Available online at www.sciencedirect.com
ScienceDirect
EJSO 34 (2008) 42–48
EJSO the Journal of Cancer Surgery
www.ejso.com

Patients' preferences for low rectal cancer surgery ☆

E. Bossema [a,b], A. Stiggelbout [b,*], M. Baas-Thijssen [b], C. van de Velde [c], C. Marijnen [d]

[a] Department of Clinical Oncology, Leiden University Medical Center, The Netherlands
[b] Department of Medical Decision Making, Leiden University Medical Center, P.O. Box 9600, 2300 RC Leiden, The Netherlands
[c] Department of Surgery, Leiden University Medical Center, The Netherlands
[d] Department of Radiotherapy, Netherlands Cancer Institute, Amsterdam, The Netherlands

Accepted 14 August 2007
Available online 1 October 2007

Abstract

Aim: To elicit surgery preferences of patients who have experience with either low anterior resection (LAR) or abdominoperineal resection (APR) and its outcomes, to support decision-making in future patients with resectable rectal cancer.
Methods: One hundred and twenty-two patients were interviewed. Surgery preference was assessed in two ways. In the treatment trade-off method, the certainty of a stoma was hypothetically weighed against the risk of incontinence. In the time trade-off method, remaining life expectancy was traded off to avoid a permanent stoma or faecal incontinence.
Results: To avoid APR, LAR patients accepted a much higher risk of incontinence than APR patients. In fact, 71% of the LAR patients chose LAR if they would certainly suffer monthly incontinence, and still 32% if they would certainly suffer daily incontinence. Nevertheless, APR patients would give up less remaining life years to be without a permanent stoma than LAR patients to be without monthly incontinence.
Conclusions: Most patients preferred LAR above APR, even if LAR involved a risk of faecal incontinence. This seems to justify that LAR, if surgically possible, is performed in the first instance. However, since APR patients could live well with a permanent stoma, we recommend clearly informing patients before surgery about the surgical options and their potential outcomes.

Keywords: Rectal cancer; Faecal incontinence; Stoma; Treatment preference; Trade-off

Introduction

Up to one third of rectal cancer patients experience faecal incontinence after low anterior resection (LAR).[1–6] This may negatively influence overall health perception, social functioning, and depression.[6–8] Despite this impact, patients with rectal cancer and physicians seldom resort to abdominoperineal resection (APR) and a permanent stoma, when low anterior resection (LAR) with sphincter preservation is possible. Reasons for this probably concern the belief that QoL is worse after APR than after LAR. However, studies do not support this view unequivocally.[9]

Given the ambivalent data, it seems important to explicitly discuss the surgical possibilities with the patient when LAR is anticipated, and to take into account the patient's preference when making the treatment decision. This preference may vary widely between patients, for example, depending on demographic characteristics and cultural background.[10,11] In order to inform patients about the pros and cons of APR and LAR, data are needed on the experiences of other patients, and especially on their preferences regarding surgery type. No studies to date have formally elicited patients' preferences for either APR or LAR, and its health outcome states, with methods such as the treatment trade-off method (TTM) and time trade-off method (TTO).[12] The TTM measures the relative strength of a treatment preference by determining the maximum risk of a poor treatment outcome one is willing to accept. The TTO assesses the relative acceptability of a treatment outcome state by determining the maximum number of remaining life years one is willing to give up to be without that outcome state.[12]

The purpose of the present study was to investigate the strength of patients' preferences for either APR or LAR, by altering the risk of faecal incontinence after LAR in

☆ *Previous communication*: Results were presented at the 28th annual meeting of the Society for Medical Decision Making, Boston, MA, October 14–18, 2006 and at a national meeting of the Dutch Colorectal Cancer Group, Noordwijk aan Zee, The Netherlands, January 12, 2007.

* Corresponding author. Tel.: +31 71 526 5137; fax: +31 71 526 6838.
E-mail address: a.m.stiggelbout@lumc.nl (A. Stiggelbout).

0748-7983/$ - see front matter © 2007 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejso.2007.08.007

a TTM, and by asking them to trade off life expectancy to avoid a treatment outcome state (permanent stoma, faecal incontinence) in a TTO. By eliciting preferences from patients who have personal experience with either APR or LAR, we aimed to obtain information about these surgical options that can support decision-making in future patients with low resectable rectal cancer.

Methods

Patients

Rectal cancer patients were randomly selected from the database of a large multicentre trial investigating the efficacy of short-term preoperative radiotherapy in treatment with total mesorectal excision (TME).[13] About two third of these patients in this trial had been treated with LAR and about one third with APR, approximately 8 years before the start of the present study. For the present study, patients were eligible if they were alive, younger than 90 years of age, living in the Netherlands, had undergone APR or LAR, and were free of local or distant recurrent disease. Also, patients should have indicated in a previous study[6] that they were willing to participate in future research. In addition, patients who had undergone LAR should have had either no stoma, or a temporary stoma within 15 days after surgery (to prevent anastomotic leakage) that had been removed again. Finally, LAR patients were only eligible if they had indicated presence of faecal incontinence in the previous study,[6] since we expected that patients without incontinence would always prefer LAR. Further selection was according to stratified random sampling[14] to attain a group of 60 patients who had undergone APR (146 eligible), 30 patients who had undergone LAR and previously had a temporary stoma (179 initially eligible, but only 91 previously reported faecal incontinence) and 30 patients who had undergone LAR and never had a stoma (112 initially eligible, but only 47 previously reported faecal incontinence). Of the 284 'truly' eligible patients, 43 could not be traced. Of the patients approached, three were excluded because of their current health state (advanced Parkinson's disease, blindness, dementia), and 13 refused to participate. Additional patients were approached to replace these patients.

Procedure

Between February and August 2006 patients were asked to participate in a semi-structured interview at their homes on the valuation of the pros and cons of (not) living with a stoma. Before the interview, patients were sent a questionnaire, including questions on demographic (e.g. age, sex, education, living with a partner) and treatment characteristics, and a question on faecal incontinence for patients without a stoma ('How frequently did you unintentionally lose stools during the last 4 weeks?'). TNM stage data were obtained from the TME dataset. The ethics committee of the Leiden University Medical Center approved the study protocol. Written informed consent was obtained from all patients.

Instruments

In the TTM, the two surgical procedures in rectal cancer (APR and LAR) and their resultant health outcomes were presented on a board. One of the outcomes, faecal incontinence, was shown as uncertainty in both a negative ('risk of no incontinence') and positive way ('risk of incontinence') to avoid bias from framing.[15] The risk of incontinence was fixed at 0 in the APR description, but was systematically varied in the LAR description. After clarifying the information on the board, patients were asked to imagine that they now had a rectal tumour which was located such that both treatments were possible. Initially, the risk of incontinence after LAR was set at 0 (like after APR), and patients were asked to choose between the two treatments. Next, the risk of incontinence after LAR was set at 100, and patients were asked for their choice. If patients then preferred APR, the risk of incontinence after LAR was set at 50, and patients indicated their choice. In the subsequent comparisons, the risk of incontinence after LAR was systematically increased or decreased, depending on the patients' previous answer, finally in steps of 1%. The maximum risk of incontinence after LAR patients found acceptable before switching to APR was the treatment trade-off score. A higher treatment trade-off score thus indicates a stronger preference for LAR. The method was presented first with daily and then with monthly incontinence.

The board of the TTO presented two health states: one was one of the three potential outcome states of rectal cancer treatment (permanent stoma, daily faecal incontinence, monthly faecal incontinence), and the other was good health. After clarifying the information on the board and informing patients on their life expectancy (based on Dutch population statistics and adjusted for gender and age), patients were asked to make a hypothetical choice between the two health states, both with the same life expectancy, i.e. remaining years of life. The life expectancy in good health was then halved and patients again were asked for their choice. In the subsequent comparisons, the life expectancy in good health was systematically varied, finally in steps of 1 year, until the point was reached at which patients were indifferent between the life expectancy in the reduced health state and the shorter period in good health. To calculate the time trade-off score (i.e. utility), the minimum number of years in good health perceived as equal to the life expectancy in the reduced health state was divided by the life expectancy. In this way, time trade-off utilities are proportions of the life expectancy, ranging from 0 (i.e. willing to give up all remaining life years to avoid a treatment outcome state) to 1 (i.e. not willing to give up any remaining life year to avoid a treatment outcome state). For convenience, in the present article, we report disutilities, i.e. percentages of life years