intervention	n/a	n/a	n/a	n/a
Clarity of intervention	n/a	n/a	n/a	n/a
Balance of intervention	n/a	n/a	n/a	n/a
Intervention helpful in making decision	+	+	n/a	n/a
Increased involvement in decision making	n/a	n/a	+	+
Improved physical / functional status	n/a	n/a	+	+
Preference for active role	n/a	n/a	+	n/a
Acceptability to patient	n/a	n/a	n/a	n/a
Acceptability to clinician	n/a	n/a	n/a	n/a
Increased perception of choice	n/a	n/a	+	n/a
Comprehension of Information	n/a	n/a	n/a	+
Decreased decisional conflict	n/a	n/a	n/a	n/a
Psychological adaptation	n/a	n/a	n/a	n/a

n/a= not assessed

Appendix D
Decision Aid Booklet

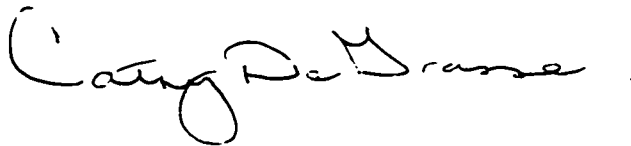
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Sincerely,

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Dr Bill Evans MD, FRCP
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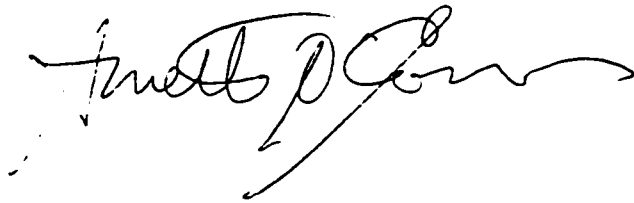
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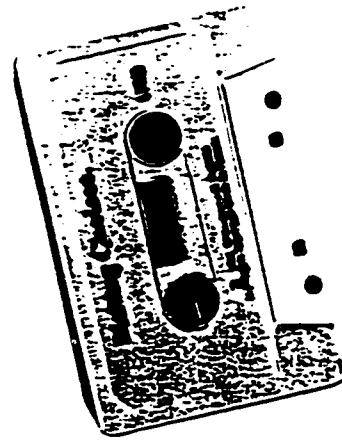
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Sincerely,

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Making Choices:

Treatment of Stage IV (Metastatic) Non-Small Cell Lung Cancer



A Decision Aid for Patients

© Evans, O'Connor & Fiset, 1997

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ORCC



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Welcome!

This workbook and cassette tape prepare you for an informed discussion with your physician about the treatment options for Stage IV non-small cell lung cancer.

Instructions:

1. Set aside 35-40 minutes.
2. Have a pencil ready to use.
3. Place the cassette in a tape recorder.
4. Press the play button.
5. Stay on the page until you are asked to turn to the next page.

Please Note:

Research studies that support statements made in the workbook are referenced by number. A complete list of references is at the back of this workbook.

This Workbook is for you if:

- You have Stage IV (Metastatic) Non-Small Cell Lung Cancer
- Your doctor has offered you chemotherapy to treat or control your lung cancer.

You will learn about:



Cancer and Non-Small Cell Lung Cancer
Staging of Cancer



Supportive Care
Radiation Therapy
Chemotherapy



Pros and Cons of Chemotherapy



How to weigh the pros and cons of taking
chemotherapy for yourself



What is Cancer and Non-Small Cell Lung Cancer?

- Cancer: an abnormal and uncontrolled growth of cells.
- Types of lung cancer: small cell and non-small cell.
- Non-small cell lung cancers are much more common.

What is Staging?

- Tests to find out if the cancer has spread from the lung to other parts of the body (metastasis).
- Helps to plan cancer treatment and determine the chance of recovery.
- In Stage IV or metastatic non-small cell lung cancer, the cancer has spread to other parts of your body.
- May spread to the liver, brain, bones and other places.
- Stage IV non-small cell lung cancer is not curable.

How can lung cancer affect your life?

- Common things other patients have said bother them are listed below. ^{references 1-4}
- Other symptoms may occur depending on where the cancer has spread. ⁵



Physical

Breathing: Coughing. Spitting up blood. Shortness of breath.

Lung infections.

Eating: Nausea. Loss of appetite. Weight loss.

Discomfort or pain: Headaches. Pain in the chest. Discomfort in the abdomen. Pain in bones.

Daily Activity

Change in sleep patterns or difficulty sleeping.

Decreased energy or pain which may limit physical activities.

Weakness, confusion or difficulty with balance or walking.



Emotional

Feeling afraid or worried.

Feeling angry or frustrated.

Feeling sad or hopeless.

Having difficulty relaxing.



Social

Feeling abandoned and lonely.

Lacking energy for social life.

Change in financial situation.

Coping

Some of the things that people do to cope with lung cancer are

listed below:

- Seek treatment to reduce symptoms.
- Rest frequently.
- Eat nutritiously.
- Ask for and accept outside help.
- Take things one day at a time.
- Seek spiritual support.
- Talk about feelings.
- Seek information about cancer.



Treatment Choices

Based on the stage of your disease and your overall physical condition, your physician is offering you the choice of two treatments:

Supportive care / Radiation Therapy



or

Supportive care / Radiation Therapy

Plus Chemotherapy



+



What is involved in Supportive Care:



What:

- Physical and emotional care, along with practical help and information.

How:

- Provided by all staff at the Cancer Centre.

Examples of Physical Care:

- Pain: controlled through medications such as pills, injections into the skin or using a pain pump.
- Constipation: prevented or treated with medications such as laxatives.
- Nausea: treated with pills or injections into the skin.
- Shortness of breath: decreased by oxygen or medications which are breathed in.
- Difficulty sleeping: helped by medications or learning relaxation techniques.
- Others...

Timing:

- Visit the Cancer Centre every 6 weeks to 3 months or as needed.

Side Effects:

- Side effects of some medications: drowsiness, constipation, nausea.

What is involved in Radiation Therapy?



What:

- Radiation: the use of high energy X-rays to shrink some cancer tumors, relieving symptoms.

Where:

- Cancer Centre

How:

- Treatment area will be marked with ink.
- Similar to a regular X-ray procedure.
- Carefully positioned on a firm table.
- No pain or other sensations during treatment.

Timing

- Length and frequency of treatment varies.
- Each radiation treatment usually lasts 2-5 minutes.
- Allow up to an hour per session.

Side Effects:

- Nausea if treatment site near stomach.
- Pain or difficulty swallowing if treatment site near throat or swallowing tube.
- Redness or tenderness of skin at treatment site.
- Temporary or permanent hair loss if brain is being treated.

Radiation therapy is very useful to help with the symptoms of lung cancer. The treatment itself is relatively convenient and the side effects are minimal.

What is involved in receiving chemotherapy?



What:

- Chemotherapy: treatment with drugs to control the growth of cancer cells and shrink tumors.

How:

- As an injection into a vein by a nurse, or as a pill.

Where:

- Usually the Cancer Centre.
- Rarely in hospital.

Timing:

Depends on:

- The drugs being used.
- How well your body tolerates the treatment.
- How the cancer responds to the chemotherapy.

Each treatment cycle involves taking chemotherapy:

- 3 days in a row every 3 weeks
or
- once per week
or
- 1 day every 2-3 weeks.
- Expect six treatment cycles over 4-6 months.

Testing:

- In some cases, blood tests once a week.
- X-rays and other tests in between treatments.

Travel:

- 1-4 trips per month to the Cancer Centre for chemotherapy.
- Possibly 1-4 trips per month to a lab near your home for blood tests.
- Total of 2-8 trips per month outside your home.

Pros of chemotherapy...



May lengthen life:¹¹⁻¹⁴

- Increases your chances of surviving one year by 10 percent. That means that 10 more people out of 100 are alive after one year because of chemotherapy.
- The median increase in survival is 1 1/2 months. That means that the typical patient lives one and a half months longer because of chemotherapy. However, the range of benefit is wide.
- The survival benefit does not extend beyond the one year point.



May improve quality of life:^{7-10, 14}

- Reduces symptoms such as cough, pain, and shortness of breath.
- 7 out of 10 people who receive chemotherapy report decreased symptoms.

Cons of chemotherapy...



Side effects:



- Side effects depend on the particular drug or drugs you receive:
 - Temporary loss of hair
 - Nausea and vomiting
 - Feeling tired or dizzy
 - Being prone to getting infections (could be potentially life-threatening)
 - Taste changes
 - Mouth sores
 - Being prone to bruising or having difficulty stopping cuts from bleeding
 - Others: numbness in hands and feet, decreased hearing, kidney damage, allergic reactions.
- Balance best possible dose with side effects that can be tolerated.
- Response and benefits are not the same for everyone.
- Many medications are available to reduce, prevent or treat side effects.

Cons of chemotherapy...



Inconvenience:

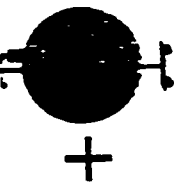
- Frequent trips outside your home each month for treatment, tests and follow-up.



Other Concerns...

- Worry that it is not possible to change your mind.
- You may stop the treatment at any time.

**Now
let's review
the pros and cons
of each choice**

Choice	What's Involved	Pros	Cons
Supportive Care / Radiation Therapy  	- Physical care such as medication or radiation therapy, information, emotional and practical support for you and your family. - Visit to the Cancer Centre every 6 weeks to 3 months and as necessary.	- Avoid side effects of chemotherapy. - Avoid extra trips to Cancer Centre and lab for treatment and follow-up. - Reduction of symptoms. - Other pros?	- May not live as long. - May have side effects from medications used to treat symptoms and radiation therapy. - Other cons?
Supportive Care / Radiation Therapy Plus Chemotherapy   	All of the above plus: - Medications by injection or pill. - At the Cancer Centre. - Every 1-4 weeks for 4-6 months. - Blood tests done at a lab near you every 1-4 weeks.	- May increase survival at one year. - May reduce your symptoms. - May allow you to decrease other medications. - Other pros?	- May experience treatment side effects of hair loss, nausea and vomiting, fatigue, being prone to infections or others. 2-8 trips outside your home every month. - Other cons?

5 Steps to Making Your Choice About Treatment

1. What are the pros and cons of chemotherapy in my situation? 
2. How important are the pros and cons of chemotherapy to me? 
3. What questions do you need to ask or discuss before deciding? 
4. Who should decide about chemotherapy? 
5. What is my overall "leaning" about taking chemotherapy? 

Situation

- ## 2. Colour my values



- ### 3. My questions

catheters or port-a-caths?

- ☐ I should decide after considering opinions of others.
- ☒ My doctor and I should decide together
- ☐ My doctor should decide
- ☐ I'm not sure

- ## 5. My leaning

Unsure

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
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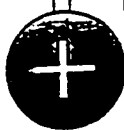
	Supportive Care/ Radiation Therapy	Supportive Care/ Radiation Therapy Plus Chemotherapy
Median survival time, months	10.1	11.5
Median survival time, months (95% CI)	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by age		
< 65	10.1 (9.2-11.0)	11.5 (10.5-12.5)
65-74	10.1 (9.2-11.0)	11.5 (10.5-12.5)
≥ 75	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by sex		
Male	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Female	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by performance		
ECOG 0-1	10.1 (9.2-11.0)	11.5 (10.5-12.5)
ECOG 2-3	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by hemoglobin		
≥ 10 g/dL	10.1 (9.2-11.0)	11.5 (10.5-12.5)
< 10 g/dL	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by albumin		
≥ 3.5 g/dL	10.1 (9.2-11.0)	11.5 (10.5-12.5)
< 3.5 g/dL	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by creatinine		
≤ 1.5 mg/dL	10.1 (9.2-11.0)	11.5 (10.5-12.5)
> 1.5 mg/dL	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by bilirubin		
≤ 1.5 mg/dL	10.1 (9.2-11.0)	11.5 (10.5-12.5)
> 1.5 mg/dL	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by weight loss		
≤ 10%	10.1 (9.2-11.0)	11.5 (10.5-12.5)
> 10%	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by weight gain		
≤ 10%	10.1 (9.2-11.0)	11.5 (10.5-12.5)
> 10%	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by weight change		
≤ 10%	10.1 (9.2-11.0)	11.5 (10.5-12.5)
> 10%	10.1 (9.2-11.0)	11.5 (10.5-12.5)
Median survival time, months (95% CI) by weight change		
≤ 10%	10.1 (9.2-11.0)	11.5 (10.5-12.5)
> 10%	10.1 (9.2-11.0)	11.5 (10.5-12.5)

Lucy's

Situation

1 List my pros and cons

2 Colour my values



May increase survival at 1 year	May reduce symptoms	Other pros
I have lived a full life	Slightly bothered by cough, weight loss, fatigue	



Side effects of chemotherapy	Inconvenience of treatment and follow-up	Other cons
Cousin had bad side effects	Live far from Cancer Centre	Chemo will make time left unpleasant

3 My questions



4 Who should decide about chemotherapy?

- ☐ I should decide after considering opinions of others.
- ☐ My doctor and I should decide together
- ☐ My doctor should decide
- ☒ I'm not sure



5 My leaning

Unsure

☐	☐	☐	☐	☐	☐	☒
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	-------------------------------------



Supportive Care/Radiation
Therapy Plus Chemotherapy

Supportive Care/
Radiation Therapy

Margaret's

Situation

1. List my pros and cons
2. Colour my values

May the cause be a viral infection Widespread eruptions	May be clinically asymptomatic Weakness and headache	Other pros
---	--	-----------------------

- ### 3 My questions

Will chemo interfere with cruise plans?

Complementary therapies?

- #### 4 Who should decide about chemotherapy?

☒ I should decide after considering opinions of others.

☐ My doctor and I should decide together

☐ My doctor should decide

☐ I'm not sure

- ## 5. My leaning

Unsure

[illegible]

**Supportive Care/Radiation
Therapy Plus Chemotherapy**

Suggested steps for a follow-up visit with your doctor



1. Review possible pros and cons of chemotherapy.
 - Ask your doctor to review your workbook to fill in gaps in information and to verify what is involved in taking the chemotherapy regimen suggested for you and its side effects.
 - Review your list of questions with the doctor.



2. Clarify your personal importance of the pros and cons.
 - Let your doctor know the importance you attach to each of the pros and cons (show your weigh scale).
 - You may adjust the colouring on your weigh scale if you receive new information.



3. Make a decision.
 - Discuss with your doctor the factors that influence your decision.
 - Considering the pros and cons and your personal values, decide to accept or decline chemotherapy, or to delay your choice.



4. Plan the next steps.
 - If your decision is to take supportive care / radiation therapy, you may want to talk about supportive care and the role of radiation therapy in your care. As well, you may want to ask about follow-up appointments.
 - If your decision is to take chemotherapy, you will be seen in the Cancer Centre. You may also want to discuss supportive care / radiation therapy and follow-up appointments.
 - If you choose to delay the decision, you and your doctor should plan follow-up activities (for example: return appointments, what to do if problems occur) and discuss supportive care / radiation therapy.

My Personal Worksheet

My Situation

1 List my pros and cons

2 Colour my values

+ (Pros)		- (Cons)	
May increase survival at 1 year	May reduce symptoms	Side effects of chemotherapy	Inconvenience of treatment and follow-up
Other pros		Other cons	

3 My questions



4 Who should decide about chemotherapy?

- ☐ I should decide after considering opinions of others.
- ☐ My doctor and I should decide together
- ☐ My doctor should decide
- ☐ I'm not sure



5 My leaning

Unsure

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

Supportive Care/Radiation Therapy Supportive Care/Radiation Therapy
 Plus Chemotherapy Plus Chemotherapy



Suggested Readings

Below are some reading materials which you may find helpful in making your decision. If you require more information, you may want to call the Cancer Information Service toll free at 1-800-263-6750.

Books:

Wendy Schlessel Harpan
Diagnosis cancer: Your guide through the first few months.
New York: W.W. Norton and Company, 1992.
This book, written from the perspective of a doctor who is also a cancer patient, provides information for newly diagnosed cancer patients, offering suggestions on how to make informed medical decisions regarding treatment, tests, questions to ask, etc.

Malin Dollinger, Ernest Rosenbaum, Greg Cable,
Everyone's guide to cancer therapy: How cancer is diagnosed, treated and managed day to day.
Toronto: Sommerville House, 1995.

This revised edition is a comprehensive and up-to-date resource for cancer patients, which enables the patient to actively participate with health professionals with regard to their illness. It discusses the diagnosis, treatment and recovery process of the 50 most common forms of cancer.

Cox, Barbara
Living with lung cancer: a guide for patients and their families.

Gainesville, FL: Triad Publishing, 1992.
This book describes the lungs and how they work; how lung cancer begins and is diagnosed, the role of surgery, radiotherapy and chemotherapy in the treatment of lung cancer.

Susan Lang & Richard Pratt

You don't have to suffer: a complete guide to relieving cancer pain for cancer patients and their families,
New York: Oxford University Press, 1994

A handbook that explores pain-relieving options in modern medicine from drugs to psychological techniques.

Booklets

Canadian Cancer Society
Chemotherapy and you: A guide to self-help during treatment.

Toronto: The Society, 1994.
This booklet describes what chemotherapy is, along with what the patient can expect during treatment and how to cope with side effects.

Canadian Cancer Society
Radiation Therapy and you: A guide to self-help during treatment.

Toronto: The Society, 1994
This booklet provides information on external and internal radiation therapy. It also describes what the patient can expect during treatment and how to cope with side effects.

Canadian Cancer Society
Taking time: Support for people living with cancer and people who care about them.

Toronto: The Society, 1994
This booklet describes what people who are living with cancer think, feel and do to cope with the disease.

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Appendix E
Clinical and Demographic Questionnaire

Patient's Opinion Survey
About a Decision Aid for Patients Considering Treatment Options
for Stage IV Non-Small Cell Lung Cancer

Demographic & Clinical Data

**Demographic Data
(From Patient)**

ID # _____

1. Gender: (check one box)

☐ Female (1)

☐ Male (2)

2. Age:

_____ years

3. Marital status:

☐ married, common law (1)

☐ single (2)

☐ widowed (3)

☐ divorced / separated (4)

4. Language most frequently spoken:

☐ English (1)

☐ French (2)

☐ Italian (3)

☐ Chinese (4)

☐ German (5)

☐ other ~ please specify _____ (6)

5. Highest grade or level of education completed?

☐ less than grade 9 (1)

☐ some high school (2)

☐ high school diploma (3)

☐ trade certificate / diploma (4)

☐ some college (5)

☐ college diploma / degree (6)

☐ some university (7)

☐ university degree (8)

Clinical Data
(From patient chart)

1. Date of first diagnosis of lung cancer: __*__*__ (mm.dd.yy)

2. Cancer cell type:

- ☐ Adenocarcinoma of Lung (1)
- ☐ Large Cell Carcinoma of Lung (2)
- ☐ Mixed Cell (Squamous / Adeno) Carcinoma of Lung (3)
- ☐ Squamous Cell Carcinoma of Lung (4)
- ☐ Non-Small Cell Lung Carcinoma (5)
- ☐ Other _____ (999)
- ☐ Missing (888)

3. Primary Tumor Location

- ☐ RUL (1)
- ☐ RML (2)
- ☐ LUL (3)
- ☐ Lingula (4)
- ☐ LLL (5)
- ☐ Right Hilum (6)
- ☐ Left Hilum (7)
- ☐ Missing (888)

4. Metastastic sites:

- | | | |
|-------------------|---------|--------|
| a. Bone | yes (1) | no (2) |
| b. Brain | yes (1) | no (2) |
| c. Liver | yes (1) | no (2) |
| d. Lymph Nodes | yes (1) | no (2) |
| e. Adrenal glands | yes (1) | no (2) |
| f. Other | yes (1) | no (2) |

If yes, indicate _____

5. Performance Status:

- Circle score 0 1 2 3 4 -9 Not done
- ☐ 0-fully active (1)
 - ☐ 1-Symptoms but ambulatory and able to do light work (2)
 - ☐ 2-No work but self care and active > 50% of waking hours (3)
 - ☐ 3-Limited self care, confined to bed or chair >50% of waking hours (4)
 - ☐ 4-Completely disabled (5)
 - ☐ Missing (888)

Appendix F
Acceptability Questionnaire

Patient's Opinion Survey
About a Decision Aid for Patients Considering Treatment Options
for Stage IV Non-Small Cell Lung Cancer

Pilot test Questionnaire

My thoughts on the tape and workbook

1. What did you like most about the tape and workbook?

2. What did you like least about the tape and workbook?

3. How would you rate the amount of information in the tape and workbook? Please check [] one.

- ☐ Much less than I needed
- ☐ Little less than I needed
- ☐ About the right amount of information
- ☐ A little more information than I needed
- ☐ A lot more information than I needed

4. What information would you add?

5. What information would you remove?

6. Did you find the information in the tape and workbook upsetting? Please check [] one.

- ☐ Not at all upsetting
- ☐ A little upsetting
- ☐ Somewhat upsetting
- ☐ Very upsetting

Please comment:

7. How would you rate the length of the tape and workbook: Please check [] one.

- ☐ Much too long
- ☐ Little too long
- ☐ About right
- ☐ Should have been a little longer
- ☐ Should have been much longer

8. How would you rate the clarity of the information in the tape and workbook? Please check [] one.

- ☐ Everything was clear
- ☐ Most things are clear
- ☐ Some things are unclear
- ☐ Many things were unclear

9. What things were unclear?

10. How balanced and fair did you find the tape and workbook? Please check [] one.

- ☐ Clearly slanted to chemotherapy
- ☐ Slightly slanted to chemotherapy
- ☐ Completely balanced
- ☐ Slightly slanted to supportive care / radiation therapy
- ☐ Clearly slanted to supportive care / radiation therapy

11. How helpful is the tape and workbook in aiding decision making about treatment? Please check [] one.

- ☐ - very helpful
- ☐ somewhat helpful
- ☐ a little helpful
- ☐ not helpful

12. Would you recommend this tape and workbook to other people who are facing treatment decisions for lung cancer? Please check [] one.

- ☐ would definitely recommend it
- ☐ would probably recommend it
- ☐ would probably not recommend it
- ☐ would definitely not recommend it

13. Do you have any other suggestions for improving the tape and workbook?

Appendix G
Pre-Test Questionnaire

Patient's Opinion Survey
About a Decision Aid for Patients Considering Treatment Options
for Stage IV Non-Small Cell Lung Cancer

Baseline Questionnaire

A. What I know about stage IV non-small cell lung cancer and treatment alternatives now

We would like to know how familiar you are with your treatment options before you use the workbook and audiotape.

Below are listed some statements about stage IV non-small cell lung cancer and treatment alternatives. Please show whether you think they are true, false or you are not sure by circling the word beside each statement.

1. Stage IV non-small cell lung cancer:

♦has <u>not</u> spread to other parts of the body	True	False	Unsure
♦can cause weight loss	True	False	Unsure
♦leads to symptoms of cough and pain	True	False	Unsure

2. Supportive Care:

♦is provided to all patients	True	False	Unsure
♦ <u>never</u> includes radiation therapy	True	False	Unsure
♦may be given with chemotherapy	True	False	Unsure

3. Taking chemotherapy involves:

♦having blood tests many times a week	True	False	Unsure
♦receiving drugs that control the growth of cancer cells and shrink tumors	True	False	Unsure
♦treatment for several months, until you or your doctor decide to stop	True	False	Unsure

4. Some "pros" of chemotherapy are:

♦improved chances of survival at one year	True	False	Unsure
♦improved symptoms of pain and cough	True	False	Unsure

5. Some "cons" of chemotherapy are:

♦permanent hair loss	True	False	Unsure
♦having less energy	True	False	Unsure
♦being prone to getting infections	True	False	Unsure
♦frequent trips for treatment and tests	True	False	Unsure

Please circle your response to the following question:

6. How much does chemotherapy for stage IV non-small cell lung cancer increase a person's chance of survival at one year?

- 0% Chemotherapy does not increase a person's chance of survival
- 10% 10 out of 100 more people will be alive at one year
- 20% 20 out of 100 more people will be alive at one year
- 30% 30 out of 100 more people will be alive at one year
- 40% 40 out of 100 more people will be alive at one year
- 50% 50 out of 100 more people will be alive at one year

B. The things that are important to me when making a decision about my treatment options

Below are listed some of the things people consider when making a decision about treatment for stage IV non-small cell lung cancer. Please show how important these are to you by circling a number from:

0 (not at all important to me)
to
10 (extremely important to me)

How important are these things to you in making a decision about treatment?

Increasing my chances of survival

0	1	2	3	4	5	6	7	8	9	10
not at all important to me in this decision										extremely important to me in this decision

Improving symptoms such as pain and cough

0	1	2	3	4	5	6	7	8	9	10
not at all important to me in this decision										extremely important to me in this decision

The side effects of chemotherapy (hair loss, low energy, prone to infections)

0	1	2	3	4	5	6	7	8	9	10
not at all important to me in this decision										extremely important to me in this decision

The inconvenience of coming in for treatment and follow-up

0	1	2	3	4	5	6	7	8	9	10
not at all important to me in this decision										extremely important to me in this decision

C. My opinion about my treatment choices

We want to know what your opinion about your treatment options is right now.

If your doctor asked you right now to make a choice about taking chemotherapy in addition to standard care, please show where you would be on the scale below by placing a check in the box I_1.

- ♦ If you wanted to take chemotherapy in addition to standard care, you would check I_1 far to the left.
- ♦ If you wanted to take standard care alone, you would check I_1 far to the right.
- ♦ If you were not sure, you would check I_1 in the middle.

--	--	--	--	--	--	--	--	--	--	--

Chemotherapy

Unsure

Standard Care

D. My difficulty making this choice

Now, thinking about the choice you just made, please look at the following comments made by some people when deciding about chemotherapy treatment for lung cancer.

Please show how strongly you agree or disagree with these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree) which best shows how you feel about making this choice.

This decision is easy for me to make.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I'm sure what to do in this decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
It's clear what choice is best for me.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree

I'm aware of the choices I have for treating my cancer.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I feel I know the benefits (pros) of chemotherapy.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I feel I know the side effects and disadvantages (cons) of chemotherapy.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I have enough advice about the choices.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about how important the pros of chemotherapy are to me in this decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about how important the cons of chemotherapy are to me in this decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about which is <u>more</u> important to me (the pros or the cons).	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I am making this choice without any pressure from others.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I have the right amount of support from others in making this decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree

Appendix H
Post-Test Questionnaire

Patient's Opinion Survey
About a Decision Aid for Patients Considering Treatment Options
for Stage IV Non-Small Cell Lung Cancer

Post-test Questionnaire

A. What I know about stage IV non-small cell lung cancer and treatment alternatives

Here are some questions about treatment options for stage IV non-small cell lung cancer. Don't worry if you can't remember everything...we did not expect you to memorize the information you received for a test! But it would help us to learn what things impressed you enough that you can recall them without having had to study them very hard.

Below are listed some statements about stage IV non-small cell lung cancer and treatment alternatives. Please show whether you think they are true, false or you are not sure by circling the word beside each statement.

1. Stage IV non-small cell lung cancer:

♦has <u>not</u> spread to other parts of the body	True	False	Unsure
♦can cause weight loss	True	False	Unsure
♦leads to symptoms of cough and pain	True	False	Unsure

2. Supportive Care:

♦is provided to all patients	True	False	Unsure
♦ <u>never</u> includes radiation therapy	True	False	Unsure
♦is given with chemotherapy	True	False	Unsure

3. Taking chemotherapy involves:

♦having blood tests many times a week	True	False	Unsure
♦receiving drugs that control the growth of cancer cells and shrink tumors	True	False	Unsure
♦treatment for several months, until you or your doctor decide to stop	True	False	Unsure

4. Some "pros" of chemotherapy are:

♦improved chances of survival at one year	True	False	Unsure
♦improved symptoms of pain and cough	True	False	Unsure

5. Some "cons" of chemotherapy are:

♦permanent hair loss	True	False	Unsure
♦having less energy	True	False	Unsure
♦being prone to getting infections	True	False	Unsure
♦frequent trips for treatment and tests	True	False	Unsure

Please circle your response to the following question:

6. How much does chemotherapy for stage IV non-small cell lung cancer increase a person's chance of survival at one year?

- 0% Chemotherapy does not increase a person's chance of survival
- 10% 10 out of 100 more people will be alive at one year
- 20% 20 out of 100 more people will be alive at one year
- 30% 30 out of 100 more people will be alive at one year
- 40% 40 out of 100 more people will be alive at one year
- 50% 50 out of 100 more people will be alive at one year

B. The things that are important to me when making a decision about my treatment options

Below are listed some of the things people consider when making a decision about treatment for stage IV non-small cell lung cancer. Please show how important these are to you by circling a number from:

0 (not at all important to me)
to
10 (extremely important to me)

How important are these things to you in making a decision about treatment?

Increasing my chances of survival

	0	1	2	3	4	5	6	7	8	9	10
not at all important to me in this decision											extremely important to me in this decision

Improving symptoms such as pain and cough

	0	1	2	3	4	5	6	7	8	9	10
not at all important to me in this decision											extremely important to me in this decision

The side effects of chemotherapy (hair loss, low energy, prone to infections)

	0	1	2	3	4	5	6	7	8	9	10
not at all important to me in this decision											extremely important to me in this decision

The inconvenience of coming in for treatment and follow-up

	0	1	2	3	4	5	6	7	8	9	10
not at all important to me in this decision											extremely important to me in this decision

C. My thoughts on the best choice for me

If your doctor asked you whether or not you wanted to take chemotherapy, with the information you now have, check I which choice looks the best for you:

- ☐ Taking chemotherapy
reason / comments

- ☐ Not taking chemotherapy
reason / comments

- ☐ I'm not sure
reason / comments

In addition to the talking to your doctor and using the tape and workbook, what other information have you based this decision on?

D. My difficulty making this choice

Now, thinking about the choice you just made, please look at the following comments made by some people when deciding about chemotherapy for lung cancer.

Please show how strongly you agree or disagree with these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree) which best shows how you feel about making this choice.

This decision is easy for me to make.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I'm sure what to do in this decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
It's clear what choice is best for me.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I'm aware of the choices I have for treating my cancer.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I feel I know the benefits (pros) of chemotherapy.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I feel I know the side effects and disadvantages (cons) of chemotherapy.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I have enough advice about the choices.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about how important the pros of chemotherapy are to me in this decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree

I am clear about how important the cons of chemotherapy are to me in this decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I am clear about which is <u>more</u> important to me (the pros or the cons).	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I am making this choice without any pressure from others.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I have the right amount of support from others in making this decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I feel I have made an informed choice.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
My decision shows what is important to me.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I expect to stick with my decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
I am satisfied with my decision.	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree

E. My thoughts on the tape and workbook

1. What did you like most about the tape and work book?

2. What did you like least about the tape and workbook?

3. How would you rate the amount of information in the tape and workbook? Please check [] one.

- ☐ Much less than I needed
- ☐ Little less than I needed
- ☐ About the right amount of information
- ☐ A little more information than I needed
- ☐ A lot more information than I needed

4. Did you find the information in the tape and workbook upsetting? Please check [] one.

- ☐ Not at all upsetting
- ☐ A little upsetting
- ☐ Somewhat upsetting
- ☐ Very upsetting

Please comment:

5. How would you rate the length of the tape and workbook? Please check [] one.
- ☐ Much too long
 - ☐ Little too long
 - ☐ About right
 - ☐ Should have been a little longer
 - ☐ Should have been much longer
6. How would you rate the clarity of the information in the tape and workbook? Please check [] one.
- ☐ Everything was clear
 - ☐ Most things are clear
 - ☐ Some things are unclear
 - ☐ Many things were unclear
7. How balanced and fair did you find the tape and workbook? Please check [] one.
- ☐ Clearly slanted to chemotherapy
 - ☐ Slightly slanted to chemotherapy
 - ☐ Completely balanced
 - ☐ Slightly slanted to supportive care / radiation therapy
 - ☐ Clearly slanted to supportive care only / radiation therapy
8. How helpful is the tape and workbook in aiding decision making about treatment? Please check [] one.
- ☐ very helpful
 - ☐ somewhat helpful
 - ☐ a little helpful
 - ☐ not helpful

9. Would you recommend this tape and workbook to other people who are facing treatment decisions for lung cancer? Please check [] one.

- ☐ would definitely recommend it
- ☐ would probably recommend it
- ☐ would probably not recommend it
- ☐ would definitely not recommend it

10. Do you have any other comments about the tape and workbook?

Appendix I
Patient Consent Forms

CIVIC DIVISION ☐
190 Melrose
Ottawa, Ontario
K1Y 4K7
(613) 725-6300

O T T A W A
R E G I O N A L
C A N C E R
C E N T R E
We care for life



C E N T R E
R É G I O N A L D E
C A N C É R O L O G I E
D ' O T T A W A
Des soins pour la vie

129

☐ GENERAL DIVISION
501 Smyth
Ottawa, Ontario
K1H 8L6
(613) 737-7700

Chief Executive Officer
Directeur général
W. K. EVANS, M.D., FRCPC

PATIENT CONSENT-Phase 1

Study:

**Evaluating the Effectiveness of a Decision Aid for Patients Considering Treatment Options
for Stage IV (Metastatic) Non-small Cell Lung Cancer**

Investigators:

V. Fiset, RN, BScN, MScN Candidate
A. O'Connor, RN, PhD, Associate Professor, Faculty of Nursing, University of Ottawa
W.K. Evans, MD, FRCPC, Chief Executive Officer, Ottawa Regional Cancer Centre
J. Logan, RN, PhD, Director, Clinical Services Research and Professional Development, Ottawa
Civic Hospital
C. DeGrasse RN, MScN, OCN, Clinical Nurse Specialist, Oncology, Ottawa Civic Hospital

Purpose:

The purpose of this study is to evaluate the acceptability of a workbook and audiotape for patients making decisions about chemotherapy for stage IV non-small cell lung cancer. The knowledge gained from this study will help doctors and nurses to provide support to future patients with lung cancer. As a person who is familiar with treatments for lung cancer, we are asking for your opinion on the workbook and audiotape. The treatments outlined in the workbook may or may not apply to your own situation, but your opinion on the approach we use will help us to improve it.

Procedure:

Your participation involves:

- ♦ reviewing a workbook and audiotape about lung cancer and treatment for 30 minutes;
and
- ♦ completing a questionnaire to comment on the usefulness of the materials for 10 minutes.

Only the researcher will see your questionnaire and all information will be kept in a locked filing cabinet when not in the researcher's possession.

Risks and Benefits:

There are no known risks of participating in this study. If you find the information in the workbook and audiotape upsetting, arrangements can be made for you to see your physician, nurse or social worker, if you wish. The possible benefit of the study is to know that your participation may some day help others who will have to make decisions about treatment for lung cancer.



Affiliated with University of Ottawa Faculty of Medicine
Affilié à la Faculté de Médecine de l'Université d'Ottawa

THE ONTARIO CANCER TREATMENT AND RESEARCH FOUNDATION
LA FONDATION ONTARIENNE POUR LA RECHERCHE EN CANCÉROLOGIE ET LE TRAITEMENT DU CANCER



Risks and Benefits:

There are no known risks of participating in this study. If you find the information in the decision aid upsetting, you will be asked if you wish to see your physician, nurse or social worker. The possible benefit of the study is to know that your participation may help others who will have to make the same decision in the future.

Rights of the Participant:

You have the right to refuse to participate in the study and the right to withdraw from the study at any time without any change in the care you receive at the Cancer Centre. Use of the decision aid is in addition to any support and information you receive from the physicians and nurses of the Cancer Centre. Therefore, the alternative to participating in this study is to receive such support and information in the usual fashion. The information collected during this study will be kept confidential. A code number will be used to identify the information so your name will not appear on any documents. If the results of the study are published, no personal identifying data will appear in the published work.

Consent:

I have read the above information and understand this consent form. I have also had the opportunity to ask questions and have them answered to my satisfaction. I agree to participate in this study.

Name _____

Date _____

Witness _____

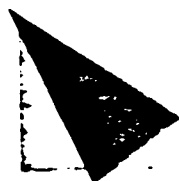
You will receive a copy of this consent. If you have any questions about this study, you can telephone the nurse investigator or her supervisor.

Valerie Fiset, RN, Master of Science in Nursing Candidate, University of Ottawa, Telephone: 824-4577

or

Annette O'Connor, RN, PhD, Associate Professor, Faculty of Nursing, University of Ottawa, Telephone: 798-5555 ext. 7582

(Valid until September 16, 1998)



Chief Executive Officer
Directeur général
W. K. EVANS, M.D., FRCPC

PATIENT CONSENT-Phase 2

Study:

Evaluating the Effectiveness of a Decision Aid for Patients Considering Treatment Options for Stage IV (Metastatic) Non-small Cell Lung Cancer

Investigators:

V. Fiset, RN, BScN, MScN Candidate
A. O'Connor, RN, PhD, Associate Professor, Faculty of Nursing, University of Ottawa
W.K. Evans, MD, FRCPC, Chief Executive Officer, Ottawa Regional Cancer Centre
J. Logan, RN, PhD, Director, Clinical Services Research and Professional Development, Ottawa Civic Hospital
C. DeGrasse RN, MScN, OCN, Clinical Nurse Specialist, Oncology, Ottawa Civic Hospital

Purpose:

The purpose of this study is to evaluate the effectiveness of a workbook and audiotape for patients making decisions about chemotherapy for stage IV non-small cell lung cancer. The knowledge gained from this study will help doctors and nurses to provide support to patients in your situation. As a person facing the decision whether or not to accept chemotherapy, you are being asked to participate in this study.

Procedure:

Before using the workbook and audiotape, you will be asked to complete a questionnaire telling us a bit about yourself, what you know about your cancer and its treatment, and how difficult this decision is for you. This questionnaire will take about 10 minutes to complete. This will take place after you have spoken initially to your physician about your treatment options.

You will then be provided with a workbook and audiotape which will give you information about your cancer and approaches to its treatment. As well, the audiotape guides you through an exercise which will help you to think about what is most important for you in deciding about chemotherapy. The audiotape and workbook can be used at home, and will take about 30 minutes to use. After you finish using the workbook and audiotape we will be asking you to answer questions similar to those you answered before, and ask you to complete a questionnaire to comment on the usefulness of the workbook and audiotape. This last questionnaire will take about 15 minutes to complete, and can be completed at the time of a follow-up visit with your physician or at a time which is convenient to you.

Only the researcher will see this information and it will be kept in a locked filing cabinet when not in the researcher's possession.



Rights of the Participant:

You have the right to refuse to participate in the study and the right to withdraw from the study at any time without any change in the care you receive at the Cancer Centre. The information collected during this study will be kept confidential. A code number will be used to identify the information so your name will not appear on any documents. If the results of the study are published, no personal identifying data will appear in the published work.

Consent:

I have read the above information and understand this consent form. I have also had the opportunity to ask questions and have them answered to my satisfaction. I agree to participate in this study.

Name _____

Date _____

Witness _____

You will receive a copy of this consent. If you have any questions about this study, you can telephone the nurse investigator or her supervisor.

Valerie Fiset, RN, Master of Science in Nursing Candidate, University of Ottawa, Telephone:
824-4577

or

Annette O'Connor, Associate Professor, Faculty of Nursing, University of Ottawa, Telephone:
798-5555 ext. 7582

(Valid until September 12, 1996)

Appendix J
Post-Card Questionnaire

The OCTPGI is VERY interested in receiving feedback from practitioners on this decision aid for patients. To help us understand what you think and how we can improve, please take a minute to complete this evaluation form.

1. How strongly do you agree or disagree with each of the following statements as it relates to the patient decision aid?	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
The aid is suitable for my patients					
The aid will complement my usual approach					
The aid will be easy to use in my practice					
The aid will save me time					
The aid will improve decision making about treatment					
The aid will streamline my counseling					

2. How likely are you to use this aid in your own practice?

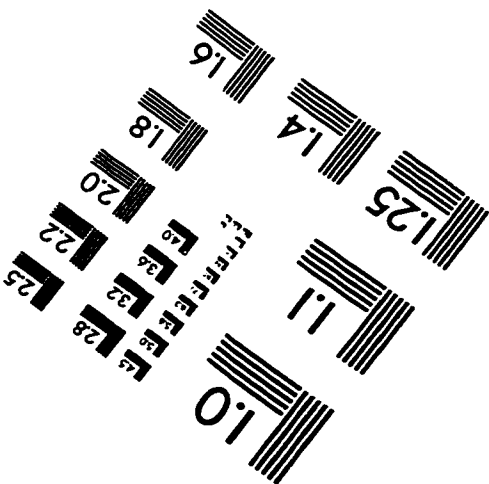
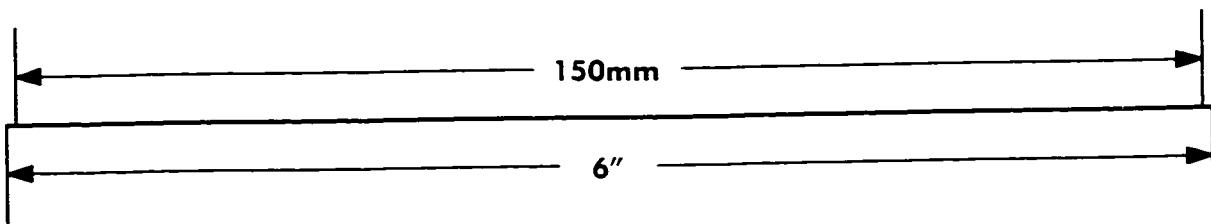
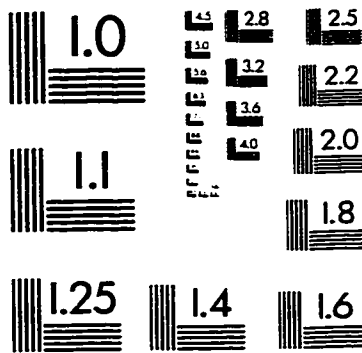
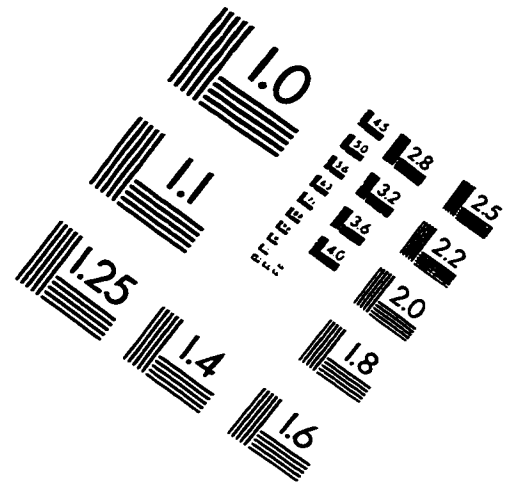
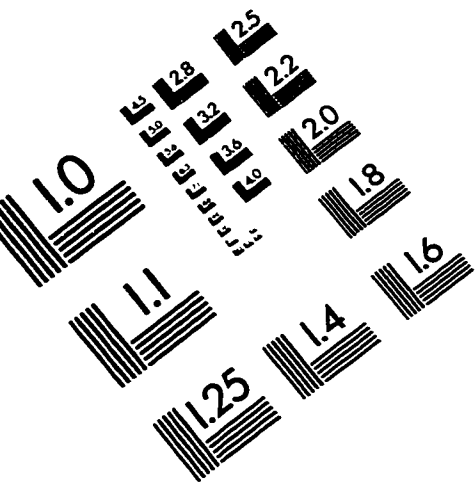
☐ very unlikely ☐ somewhat unlikely ☐ unlikely ☐ somewhat likely ☐ very likely ☐ don't know

3. Are you a:

☐ family physician ☐ surgeon ☐ medical oncologist
☐ radiation oncologist ☐ other, please specify _____

4. Suggestions for improving the decision aid and /or other comments: _____

IMAGE EVALUATION TEST TARGET (QA-3)



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