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Screening perception and health-related quality of life in colorectal cancer screening: A review

Elena Pizzo, PhD^{a,*}, Alessandro Pezzoli, MD^b, Reinhold Stockbrugger, MD, PhD^{b,c}, Enrico Bracci, PhD^{d,e}, Emidia Vagnoni, PhD^{d,e}, Sergio Gullini, MD^b

^a Imperial College London, Business School, London, UK

^b S. Anna University Hospital, Department of Gastroenterology, Ferrara, Italy

^c University Hospital Maastricht, Department of Gastroenterology and Hepatology, Maastricht, The Netherlands

^d Crisal Research Center, Villa Maria Foundation, Ferrara, Italy

^e University of Ferrara, Department of Economics, Ferrara, Italy

ABSTRACT

Keywords:

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Screening for colorectal cancer (CRC) has become established to varying degrees in several Western countries for the past 30 years. Because of its effectiveness, screening has been adopted or is planned in a number of other countries. In most countries, the screening method (e.g., fecal occult blood test [FOBT], sigmoidoscopy) is followed by colonoscopy, for verification. In other countries (e.g., United States, Germany), colonoscopy is the preferred first-line investigation method. However, because colonoscopy is considered to be invasive, might be poorly tolerated, and can be associated with complications, the idea of adopting colonoscopy as the primary screening method suffers. Negative effects of screening methods can reduce participation in programs and thereby negate the desired effect on individual and societal health. At present, there is no generally accepted method either to assess the perception and satisfaction of patients screened or the outcome of the screening procedures in CRC. In this review, we discuss the past development and present availability of instruments to measure health-related quality of life (HRQoL), the scarce studies in which such instruments have been used in screening campaigns, and the findings. We suggest the creation of a specific instrument for the assessment of HRQoL in CRC screening.

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Introduction

Incidence of colorectal cancer (CRC) has increased sharply in the Western world since 1970 [1]. In the United States, CRC is the third most common cancer in terms of incidence and the third leading cause of cancer death after lung cancer, prostate cancer in men, and breast cancer in women [2,3]. In Europe, CRC is the second most frequent cancer and the third leading cause of cancer death after lung and breast cancers in men and women [3]. A steady increase of environmental risk fac-

tors for CRC (obesity, smoking, low physical activity, poor diet) has created the need for CRC prevention not only in Western countries but recently also in Asia [4]. This need has resulted in an appeal from the European Commission to its member states to establish CRC screening programs nationwide. At present, this recommendation has been followed to varying degrees—with a certain eagerness of some Eastern European countries in which the level of CRC incidence was particularly high [5], and with hesitation and slowness in some Western European countries with a similar incidence [1].

* Address correspondence to: Elena Pizzo, Imperial College London, Business School, South Kensington Campus, London SW7 2AZ, UK.
E-mail: e.pizzo@imperial.ac.uk

Table 1 – Characteristics of primary colorectal cancer (CRC) screening tools currently in use [6].

Characteristics	Fecal occult blood test (FOBT)	Sigmoidoscopy	Colonoscopy (CS)
Invasiveness/discomfort	Noninvasive, minimal discomfort ⁺	Moderate invasiveness and discomfort ⁺⁺	Invasive
Risk of complications	No risk of complications ⁺	Complications are rare ⁺⁺	Sedation useful/necessary [§] Complications are possible (bleeding/perforations) [§]
Sensitivity	Low sensitivity for target lesions (25%–50%) Fails to detect most polyps and some cancers False-positive results are possible ⁺	Lower sensitivity than CS (70%–80%) Only rectum and left part of the colon are examined ⁺⁺	High sensitivity (95%–100%) Allows exploration of rectum and entire colon [§]
Need for additional procedures and/or repetition	Requires CS if positive Useless/hazardous without annual or biannual repetition [§]	Requires CS if positive Biopsies can be performed and precancerous polyps removed during the test Repetition every 5 years ⁺⁺	Additional procedures not required Biopsies can be performed and precancerous polyps removed during the test Repetition every 10 years ⁺
Reduction of CRC mortality	Annual/biannual FOBT in ages 50–80 years can reduce CRC mortality by 15%–33% ⁺	Effectiveness in reducing CRC mortality has not yet been proved in RCT ⁺⁺⁺	Effectiveness in reducing CRC mortality has not yet been proved in RCT ^{§*}

* Indirect evidence available.

⁺, low; ⁺⁺, medium; [§], high; RCT, randomized controlled trials.

Fecal occult blood test (FOBT) traditionally has been the most common test used in CRC screening, but in later years sigmoidoscopy and colonoscopy have become increasingly popular choices. In the United States and Germany, colonoscopy is strongly promoted as the first-line screening method, whereas prescreening with FOBT is recommended in other countries, such as the United Kingdom. An overview of the characteristics of currently recommended CRC screening tools is given in Table 1 [6]. However, no reliable data are available at present about the actual cost of various screening methods in relation to the gain of quality-adjusted life years (QALYs), as those will very much depend on the management costs for the neoplastic lesions identified [7].

Differences in screening recommendations are motivated to some extent by organizational and economic reasons but also by the scarcely documented public presumption that the more invasive endoscopic procedure might create negative perceptions and impair the health-related quality of life (HRQoL) of potential screenees. Frequently, the medical community shares this worry and tends to favor less burdensome (but also less sensitive) imaging procedures for CRC screening such as CT-colonography. Non-evidence-based opinions can survive for long periods, not only in general but also in professional communities, and can potentially inhibit beneficial medical developments.

At present, there is no generally accepted method either to assess the perception and satisfaction of those screened or the outcome of the screening procedures in CRC in terms of quality of life. The aim of the paper is to highlight the need for an instrument that assesses patient satisfaction with various screening tools and the HRQoL resulting from differently designed screening procedures. Thus, an overview is given of methods presently used to assess HRQoL in general. Thereafter, a review is provided of the limited number of attempts to assess and describe participants' perceptions of screening and their HRQoL before and after various CRC screening invita-

tions and procedures. Some characteristics necessary for a specific HRQoL instrument to be used in CRC screening are also mentioned.

General Instruments for the Assessment of Health-Related Quality of Life

Background and history

Quality of life (QoL) is a notion that has been discussed, in various guises, throughout the history of philosophy. The notion of QoL appears in the health care sector quite early, and in the 1960s, the health-related literature started showing interest for this concept [8,9].

According to Apolone [10], we can distinguish three outcome categories in health management: clinical/epidemiological, humanistic, and economic (Table 2). The components of the first type of outcome are measured by objective indicators derived by diagnostic procedures and clinical events, such as recurrences and mortality. The economic outcome assessment measures both direct and indirect costs, such as hospitalization, examinations, resource consumption, lost working hours, and productivity reduction. The category of humanistic outcomes contains the measures that will mainly be addressed in this review: severity of symptoms, functional impact of disease, well-being and QoL. These elements synthesize the main part of the variety that reflects different approaches of health-related quality of life (HRQoL).

According to Spilker et al., HRQoL represents the functional effects of disease and therapeutic actions on the patient, in the way the patient defines them [11], and is therefore considered to be one of the primary indicators of outcome [12]. The World Health Organization (WHO) defines QoL as the subjective perception that an individual has of his position in life, in

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