Treatment decision support for early breast cancer patients
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Chapter 1

Introduction
Introduction

In modern health care, multiple treatment options exist for many diseases and patients are often asked to participate in the treatment selection. For example, women with breast cancer may be offered a choice between breast conservation therapy and mastectomy. In a period already surrounded by emotions, making treatment decisions may be difficult, especially without adequate information and support. How patients’ decision making about surgical therapy for early stage breast cancer can be supported is the subject of this thesis.

Patient participation in treatment decision making

In earlier days, physicians made decisions on behalf of their patients. In today’s evolving health care, enhancing patient participation in decision making is regarded as more appropriate. A number of trends in society and medicine have fostered this change.

First, patients have become better educated and more critical consumers of health care. Most patients wish to be furnished with current information about their disease, the available treatment options, and what these entail for their daily lives. The internet has become a popular medium to search for information. As a result, patients will expect their physicians to be more open and comprehensive when giving information. Moreover, fewer patients feel comfortable when decisions are made for them, and many prefer to participate to some extent in treatment decision making.

Second, the ethical imperative to respect patients’ autonomy gained momentum. Before starting treatment, patients’ consent has to be obtained. Patients can only give their consent in a meaningful manner, if they receive adequate information regarding the disease, treatment options, potential benefits, shortcomings, and risks. An informed consent act has been included in the legal system of the Netherlands, as in many other Western societies. Despite widespread acceptance of the law, giving shape to informed consent in practice has been identified as problematic. Specifically, information about risks and treatment options is not always forthcoming.

Third, concerns regarding the quality of care have resulted in a plea for more active patient participation in treatment decision making also. Researchers identified unwarranted variations in medical practices, and in the outcomes of care. It has been concluded that treatment decisions were depending too much on the physicians’ own experience and tradition, rather than on evidence-based information and patients’ values and needs.

Fourth, advancements in medical technology have resulted in the increased availability of a variety of treatment options for many conditions. Typically, treatment options may have different profiles of potential benefits, shortcomings and risks.
Different patients may have different values regarding what a treatment has to offer. Decisions between treatment options should therefore be sensitive to the preferences of the patient, and thus be individualised.\textsuperscript{17-19} Consequently, physicians will have to involve patients in medical decision making. This is believed to improve patients’ outcomes related to feelings of control, satisfaction, adherence, psychosocial adjustment, and clinical outcomes.\textsuperscript{20,29}

**Shared decision making**

Due to the developments described above, patient participation in treatment decision making is now considered important. However, one may ask how exactly patient participation in decision making would have to be structured. In an effort to provide more clarity, the model of shared decision making has been proposed by Charles et al.\textsuperscript{5,7} Charles et al.\textsuperscript{5,7} emphasize that treatment decisions should be made in close cooperation between physicians and patients. Much emphasis is given on a two-sided exchange of information. Physicians first provide patients with information on treatment options and their outcomes. In return, patients must provide information about their personal values and preferences with regard to the available treatment alternatives. When outcome information and values are ‘on the table’, the patient and the physician will decide together upon the course of action.

Although the rationales for increased participation are generally accepted, shared decision making is not common practice yet. This may be due to concerns regarding the feasibility of involving patients in decision making. For example, one may believe that it would increase the time physicians have to spend on information giving. Moreover, critics may question whether involvement of patients in treatment decision making is beneficial to them. They fear it may evoke unwarranted effects, such as increased anxiety, distress, and distrust in the health care provider.\textsuperscript{19}

A specific kind of interventions to facilitate shared decision making in practice and to prepare patients to participate, without adverse effects, has been developed. They are referred to as ‘decision aids’.\textsuperscript{1,2,31} Decision aids are educational interventions for patients, designed to help them make specific and deliberative choices among treatment options, by providing information on these options and their outcomes, relevant to a person’s health status.\textsuperscript{31} Clearly, decision aids differ from more traditional patient education programs. The latter are usually meant to obtain informed consent for a procedure already selected. Decisions aids are provided during decision making, before the decision is made. It is anticipated that decisions aids will improve decision making and may contribute to patients’ satisfaction, adherence and health outcomes.\textsuperscript{27,31} Still, decision aids remain a rather new phenomenon and the pros
and cons of decision aids are largely unknown. Studies evaluating their contribution to health care are therefore needed.

**Treatment decision making in early stage breast cancer**

Breast cancer represents a major health problem in the Netherlands. Each year, more than 11,000 women are diagnosed, and the incidence of breast cancer is among the highest in the world. It is estimated that one in every nine Dutch women will develop breast cancer during her lifetime.

In early stage breast cancer (stage I/II), breast conserving therapy and mastectomy are two equally effective treatments, in terms of survival. Beyond survival, the aim of treatment is to maximize patients' quality of life. Women may have different viewpoints regarding the impact of breast conservation therapy and mastectomy on their subsequent quality of life. Some may opt to undergo breast conservation therapy to preserve their body image, while others may prefer mastectomy to avoid undergoing radiotherapy and to minimize the probability of local recurrence. To ensure that the decision between breast conservation therapy and mastectomy reflects the individual preferences, guidelines of physicians recognize that patients should be involved in the decision making process. This appears to coincide with what patients themselves want; studies consistently show that most women with breast cancer want to participate in treatment decisions and that their need for information is high. Active involvement of women with breast cancer in treatment decision making appears to contribute to patients' feelings of control, and to improve psychosocial outcomes and quality of life.

**A decision aid on breast conservation therapy and mastectomy**

Four organizations with an interest in breast cancer, the Academic Medical Centre (AMC), the Dutch Cancer Institute, the Amsterdam Comprehensive Cancer Centre and the Dutch Breast Cancer Patients' Association, have collaborated in developing a decision aid providing interactive information for patients diagnosed with this condition (Figure 1). Different experts, including a general physician, oncologists, psychologists, professionals in health education and patients, have contributed to its development. The decision aid is meant to support patients who have been given a choice between breast conservation therapy and mastectomy.

The decision aid sets out the purpose, procedure, advantages and disadvantages of both treatment options, making use of text, photos, audio and video clips. To facilitate a match of the provision of information with the needs and interests of the individual patient, an interactive format was chosen. A patient is able to select exactly what
information she wishes to see, at her own pace and in any preferred order.

The main focus of this thesis is to investigate the effect of providing this decision aid to women with breast cancer on the treatment decision, satisfaction, and quality of life.

**Figure 1:** Interactive decision aid on breast cancer

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**Structure of this thesis**

In the next chapter (Chapter 2), a literature review of decision aids will be presented. The aim of this review was to arrive at a better understanding of the feasibility and effectiveness of decision aids. The review addresses: a) which types of decision aids were developed; b) whether they were feasible, and acceptable to patients and health care providers; and c) whether decision aids affected the decision making process and patients’ outcomes. An update of the literature over the period August 1999 to April 2004 is presented as an Addendum to Chapter 2.

Generally, decision aids were found to be feasible and acceptable to patients (Chapter 2). Whether this conclusion applies to the interactive breast cancer decision
aid too, is the aim of the study presented in Chapter 3. We shall describe the results of a descriptive study in which the acceptability of the breast cancer decision aid was investigated among patients and their physicians.

Few controlled studies are available that investigated the effects of decision aids on outcomes. In Chapter 3, the results will be presented of a controlled, longitudinal study with follow-up of patients scheduled at three and nine months post-surgery. The aim of this study was to establish whether the introduction of the breast cancer decision aid would influence patients' a) treatment decisions; b) satisfaction with information, the decision making process, the treatment decision, and care; and c) quality of life.

Better insight with regard to the relative contribution of different factors that determine patients' preferences and decisions, may establish more effective decision making among patients and physicians. The aim of the study presented in Chapter 5 is to investigate whether treatment preferences and choice of breast conservation therapy or mastectomy, could be predicted by: a) socio-demographic; b) psychological; and c) and decision making variables, and by the provision of the decision aid on breast cancer.

In chapter 6, the results will be presented of a study addressing what and how much information women selected from the breast cancer decision aid. The results of this study may help further program development, provide insight into the elements of decision aids that are essential or redundant, and may help to explain why the decision aid is, or isn't, effective. Moreover, associations between patients' characteristics and information selection were explored. The aim of this study is thus to: 1) describe patients' use of the decision aid addressing breast cancer surgery; and 2) investigate possible associations of socio-demographic background, psychological, and decision-related factors and patients' information seeking behaviour in the interactive decision aid.

In the field of research on treatment decision making, only a few valid and reliable instruments are available to investigate the effects of decision aids and the quality of decision making processes. One such measure is the Decisional Conflict Scale, which was validated in North America, mainly in healthy populations. In Chapter 7, the validation of the Decisional Conflict Scale in two samples of Dutch patients is described. Finally, Chapter 8 will provide a summary and general discussion of the study results and the implications of this thesis.
References


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