



Medical decision making

Shared decision-making about colorectal cancer screening: A conceptual framework to guide research

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ABSTRACT

Objective: To develop a conceptual framework to guide research on shared decision-making about colorectal cancer (CRC) screening among persons at average risk and their providers.

Methods: Based upon a comprehensive review of empirical literature and relevant theories, a conceptual framework was developed that incorporated patient characteristics, cultural beliefs, provider/health care system variables, health belief/knowledge/stage of adoption variables, and shared decision-making between patients and providers that may predict behavior. Relationships among concepts in the framework, shared decision-making process and outcomes, and CRC screening behavior were proposed. Directions for future research were presented.

Results: Many of the concepts in the proposed framework have been examined in prior research. However, these elements have not been combined previously to explain shared decision-making about CRC screening.

Conclusion: Research is needed to test the proposed relationships and hypotheses and to refine the framework.

Practice Implications: Findings from future research guided by the proposed framework may inform clinical practice to facilitate shared decision-making about CRC screening.

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1. Introduction

Colorectal cancer (CRC) incidence and mortality can be significantly decreased through regular screening and the removal of adenomatous polyps [1–6]. Screening guidelines are stratified by CRC risk based on assessment of risk factors such as a history of adenomatous polyps, family history of CRC, age, and certain medical conditions and genetic syndromes [7]. Individuals are at average risk for the disease if they lack risk factors other than increasing age [7]. For these individuals, screening starts at age 50 and includes six test options: (1) annual guaiac fecal occult blood test or fecal immunochemical test; (2) single-strand DNA; (3) flexible sigmoidoscopy every 5 years; (4) virtual colonoscopy every 5 years; (5) double-contrast barium enema every 5 years; or (6) colonoscopy every 10 years [8].

Provider recommendation is an important predictor of many behaviors including CRC screening [9–12]. It seems logical that a

discussion about CRC screening must occur between patients and providers in order for a recommendation to be made. To be consistent with published guidelines, providers should tailor their CRC screening test recommendation based on a complete assessment of risk factors [8]. For persons at increased risk, colonoscopy is the most appropriate test and the decision to be made is relatively simple – to have a colonoscopy or not [8]. For those at average risk, decision-making about CRC screening is more complex, involving at least two decisions: (1) whether or not to have any CRC screening test, and, if screening is desired, (2) which of the six test options to choose [8]. Questions remain about how these decisions are made by both patients and providers and to what extent these decisions are shared.

A variety of terms have been used to describe decision-making within the context of the patient–provider relationship [13] and in research [14–16], and the lack of a common definition of the concept has been reported [17]. Given the absence of common terminology, the literature reviewed in this paper will reflect both “shared decision-making” (SDM) and “informed decision-making” (IDM) and will indicate which term was utilized in referenced works. However, to simplify, “shared decision-making” will be used in this paper to refer to both SDM and IDM. SDM has been defined as

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a particular process of decision making by the patient and clinician in which the patient: (1) understands the risk or seriousness of the disease or condition to be prevented; (2) understands the preventive service, including the risks, benefits, alternatives, and uncertainties; (3) has weighed his or her values regarding the potential benefits and harms associated with the service; and (4) has engaged in decision making at a level at which he or she desires and feels comfortable [13] (p. 59).

In the current paper, SDM is defined to be consistent with this definition. Although SDM has been defined as a process, it can also be conceptualized as an outcome [18]. When conceptualized as an outcome, one can assess the presence of elements of the process, whether a shared decision was ultimately made, and patients' satisfaction with the process [18]. Regardless of whether SDM is defined as a process or an outcome, it is imperative that investigators clearly define the term both conceptually and operationally in future research.

Although patients report a desire to engage in SDM about preventive health services [19] and providers report openness to SDM [20–23], investigators have questioned whether SDM about CRC screening actually transpires during clinical visits. Decision-making about CRC screening has been studied [14,16,24–26] with mixed results [15,24,27]. One study found that only 47% of individuals reported they engaged in SDM about CRC screening during their provider visit [19]. However, this same study showed that only 1 of 363 visits included all essential elements of SDM [19]. One component of SDM assessed in this study was elicitation of patient preferences; that is, health care decisions must take into account each patient's values and preferences for CRC screening tests. Individuals weigh the advantages and disadvantages associated with each CRC test differently and test preferences vary widely [28,29].

Shared decision-making is especially important for individuals at average risk for CRC, since multiple test options with varying schedules are available [8]. Patient preferences should be solicited before CRC screening decisions are made. However, questions remain about whether providers order screening tests based on patient or provider preferences since colonoscopy is more frequently recommended than any other test modality [27,30]. In one study, 77% of patients reported concordance between their preference and CRC screening decisions [24], whereas another study showed that only 50% of individuals who completed screening reported they received their preferred test [29]. In a randomized, controlled trial testing a decision aid to promote SDM about CRC screening, knowledge about CRC, satisfaction with the patient–provider decision-making process, and intention to be screened were higher in the intervention groups [26]. In addition, those who had had a CRC test ordered that matched their test preference were more likely to intend to complete the test [26]. Although this intervention showed promise for promoting SDM about CRC screening, only 59% of tests ordered matched patients' reported test preferences [26]. Importantly, screening behavior was not evaluated [26]. In a recent study, researchers found that CRC screening was mentioned in 48% of the primary care visits; however, in almost half of those visits, no additional discussion of CRC screening occurred [25]. One-third of those visits included both a discussion of CRC screening and an assessment of the patient's understanding of CRC screening [25]. However, only 6% of those CRC screening discussions included assessment of patient test preferences; therefore low levels of IDM were found [25]. More research is needed to understand the elements necessary for effective interventions to promote SDM about CRC screening.

CRC screening requires a partnership between both provider and patient, with action required of both parties. However, it is

critically important to acknowledge that some patients may decide not to be screened at the present time and multiple discussions about CRC screening may be needed. With a foundation in health behavior theories and the empirical literature, a conceptual framework that has great potential to guide research in this area is proposed.

2. Theoretical foundations

Multiple health behavior change theories have been used to study CRC screening [31–37]. The Health Belief Model (HBM) is commonly used as a framework to explain CRC screening behavior [36,38,39]. The Precaution Adoption Process Model (PAPM) has been suggested as a framework for categorizing an individual's readiness for CRC screening completion as it takes into account the possibility that individuals may have made the decision not to perform a behavior [40–42]. Health locus of control for CRC screening has also been studied [43,44]. Although not previously examined in relation to CRC screening, the God Locus of Health Control construct may be informative when considering CRC screening behavior. In addition to these variables, cultural variables also may be associated with patient–provider interactions, SDM, and CRC screening in minority populations.

3. Overview of the framework

A comprehensive literature review was conducted to inform development of the conceptual framework which is theoretically grounded in HBM and PAPM (see Fig. 1). Many of the major components of the framework have been shown to be related to CRC screening behavior and/or SDM in prior work (see Table 1 for relevant theory construct definitions). Proposed relationships among patient characteristics, cultural variables, provider/system variables, health beliefs, knowledge, and stage of adoption, the SDM process, SDM outcomes, and ultimately, CRC screening behavior are depicted in Fig. 1.

3.1. Patient characteristics

Demographic and other patient characteristics that have been related to CRC and other cancer screening behaviors are included in the proposed framework [45–63]. Higher levels of education [45–48] and older age [49–52] have been associated with CRC screening test completion. Lower socioeconomic status has been associated with lower likelihood of CRC screening [53–58]. Lack of health insurance has been cited as a barrier to screening [47,59,60]. Higher levels of social support have been associated with breast cancer screening [61] and subjective norms have been associated with CRC screening [62]. Similarly, perceived social support for CRC screening has predicted screening behaviors [63]. The framework proposes that these patient characteristics may be associated with a number of other components of the framework, including health beliefs, knowledge, stage of adoption, cultural variables, SDM outcomes, and CRC screening behavior.

3.2. Cultural variables

Cultural variables have been examined in various studies of cancer screening behaviors, including CRC screening [53,64–70]. Researchers found that cultural beliefs and values influence minority patients' perceptions of communication with their providers, but providers may fail to consider culture when engaging in discussions about CRC screening [71]. Furthermore, minority patients may not disclose cultural beliefs or values when discussing CRC screening with their providers [71]. Previous studies have shown that cultural beliefs and values influence

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