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Accessibility of standardized information of a national colorectal cancer screening program for low health literate screening invitees: A mixed method study

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ABSTRACT

Objective: To explore the accessibility of standardized printed information materials of the national Dutch colorectal cancer screening program among low health literate screening invitees and to assess the effect of the information on their knowledge about colorectal cancer and the screening program.
Methods: Linguistic tools were used to analyze the text and design characteristics. The accessibility, comprehensibility and relevance of the information materials were explored in interviews and in observations (n = 25). The effect of the information on knowledge was assessed in an online survey (n = 127).
Results: The materials employed a simple text and design. However, respondents expressed problems with the amount of information, and the difference between screening and diagnostic follow-up. Knowledge significantly increased in 10 out of 16 items after reading the information but remained low for colorectal cancer risk, sensitivity of testing, and the voluntariness of colorectal cancer screening.
Conclusion: Despite intelligible linguistic and design characteristics, screening invitees with low health literacy had problems in accessing, comprehending and applying standard information materials on colorectal cancer screening, and lacked essential knowledge for informed decision-making about participation.
Practice implications: To enable equal access to informed decision-making, information strategies need to be adjusted to the skills of low health literate screening invitees.

1. Introduction

1.1. Population-based colorectal cancer screening

Colorectal cancer (CRC) is one of the most common causes of cancer-related deaths worldwide [1]. CRC screening aims to reduce the population burden of CRC by early detection and treatment of CRC and premalignant precursors in asymptomatic persons [1,2]. In the Netherlands, a national population-based CRC screening program was implemented in 2014. Every two years all individuals aged 55–75 years are invited by mail to perform an Immunochemical Fecal Occult Blood Test (iFOBT) at home. In case of a positive iFOBT result, an individual is referred for a follow-up colonoscopy.

The invitees receive an announcement letter by mail, followed a few weeks later by a test package including an invitation letter, an information leaflet, the iFOBT, and instructions on how to collect the sample. Commissioned by the Dutch Government, the Centre for Population Screening at the National Institute of Public Health and Environment developed the information materials specifically for the CRC screening program. The materials were edited in several rounds by a working group of patient representatives and experts in the field of public health, decision-making and screening, and were pretested in a general population sample.

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1.2. Informed decision-making about participation for individuals with low health literacy

The goal of the information materials is to enable individuals to make an autonomous, well-informed decision as to whether or not to participate in the CRC screening program [3]. An informed decision is commonly defined as being based on adequate decision-relevant knowledge and consistent with the decision-maker's attitude towards undergoing the screening [4].

Decision-making about cancer screening participation may be particularly difficult for individuals with low health literacy (HL) who have a lower capacity to assess, understand and use health information to make appropriate health decisions [5]. People with low HL are less likely to seek relevant information on CRC screening, are more often unaware of CRC screening, and have less knowledge on CRC screening [6–12]. They also have more negative expectations about undergoing CRC screening, perceive more barriers towards having and completing CRC screening, and have less self-efficacy for CRC screening participation [7,10,13]. Insufficient knowledge about the possibility of a false-negative iFOBT result can lead to false reassurance and, thus, to a delayed diagnosis of CRC in case of later symptoms [14].

1.3. Objectives of this study

First, we explored the complexity, accessibility, comprehensibility and perceived relevance of the standard CRC screening information materials for screening invitees with low HL. The second objective was to assess the effect of these materials on their knowledge about CRC and CRC screening. Thirdly, we assessed the respondents' ability to apply this information in their own decision-making process concerning participation and their actions regarding the screening test.

2. Methods

Accessibility and comprehensibility of CRC screening information is a function related to both the receivers and the providers. Therefore, we used linguistic evaluation to assess the complexity of the information itself and also interviewed users with low HL to assess their understanding and the relevance of the information.

Three complementary studies were conducted:

Study 1. Objective linguistic evaluation of the complexity of the printed information materials;

Study 2. Qualitative exploration of the accessibility and comprehensibility of the materials among individuals with low HL;

Study 3. Quantitative assessment of the effect of the information materials on the screening-relevant knowledge of individuals with low HL and on their ability to apply the information materials in their decision-making process regarding screening participation.

2.1. Objective linguistic evaluation of the information materials (Study 1)

Text characteristics and design of the announcement letter, the invitation letter, the leaflet and the instructions were systematically analyzed using the Evaluative Linguistic Framework (ELF) of Clerehan et al. for assessment of the complexity of text [15]. The framework provides an overall assessment of quality, is based on linguistic theory for assessing the quality of written patient information, and has been validated [16]. In the framework, the assessment criteria include: overall organizational structure of the text; rhetorical elements (the function of each 'move' in the text, e.g. to define, inform or instruct the reader); the technicality of the vocabulary; the 'metadiscourse' (language about the text itself that explains its purpose and assists the reader's movement around the text); relationship language (e.g. less or more personal language); the use of headings; the average number of content words per clause (lexical density); and the validity of the factual content of the information. While not a linguistic consideration, the visual aspects of the information materials were also taken into account in the quality assessment. This analysis included length, format, layout and various graphical aspects.

In addition, we used the T-Scan tool to specifically analyze the readability of the texts in the information materials at word and sentence level. This is a software tool used to analyze text materials in the Dutch language by: the length of words, length of sentences, syntactic complexity (i.e. occurrence of sub-sentences), and lexical diversity (i.e. repetition of words). In the T-Scan, the characteristics of the words and sentences are compared with text from a magazine for the general public (simple text) and from a scientific journal (complex text) [17].

2.2. Recruitment of research populations and data collection strategies (Studies 2 and 3)

The populations for the qualitative interviews (Study 2) and the survey (Study 3) consisted of individuals who were eligible for CRC screening (aged 55–75 years), were able to adequately communicate and read in Dutch, and had scores indicative of low HL on the Newest Vital Sign in Dutch (NVS-D) and/or the Short Assessment of Health Literacy in Dutch (SAHL-D) [18,19]. In the Netherlands, in conformance with the Medical Research Involving Human Subjects Act, the present study did not require medico-ethical approval, as was confirmed in writing by the medical ethical committee of the Academic Medical Center Amsterdam (May 13, 2013). Every possible precaution was taken to protect the privacy of all respondents.

Respondents for the qualitative study (Study 2) were primarily recruited from the patient files of three general practices in a disadvantaged neighborhood in the southeast of Amsterdam, 500 randomly selected patients (aged 55–75 years) were invited by postal mail. Respondents who expressed their interest to participate in Study 2 (by means of a prepaid response card) were contacted for HL assessment by telephone (see below). Respondents with low HL scores were invited for a face-to-face qualitative interview at a location of their preference. The sample from general practices was complemented by 9 volunteers with low HL who were purposively recruited by two Dutch organizations that act as representatives of the interests of people with low HL in Dutch society. The total number of included respondents was based on data saturation.

Respondents for the quantitative study (Study 3) were recruited via the online Health Care Consumer Panel of the Netherlands Institute for Health Services Research [20]. In November and December 2013, all 1500 members aged 55–75 years were invited to participate in the study. Those who provided consent to be contacted for participation in Study 3 and filled in the questionnaire were approached for HL assessment by telephone until we reached a sample size of 125 respondents with low HL. This sample size was based on the response, age and HL levels of the population in our previous studies that aimed to validate HL measures [18,19].

HL was assessed by a telephone interview using the NVS-D and the SAHL-D. The NVS-D is a six-item tool to assess an individual's ability to find and interpret text and numerical information presented in an ice cream nutrition label. The SAHL-D is a test based on word recognition and comprehension in the health domain. Both are international tools that have been adapted for the Dutch language [18,19]. During the telephone interview, respondents received an email with the SAHL-D and NVS-D attached as pdf files. After opening the SAHL-D file they were asked to read each

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