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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, health beliefs/stage of adoption, 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.

Keywords

Colorectal cancer screening; shared decision-making; patient-provider communication

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

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[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:

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 Figure 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. Proposed relationships among patient characteristics, cultural variables, provider/system variables, health beliefs and stage of adoption, the SDM process, SDM outcomes, and ultimately, CRC screening behavior are depicted in Figure 1.

3.2.1 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.

3.2.2 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 health behaviors [53, 65–69], and several cultural variables are included in the proposed framework (i.e., temporal orientation, trust in one's physician, trust in the medical system, acculturation/time in the U.S., collectivism, and religiosity). Individuals with a present time orientation have been shown to be less concerned about making decisions to prevent future health problems and have a lower likelihood of being screened for CRC [53] or breast cancer [66]. As studies have shown that medical system and/or physician mistrust negatively influences help-seeking behavior in U.S. minority groups [72–75], these constructs are also included in the proposed framework. Studies with minority patients have suggested that medical mistrust is a barrier to CRC screening [64, 65]. Collectivism and level of acculturation may be important to consider when working with individuals from minority groups [76, 77]. Studies of the associations between CRC screening and acculturation and/or length of time in the U.S. have yielded mixed results; these associations may depend upon the characteristics of specific minority groups [78–87]. Similarly, language barriers also may contribute to low CRC screening rates [88]. However, studies of language and CRC screening have also shown mixed results, with some studies finding that patient-provider language discordance was not associated with screening rates and other studies finding language differences to be a barrier to screening [48, 79, 87, 89–92].

Several ethnic minority groups, including African Americans and Latinos, report high levels of religiosity [93, 94] which may influence CRC screening. Church attendance has been associated with increased likelihood of mammography in African American women [67, 68], however, religiosity has been inversely related to other protective health behaviors (i.e., physical activity) [69]. The relationships among cultural variables, SDM outcomes, and CRC screening behavior are proposed to be mediated by the SDM process variables. Potential hypotheses that could be explored in future research include: 1) higher levels of medical mistrust and lower trust in one's physician may be related to communication quality and discussions about CRC risk, screening test options, and patient preferences; 2) temporal orientation, religiosity, and collectivism are hypothesized to be directly related to the health belief and stage of adoption variables.

3.2.3 Provider/System variables

Provider and health care system variables have been shown to be related to the SDM process, SDM outcomes, and CRC screening [19, 48, 95–97]. Individuals with more frequent health care provider visits [95] and those who felt that they had adequate time with their provider [48] have higher rates of CRC screening. Factors such as length of primary care visit and reason for visit may influence whether there is sufficient time available to have a CRC screening discussion and/or receive a provider recommendation. Provider race is included in the framework but it is unclear whether patient-provider racial concordance results in better outcomes [96, 97]. Provider gender is also included in the proposed framework because having a female provider has been associated with SDM [19]. In addition, due to their potential to influence the SDM process, provider attitudes toward both SDM and CRC screening are included in the proposed framework. The provider's attitudes toward SDM and length of the visit are hypothesized to be positively related to the SDM process, SDM outcomes, and CRC screening variables in the framework.

3.2.4 Health beliefs, knowledge, and stage of adoption

Health beliefs, knowledge, and stage of adoption for CRC screening are included in the proposed framework because they have been shown to predict CRC screening behavior [36, 37, 39, 40, 63, 70, 84, 98–106]. HBM variables shown to predict CRC screening include perceived susceptibility, perceived barriers, perceived benefits, and self-efficacy [36, 38, 39]. Perceived benefits have been positively associated with CRC screening [107, 108], whereas perceived barriers have been negatively associated with this behavior [104, 107, 108]. Knowledge of CRC and CRC screening [63, 103, 104], perceived susceptibility to CRC [63, 70, 84, 102, 105, 106], and self-efficacy [29, 100, 109] for completing specific tests have been associated with stage of adoption, intentions to complete screening, and CRC screening behavior. In addition, higher levels of certain health locus of control beliefs (i.e., that powerful others influence one's health) have been negatively associated with CRC screening [43]. Although not previously examined in relation to CRC screening, high scores on the God Locus of Health Control scale have been associated with nonadherence to mammography [110]. Cancer fatalism and cancer fear have been shown to be barriers to CRC screening [40, 65, 111–115].

Stage of adoption, often defined by the Transtheoretical Model (TTM), has been an important predictor of CRC screening beliefs and behaviors in prior research [32, 41, 116]. Significant predictors of stage of adoption for flexible sigmoidoscopy have included participants' perceived risk for developing CRC, CRC beliefs, screening barriers, CRC worry, and prior provider recommendation [32]. Receipt of prior cancer screening and the belief that "screening is important" (p. 329) have been associated with CRC screening stage of adoption [41]. Demographic and clinical variables have also been associated with stage of adoption [116]. Although much of the prior research regarding stage of adoption has been based on TTM, the PAM has been suggested as a more appropriate stage model due to the periodic nature of CRC screening [40–42]. As shown in the proposed framework, individuals may move through the PAM stages as their global and CRC-specific health beliefs change and they engage in the SDM process with their provider [40–42]. Perceived benefits, risk, self-efficacy and knowledge are hypothesized to be positively related to SDM outcomes, whereas God Locus of Health Control is hypothesized to be inversely related to CRC screening performance. In addition, health belief, knowledge, and stage of adoption variables are proposed to be directly related to the SDM process variables as these variables may influence each other, are modifiable, and change over time.

3.2.5 SDM Process

Several variables that characterize interactions between patients and providers have been included in the framework because evidence has shown they predict CRC screening [9–11, 48, 117, 118]. Provider recommendation has consistently been a significant predictor of CRC screening [9–11]. Quality of the patient-provider relationship and patient-provider communication have been predictive of CRC screening [117]. Patients who felt their providers communicated well and informed them about their health care were more likely to complete FOBT [48]. African American patients who reported better quality patient-provider communication were more likely to have completed CRC screening [118]. Among those individuals who reported “good” communication with their provider, increased knowledge about CRC was associated with screening test performance [118]. It is hypothesized that the SDM process variables in the framework will both influence and be influenced by health beliefs and stage of adoption. For example, the SDM process may result in changes in patients’ health beliefs (e.g., perceived risk, benefits, and barriers), knowledge, and stage of adoption (e.g., moving from unaware to decided to act or decided not to act). However, this process may occur over numerous interactions and multiple CRC screening discussions. The double-headed arrow linking health belief and stage of adoption variables to the SDM process illustrates that these variables likely influence each other and that multiple discussions may be necessary to move a patient forward in their stage of adoption toward a decision to participate in CRC screening, to not participate, or to delay making a decision.

3.2.6 SDM Outcomes

In the proposed framework, SDM is conceptualized as the sharing of information about CRC screening and risk factors, discussion of pros and cons associated with screening, and collaboration in decision-making [14]. For SDM to occur, patients should: 1) be aware of their risk for developing CRC and the seriousness of CRC; 2) understand the risks, benefits, alternatives, and uncertainties of the various CRC screening tests; 3) weigh his/her values regarding the potential benefits and harms associated with CRC screening; and 4) engage in decision-making about CRC screening at a level at which he/she desires and feels comfortable [13]. Thus, these variables are incorporated in the framework as SDM outcomes. Only when these goals are achieved can a shared, preference-concordant decision be reached. A preference-concordant decision which results from the SDM process has three outcomes: a patient may be screened, may not be screened, or may be undecided/delay making a decision about CRC screening. The decision that the patient will be screened is hypothesized to be related to CRC screening behavior. Recognizing that there may be differences in SDM preferences [24], it is also important to assess whether or not individuals were involved at the level in which they wanted to be involved.

Shared decision-making has received increased attention in recent years [13–17]; this concept has also been applied to decisions about CRC screening [14, 16, 24]. Researchers found that of the 2,463 primary care patients reporting whether they discussed CRC screening with their provider, most reported having a discussion with the provider (80%) [14]. Of these, the vast majority reported receiving a CRC screening recommendation and a test referral or FOBT kit (94% and 86%, respectively) [14]. The majority of these individuals also reported having their interest in screening assessed (70%), being presented with pros and cons of screening (66%), being informed about post-screening follow-up (65%), and being scheduled for screening (59%) [14]. Despite the fact that only one-third had been asked about their preferences or offered a choice among the tests, the majority of patients reported they were involved in CRC screening decision-making at the level they desired (79%) [14]. Furthermore, those who were involved in decision-making at their preferred level were more likely to be screened [14]. In multivariate analyses, greater

likelihood of CRC screening was associated with discussion of either colonoscopy or sigmoidoscopy, how results would be communicated or a follow-up would be scheduled, and assistance with making the appointment [14]. Interestingly, being offered a choice of screening test was associated with decreased likelihood of screening [14]. These results are similar to those of another study in which discussions of patient preferences and pros and cons of test options were associated with decreased CRC screening [16].

Research has demonstrated that individuals' vary in their preferences for CRC screening tests [119]. In one study, 41% of patients currently non-adherent to CRC screening recommendations preferred colonoscopy, 35% preferred FOBT, 13% preferred sigmoidoscopy, and 6% preferred barium enema [29]. Racial/ethnic differences may also exist; Latinos were more likely to prefer FOBT than Whites [120]. Although providers often recommend CRC screening, they most frequently recommended colonoscopy as opposed to any other test [27]. The authors suggested that individuals who might be willing to complete other, less invasive screening tests may not get screened due to the emphasis on colonoscopy [27].

Although a primary care visit is the most appropriate opportunity for engaging in SDM about CRC screening, providers may also need to consider patient preferences about engaging in SDM. Researchers found that 45% of community-dwelling adults aged 50–75 desired SDM, 25% wanted to consider their provider's opinion while making their own decision, 16% wanted their doctor to make CRC testing decisions for them, and 15% wanted to make CRC testing decisions themselves [24]. Those with less education preferred that the doctor make decisions about CRC screening and had less interest in SDM [24, 121]. African American patients reported greater interest in SDM compared to White patients [24]. However, compared to Whites, African American patients had lower odds of reporting knowledge of the risks and benefits of cancer screening, having engaged in IDM about cancer screening, and having their provider allow them "some control" over screening choices [121] (p. 421). Investigators found that patients who reported "relational communication" (e.g., "my doctor was interested in talking to me," "my doctor was sincere") with their providers were more likely to report having engaged in SDM about CRC screening [19] (p. 362). Prior research has found the following CRC outcome variables to be related to CRC screening: 1) the patient is aware of risk for developing CRC; 2) the patient is aware of the seriousness of CRC; 3) the patient is engaged in decision making about CRC screening at a level at which he/she desires and feels comfortable [14, 32, 63, 70, 84, 102, 105, 106]. However, also based upon prior research [14, 16], the following SDM outcomes have been shown to be associated with *not* completing a CRC screening test: 1) the patient understands the risks, benefits, alternatives, and uncertainties of the various CRC screening tests and 2) the patient has weighed his/her values regarding the potential benefits and harms associated with CRC screening. It is proposed that engaging in the SDM process could result in three distinct preference-concordant outcomes: 1) to be screened; 2) not to be screened; and 3) not deciding right now (undecided). The patient deciding to be screened is a necessary precursor to CRC screening behavior. More research is needed to understand both the process and outcomes of SDM in the context of a variety of health behaviors including CRC screening. Further research is needed to understand preferences for SDM and the process and outcomes of SDM about CRC screening among minority patients in particular.

4. Discussion and conclusion

4.1. Discussion

A conceptual framework that has potential to guide research and enhance understanding of SDM regarding CRC screening between average-risk patients and their providers is proposed. Given the myriad CRC screening test choices for people at average risk for CRC,

SDM may be especially important for these individuals. In addition, when examining CRC screening outcomes among minorities, considering cultural and SDM process variables may be essential. Informed by prior CRC screening research and health behavior theories, the framework includes a number of variables that have already been associated with cancer screening behavior (e.g., demographics, health beliefs, stage of adoption), while taking into account cultural, provider/health care system, and SDM process variables. The framework suggests that these variables may be related to SDM outcomes and, ultimately, to CRC screening behavior.

The paper makes an important contribution because it describes a theoretically and empirically-based framework to guide future research and clinical practice about CRC screening and SDM with diverse groups of patients. However, some limitations should be noted. Not all of the proposed relationships in the framework have been empirically tested and thus research is needed to test the proposed hypotheses as well as the relationships illustrated in the framework.

A number of directions for future research are proposed. Future studies should focus on SDM as both a process *and* an outcome. Consistent and clear conceptual and operational definitions of SDM are urgently needed if we are to move research in this area forward. Empirical studies are needed to test the proposed relationships depicted in the framework; findings from these studies will likely lead to additional refinement of the framework which can then be used to inform future research and clinical practice. Because prior research has found inverse associations between CRC screening completion and two components of SDM (eliciting patient preferences and discussing pros and cons of the tests), future research is needed to explore these components [14, 16]. Valid and reliable measures of the SDM processes and outcomes are urgently needed. Following clarification of SDM concepts and measures, future studies are needed to develop and test interventions to promote SDM about CRC screening. Research is also needed to understand whether interventions that are tailored on cultural beliefs improve the SDM process and ultimately lead to screening completion. Furthermore, although providers have reported being open to SDM, it is not known how providers' beliefs about and desire to engage in SDM may affect SDM about CRC screening and screening behavior [20–23]. Given the limited time available for preventive care in most provider visits, it is important to acknowledge that multiple conversations may be required to fully engage in SDM about CRC screening. Studies that focus on both the process and outcomes of SDM in the context of CRC screening are needed.

4.2. Conclusion

The proposed framework is offered as a guide for future research aimed at understanding the processes and outcomes of SDM about CRC screening. The inclusion of cultural variables also makes the proposed framework particularly useful for research on SDM with minority patients. Findings from future research may inform clinical practice in order to facilitate SDM between patients and their providers. Future research should focus on testing the proposed relationships and refining the framework.

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Figure 1.
Conceptual framework of shared decision-making about CRC screening among average-risk patients and their providers.

Table 1

Definitions of concepts included in proposed framework.

Concept	Definition	References
Perceived susceptibility	one's belief about the chances of getting CRC	Champion et al., 2008; Champion, 1993; Champion, Foster, Menon, 1997; Rawl, Champion, Menon, et al., 2001; Kreuter & Strecher, 1995
Perceived barriers	one's belief about the costs associated with attending CRC screening	Champion et al., 2008; Champion, 1993; Champion, Foster, Menon, 1997; Rawl, Champion, Menon, et al., 2001; Kreuter & Strecher, 1995
Perceived benefits	one's belief about the benefits associated with attending CRC screening	Champion et al., 2008; Champion, 1993; Champion, Foster, Menon, 1997; Rawl, Champion, Menon, et al., 2001; Kreuter & Strecher, 1995
Knowledge	the amount of knowledge one has about CRC and CRC screening	Champion et al., 2008; Champion, 1993; Champion, Foster, Menon, 1997; Rawl, Champion, Menon, et al., 2001; Kreuter & Strecher, 1995
Self-efficacy	confidence that one can complete behaviors associated with CRC screening	Champion et al., 2008; Champion, 1993; Champion, Foster, Menon, 1997; Rawl, Champion, Menon, et al., 2001; Kreuter & Strecher, 1995
Stage of adoption	one's readiness to complete CRC screening	Ferrer, Hall, Portnoy, et al., 2011; Weinstein, Sandman, Blalock, 2008
Cancer fatalism	the belief that a cancer diagnosis will result in death as opposed to the possibility of cure	Powe, 1995a; Powe, 1995b
Cancer fear	fear of what a CRC diagnosis might entail or mean	Champion, Skinner, Menon, et al., 2004
Health locus of control	belief that individuals are able to control their health	Wallston, Wallston, DeVellis, 1976
God locus of health control	belief that God or a higher power is in control of one's health	Wallston, Malcarne, Flores, et al., 1999
Collectivism	belief that group goals take priority over individual goals	Lukwago et al., 2001
Temporal orientation	the time frame one uses to make health-related decisions	Lukwago et al., 2001
Trust in physician	the amount of trust one places in their physician and in the patient- physician relationship	Dugan et al., 2005
Religiosity	the strength of one's religious beliefs and how one's religious beliefs are associated with one's perception of sources of health	Lukwago et al., 2001
Acculturation Social support	"a process of change in values and behaviors made by individuals because of continuous interaction with people of a different ethnic group" Buscemi et al., 2012, p. 1 perceived support for CRC screening from important others (i.e., friends and family members)	Buscemi et al., 2012 Allen et al., 1999; Allen et al., 2008