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Medical decision making

Informed decision-making in colorectal cancer screening using colonoscopy or CT-colonography

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ABSTRACT

Objective: To evaluate the level of informed decision making in a randomized controlled trial comparing colonoscopy and CT-colonography for colorectal cancer screening.
Methods: 8844 citizens aged 50–75 were randomly invited to colonoscopy ($n = 5924$) or CT-colonography ($n = 2920$) screening. All invitees received an information leaflet. Screenees received a questionnaire within 4 weeks before the planned examination, non-screenees 4 weeks after the invitation. A decision was categorized as informed when characterized by sufficient decision-relevant knowledge and consistent with personal attitudes toward participation in screening.
Results: Knowledge and attitude items were completed by 1032/1276 colonoscopy screenees (81%), by 698/4648 colonoscopy non-screenees (15%), by 824/982 CT-colonography screenees (84%) and by 192/1938 CT-colonography non-screenees (10%). 1027 colonoscopy screenees (>99%) and 815 CT-colonography screenees (99%) had adequate knowledge; 915 (89%) and 742 (90%) had a positive attitude. 675 non-screenees invited to colonoscopy (97%) and 182 invited to CT-colonography (95%) had adequate knowledge; 344 (49%) and 94 (49%) expressed a negative attitude.
Conclusion: A large majority of screenees made an informed decision on participation. Almost half of responding non-screenees, made an uninformed decision, suggesting additional barriers to participation.
Practice implications: Efforts to understand the additional barriers will create opportunities to facilitate informed participation to colorectal cancer screening.

1. Introduction

Colorectal cancer is the second most prevalent cause of cancer related deaths in the Western world [1–3]. Without screening the life-time risk of colorectal cancer is 5–6% in Western countries [4]. The majority of colorectal cancers develop from adenomatous polyps – benign precursors – after a long premalignant period. Colorectal cancer screening can reduce both the incidence and mortality of colorectal cancer by early detection and removal of adenomatous polyps and colorectal cancer [5–11]. A recent study showed that the lifetime risk decreases to 4.4% when colorectal cancer screening is offered to the general population [12].

Patient autonomy requires that people should be able to choose at the individual level, free from coercion, whether they wish to participate in screening or not [13]. To make a balanced decision invitees require unbiased information on both the benefits as well as the harms of screening [14–17].

There are several definitions of informed decision, all including the following two dimensions: the decision should be based on decision-relevant knowledge and be consistent with the decision maker's attitude [18–21]. Screenees with adequate knowledge about colorectal cancer and colorectal cancer screening and a positive attitude toward participation make an informed decision to participate. Analogously, non-screenees with adequate

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knowledge and a negative attitude toward participation, make an informed decision not to take part in screening. In case of inadequate understanding or when making a decision not in line with one's attitudes, the action cannot be classified as an informed decision.

Relevant knowledge can be evaluated by measuring the invitees' knowledge on characteristics of the condition for which screening is offered, the screening test and implications of possible results [22,23]. Previous studies showed that required knowledge on the type of cancer (i.e. incidence) and the properties of a screening test (i.e. accuracy and complication risk) is often limited [24,25].

Colonoscopy and computed tomography-colonography (CT colonography) are attractive options for colorectal cancer screening, as they are both full colonic examinations with a high accuracy for advanced neoplasia [26,27]. As both are invasive techniques, requiring preparation by laxatives or contrast agents, invitees may be more inclined to reject participation to screening than when invited for less invasive tests. To make an informed decision on participation invitees should have enough decision-relevant knowledge on colorectal cancer, as well as on the (dis)advantages of colonoscopy or CT colonography. We evaluated the level of informed decision making on participation in a randomized trial comparing colonoscopy and CT colonography screening.

2. Methods

2.1. Patients and settings

Between June 2009 and July 2010, Dutch citizens aged 50–74 years were identified in the population registry in the regions of Amsterdam and Rotterdam, and invited by postal mail to participate in screening, randomly allocated 2:1 to colonoscopy or CT colonography. The trial protocol has been described in detail elsewhere [28]. Invitees were stratified for age, sex (individual level data from the Dutch population registry) and socio-economic status (very low – very high). In the Netherlands, postal area code can be linked to aggregated data on income level, education and type of occupation of Dutch citizens (based on data from Statistics Netherlands) [1]. At the time of the trial, the Netherlands did not have a population-based colorectal cancer screening program. Invitees were only allowed to undergo the allocated screening modality. Ethical approval was obtained before study initiation from the Dutch Health Council (2009/03WBO, The Hague, The Netherlands). The trial was registered in the Dutch trial register: NTR1829 (www.trialregister.nl).

2.2. Information leaflet and prior consultation

With the invitation, colonoscopy and CT colonography screening invitees received identically designed leaflets with information on colorectal cancer and colorectal cancer screening. These leaflets were derived from similar leaflets used in previous colorectal cancer screening pilots. The information leaflet for colonoscopy invitees contained specific information on benefits and risks of colonoscopy, while the information leaflet of CT colonography invitees contained information on benefits and risks of CT colonography. Both leaflets contained information on follow-up in case of a positive test result (e.g. follow-up colonoscopy in case of a positive CT colonography result).

Invitees who responded to the invitation were scheduled for a standardized consultation with a research fellow or research nurse to inform them about the bowel preparation and the procedure itself. In the CT colonography group all invitees were invited for a prior consultation by telephone, while in the colonoscopy group half of invitees were invited for a prior consultation at the outpatient clinic [28]. Data on differences between the two colonoscopy groups were recently published by Stoop et al. [29]. Responders were excluded from participation when they had undergone a full colonic examination in the previous five years, when they had a life expectancy of less than 5 years, or when they had been previously scheduled for surveillance colonoscopy

Table 1
Demographic characteristics of invitees returning their questionnaire.

Total invitees (*n*)	Colonoscopy, *n* = 5924		CT colonography, *n* = 2920	
	Screenees, *n* = 1276	Non-screenees, *n* = 4648	Screenees, *n* = 982	Non-screenees, *n* = 1938
Responding invitees	1167 (91%)	915 (20%)	927 (94%)	257 (13%)
Median age in years (IQR)	60 (55–65)	60 (55–65)	59 (55–65)	61 (56–67)
Gender (% male)	50.8	44.3	51.1	41.2
Married or living together (%)	86.4	82.8	85.0	80.8
Children (% yes)	85.5	83.5	87.2	89.1
Socio-economic status (mean, SD)[a]	3.2 (SD 1.4)	3.1 (SD 1.4)	3.1 (SD 1.4)	3.1 (SD 1.4)
Education				
Elementary (%)	3.8	6.1	5.0	8.1
Secondary (%)	67.8	68.1	60.5	57.9
Tertiary and postgraduate (%)	26.1	24.4	31.9	31.6
Other (%)	2.3	1.4	2.6	2.4
Employment status				
Paid job(%)	50.1	47.6	50.4	40.5
Not able to work (%)	4.9	5.8	3.4	6.1
Retired (%)	33.8	34.3	35.0	42.1
Other (%)	11.2	12.4	11.2	11.3
Ethnical origine				
Dutch	1094 (94%)	846 (92%)	874 (94%)	237 (92%)
Other	57 (5%)	59 (6%)	49 (5%)	20 (8%)
Unknown	16 (1%)	10 (1%)	4 (<1%)	0 (0%)
Prior colonoscopy experience[b]				
Yes	138 (12%)	–	96 (10%)	–
No	859 (74%)		708 (76%)	
Unknown	170 (15%)		123 (13%)	

[a] Socio-economic status was scored as very low (1), low (2), medium (3), high (4) and very high (5).
[b] This information was only collected in screenees.