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Patient Perceptions of Shared Decision Making:
What Does It Mean and How Does It Affect Patient Outcomes?

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of
Philosophy at Virginia Commonwealth University.

by

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I dedicate this dissertation to Patrick and Elliot. I love you both.

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Abstract

PATIENT PERCEPTIONS OF SHARED DECISION MAKING: WHAT DOES IT MEAN AND HOW DOES IT AFFECT PATIENT OUTCOMES?

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

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Introduction: Shared decision making (SDM) has been advocated as an optimal approach to medical decision-making. Yet, little is known about how patients perceive SDM and whether patient-defined SDM is associated with patient outcomes.

Methods: This three-manuscript dissertation used a mixed-methods approach including a systematic literature review and both qualitative and quantitative research methods. The aims were to: (1) systematically review the patient outcomes studied in relation to SDM and identify under what measurement contexts SDM is associated with which types of patient outcomes; (2) use in-depth, qualitative interviews to develop a conceptual model of patient-defined SDM and compare this to recent decisions that patients labeled as shared; and (3) apply the model of patient-defined SDM to the context of colorectal cancer screening.

Results: Study 1 found that 39 studies measured SDM and evaluated it with a patient outcome, and only 43% of patient outcomes assessed were significantly associated with SDM. Patient reports of SDM were most likely to be associated with outcomes.

Study 2 found that patients' conceptual definition of SDM included four components: exchange of information, active listening, patient-self advocacy, and a personalized physician recommendation. Patient descriptions of recent decisions labeled as shared ranged from very simple recommendations through complex interactions, with the only commonality among shared decisions being that the patient and physician ultimately agreed.

Study 3 found that the most commonly observed component of patient-defined SDM was patient self-advocacy (76%) and least common was a personalized physician recommendation (23%). Only 9% visits contained all four patient-defined SDM components. In adjusted models, physician provision of information around the process and potential side effects of colorectal cancer screening was associated with an increase in screening. There were differences in screening rates by the patient's initial verbal response to the physician recommendation with those who initially refused being least likely to be screened (40%) and patients who did not verbalize a response to the recommendation being most likely to be screened (70%).

Discussion: Findings across the three studies highlight the complexity of studying and measuring SDM and emphasize the importance of the patient's perspective on SDM.

Chapter 1: Introduction

In recent years, shared decision making (SDM) has been suggested as an optimal approach to medical decision making.¹ While relatively new, the literature on SDM is large and growing, with an increasing emphasis on determining the patient outcomes associated with the use of SDM. Accordingly, physicians are being encouraged to employ a SDM process with patients. For example, the National Cancer Institute's monograph on patient-centered communication identified decision-making as one of the six core functions of patient centered-communication, stating that decision-making should be characterized by active engagement by both patient and physician.² Furthermore, the U.S. Preventive Services Task Force advocates for physicians to use SDM when making cancer screening and other preventative health recommendations to patients.³ Despite the widespread endorsement of SDM, there not a clear consensus on what SDM actually entails. Furthermore, there is little knowledge of the empirical evidence of either what it means to the parties involved or its impact on outcomes.

A recent review of SDM literature found that over 61% (257 of 418) of articles provided no definition of SDM.⁴ However, of the articles that provided definitions, that developed by Charles et al. (1997) was most often cited. Charles et al. (1997) define SDM as having four key components that all must be present for a decision to be considered shared: (1) at least two participants (patient and physician) are involved in all phases of the decision-making process; (2) both parties share information; (3) both parties take steps to build a consensus around the decision; and (4) agreement is reached.⁵ While this definition was cited three times as often as

any other published definition,⁴ there remains some disagreement about the critical components of SDM. For example, the U.S. Preventive Services Task Force's definition of SDM does not require that the patient be involved actively but rather that "the patient has engaged in decision-making at a level at which he or she desires and feels comfortable."³ Others have suggested that patient and physician need not reach an agreement to have participated in a SDM process.⁴ However, because the Charles et al. (2007) definition is the most commonly used definition, it will be used in this study as the normative definition of SDM, upon which other perceptions of SDM will be compared.

Measurement of SDM

In addition to differing definitions of SDM in the literature, there are also many approaches to measuring SDM in practice. The two most common methods of measuring SDM are observer ratings (via coding of direct observation or recordings of medical consultations) and patient self-reports of having participated in SDM. In recent years there have been a variety of formal coding systems created to measure medical decision-making including the Decision Analysis System for Oncology scale (DAS-O⁶), the Decision Support Analysis Tool (DSAT⁷), the Shared Decision Making Scale,⁸ and the OPTION scale.⁹ While some of these coding systems have been found to be moderately correlated with one another, they each focus on different aspects of SDM and have been validated in separate populations.¹⁰ These differences represent the continued disagreement within the academic community about what constitutes a shared decision. Additionally, these coding systems all focus primarily on physician behaviors and do not specifically take into account patient involvement.¹¹

The most common way of measuring SDM is through patient self-report.¹¹ Instruments that measure patient self-reports of SDM range from single-item scales (e.g. Control Preference

Scale ¹²) to multi-item, single dimensional scales (e.g. 9-item Shared Decision making Questionnaire SDM-Q-9 ¹³; Facilitation of Patient Involvement Scale ¹⁴), through multi-dimensional scales in which SDM is one of many aspects (e.g. Decisional Conflict Scale ¹⁵; Decision Evaluation Scales ¹⁶; Perceived Involvement in Care Scale ¹⁷; Combined Outcome Measure for Risk Communication and Treatment Decision-making Effectiveness (COMRADE) ¹⁸). As with observer rating instruments, there is no clear gold standard on how to measure patient-reports of SDM.

Patient and physician perceptions of SDM

While there are many measurement tools for patient reports of SDM, very few studies have looked specifically at understanding patient and physician perceptions of SDM. There is evidence, however, that patients may understand SDM differently than researchers. For example, a recent study using audio-recordings of routine annual physical examinations found that researcher-defined SDM (using the Charles et al. (1997) definition ⁵) was not correlated with patient reports of SDM. ¹⁹ After the exam, patients were asked about their role in the colorectal cancer screening decision-making and 47% (171 of 363) reported using a SDM process. However, when the audio-recordings of the visits were coded using Charles et al.'s (1997) model of SDM, only 0.3% (1 of 363) met the criteria for SDM. Another recent study measured SDM from three perspectives (patient, physician, and observer) and found that observer ratings of SDM were completely unrelated to patient or physician ratings, and that patient and physician perceptions were only moderately correlated. ²⁰ Taken together, these results point to a likely and substantial discrepancy between patients' and researchers' perceptions of SDM.

We know of only two studies that have directly explored the meaning of SDM to patients; both qualitative studies conducted in the context of diabetes treatment. ^{21,22} The study

by Peek and colleagues (2008) looked specifically at the meaning of SDM to African Americans with diabetes. They found that patients emphasized the importance of being able to “tell their story and be heard” and reported that information sharing was a vital part of SDM. However, the patients also suggested that negotiation and sharing of the actual decision were not necessary to have participated in SDM.²¹ The second study by Entwistle and colleagues (2007) used in-depth interviews to investigate the meaning of involvement in treatment decisions among 18 adults with diabetes. This study also found that patients felt they were involved in decision-making when they were able to communicate their views and believe that their physician listened.²² In addition, patients reported that the “feel” of the appointment was important and patients were more likely to report being involved when they perceived that their physician respected them. The results from these two studies indicate that relational components of SDM may be more important to patients than current published definitions of SDM indicate, consistent with the recent finding that patient ratings of physician relational communication are associated with patient reports of SDM.¹⁹

Patients may also perceive SDM differently than physicians. In a study of women in treatment for breast cancer, for example, patients and physicians were asked to indicate who made the treatment decision using a modification of the Degner et al. (1997) Control Preferences Scale.^{12,23} This scale is commonly used in measuring patient perceptions of SDM and asks patients to rate their role in making a specific decision among 5 choices: (1) I made the final decision, (2) I made the final decision after seriously considering my doctor’s opinion, (3) My doctor and I shared the responsibility for deciding, (4) My doctor made the final decision but seriously considered my opinion, and (5) My doctor made the final decision. Choice 3 is considered a shared decision.¹² On this scale, only 38% of patients and physicians agreed on

who made the treatment decision. Moreover, 50% of physicians reported making a shared decision, while only 30% of patients reported the decision as shared.²³ The poor concordance between patient and physician reports indicates a discrepancy in how physicians and patients perceive medical decision making.

Taken together, these studies indicate that there are differences in how patients and physicians perceive SDM and that the commonly used Charles' et al. (1997) definition may not represent the perceptions of either group. Additionally, it is not clear which of these perspectives are associated with positive patient outcomes. Therefore, richer understanding of how patients and physicians perceive SDM is required to foster the type of active medical decision making that meets patients' expectations and promotes health.

SDM and colorectal cancer screening

The U.S. Preventive Services Task Force (USPSTF), as well as numerous other medical societies, recommends that adults aged 50 to 75 receive regular colorectal cancer screening. Although there is general evidence to support the benefits of timely screening, there is less agreement regarding how patients should be screened. The USPSTF recommends screening via: (1) a fecal occult blood test every year, (2) a flexible sigmoidoscopy every 5 years, or (3) a colonoscopy every 10 years.²⁴ The USPSTF also advises that physicians use a shared decision making process when recommending colorectal and other preventive services to patients.³ Despite these recommendations, some 40% of the US population remains unscreened for colorectal cancer²⁵ and approximately 50,830 men and women in the United States will die of colorectal cancer in 2013.²⁶ The CDC estimates that 60% of colorectal cancer deaths could be prevented if everyone were screened as recommended.²⁷

Known barriers to colorectal cancer screening include a lack of a physician recommendation for colorectal cancer screening, cost, lack of health care insurance, and embarrassment or fear over the screening test or preparation for the test.²⁸ A recent study surveyed over 3,000 primary care patients and asked them to identify the most significant obstacle to receiving CRC screening among a list of known barriers. The list included both generic barriers, or those that apply across screening modalities, and specific barriers for each type of screening modality. Of the generic barriers, “my healthcare provider never suggested I get this test” and “I did not know I should have this test” were most often identified as the top overall barrier to screening.²⁸ These findings indicate that not having a discussion about the need for colorectal cancer screening is among the most important barriers to screening, as identified by primary care patients.

Similarly, another recent study found that although physicians pointed to patient factors, such as fear of pain and embarrassment about testing, to be important barriers to colorectal cancer screening, patients eligible for colorectal cancer screening who had never been screened cited not having a physician recommendation as their most important barrier to screening.²⁹ While we know that screening use increases with a greater number of primary care visits, and thus more opportunities for a physician recommendation,^{30,31} a simple recommendation or discussion does not guarantee colorectal cancer screening use. Even among those with a physician recommendation, some 40% will still go unscreened.³²

The content of the discussion is important as well, with more comprehensive discussions about colorectal cancer screening being associated with increased screening use.³³ In line with these findings, patient reports of having participated in SDM are associated with increases in colorectal cancer screening rates,³⁴ and a recent randomized controlled intervention trial of the

behavioral mediators of colorectal cancer screening found that patient-provider communication about colorectal cancer screening was the most important behavioral mediator for screening usage.³⁵

Thus, colorectal cancer screening discussions and decisions have a direct impact on patient health outcomes, illustrating the need for a better understanding of patient and physician perceptions of SDM around colorectal cancer screening.

The aims of my research

Patient perceptions of having participated in SDM are associated with a variety of positive outcomes (e.g.^{36,37}). However, little is known about what leads patients to perceive and thus report a decision as shared. As communication and decision-making processes are amenable to change, there is potential to foster SDM in practice. Yet, without an understanding of how patients perceive SDM, our ability to foster decision-making processes that are associated with positive outcomes is hindered. My research is designed to: (1) understand under what measurement conditions SDM is associated with what types of patient outcomes; (2) provide insight into how patients perceive SDM; and (3) apply a patient-informed definition of SDM to the context of colorectal cancer screening and evaluate the relationship between patient-defined SDM and adherence to physician recommended colorectal cancer screening. With this knowledge, future research can focus on developing interventions that help patients and their physicians achieve SDM and its associated benefits in practice.

Chapter 2: Where is the evidence? A systematic review of shared decision-making and patient outcomes

Abstract

Background: Despite widespread advocacy for shared decision making (SDM), the empirical evidence regarding its effectiveness to improve patient outcomes has not been systematically summarized.

Purpose: To systematically review the patient outcomes studied in relation to SDM and identify under what measurement contexts SDM is associated with which types of patient outcomes.

Data Sources: PubMed (through December 2012) and hand search of article bibliographies.

Study Selection: Studies were included if they empirically (1) measured SDM in the context of a patient-clinician interaction, and (2) evaluated the relationship between SDM and at least one patient outcome.

Data Extraction: Outcomes were categorized by SDM measurement perspective (patient-reported, clinician-reported, or observer-rated) and outcome type (cognitive, behavioral, or health).

Data Synthesis: Thirty-nine studies met inclusion criteria. Thirty-three used patient-reported SDM, six used observer-rated, and two used clinician-reported SDM. Ninety-seven unique patient outcomes were assessed; 51% cognitive, 28% behavioral, and 21% health. Only 43% of assessments (n=42) found a significant and positive relationship between SDM and the patient outcome. Results varied by SDM measurement perspective and outcome category. 52% of outcomes assessed with patient-reported SDM were significant and positive, compared to 21% with observer-rated and 0% with clinician-reported SDM. Regardless of measurement perspective, cognitive patient outcomes were most likely to be associated with SDM (54%), compared to 37% of behavioral, and 25% of health outcomes.

Conclusions: SDM, when perceived by patients as occurring, seems to improve cognitive outcomes, such as decisional conflict. Yet, available empirical evidence does not yet support an unequivocal relationship between SDM and patient behavioral and health outcomes.

Introduction

Since the early 1980s, shared decision making (SDM) has been suggested as an optimal approach to making health care decisions.^{1,38,39} Both the Institute of Medicine and the U.S. Preventive Services Task Force have advocated for clinicians to use SDM when making preventive health and treatment recommendations.^{3,40} Most recently, language contained in the Affordable Care Act specifically calls for programs to facilitate shared decision making and the establishment of the Patient Centered Outcomes Research Institute.⁴¹ Furthermore, a recent systematic review of patient decision-making preferences found that the majority of patients prefer to be actively involved in decision-making and that the trend for a preference for shared decisions has increased over time.⁴²

While the concept of SDM is often intertwined with decision aids, there are conceptual differences in the two. Although there is not universal agreement around a definition of SDM, it is generally thought to be a process in which a patient and clinician collaborate to make the best possible medical decision for the patient.⁴³ Decision aids most often are defined as tools to help patients to become better informed about the potential benefits and harms of treatment choices, to weigh the pros and cons based on their unique values and medical characteristics, and to be prepared to actively participate with their clinician in making a medical decision.⁴⁴ Thus, while both SDM and decision aids have the same end goal of a patient making a well-informed and value-concordant decision,⁴⁴⁻⁴⁶ decision aids may or may not employ SDM to reach this end and SDM can occur outside of the use of a decision aid.

Previous systematic reviews have pointed to the effectiveness of decision aids for improving patient outcomes,⁴⁴ but as evidenced by these reviews, use of a decision aid does not ensure that SDM occurred. For example, in the most recent Cochrane review of decision aids

(2011), only 16 of the 86 randomized trials reviewed explicitly measured the effects of decision aids on patient participation in decision-making. Among these studies, there were no differences in patient reports of having participated in SDM between those given a decision aid or those receiving usual care.⁴⁴ Thus, the positive effects of decision aids on patient outcomes may not be attributable to SDM. Moreover, the empirical evidence surrounding SDM is not confined to studies of decision aids only.

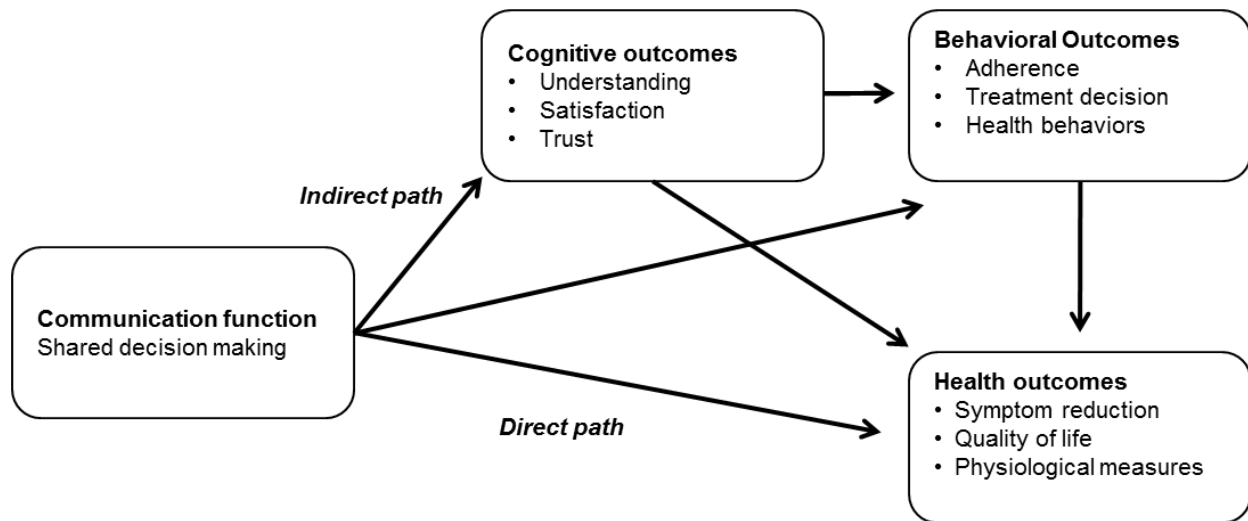
Despite widespread advocacy for SDM and a growing body of literature evaluating its use, the empirical evidence regarding its effectiveness as a mechanism to improve patient outcomes has not been systematically summarized. Additionally, SDM has been measured in a variety of ways across studies, and whether these different measurement perspectives are differentially associated with patient outcomes is not known. The objectives of this systematic review are to (1) describe the patient outcomes that have been studied in relation to SDM and (2) identify under what measurement contexts SDM is associated with which types of patient outcomes.

Methods

Conceptual Framework

The conceptual framework guiding this systematic review was adapted from models by Street and colleagues⁴⁷ and Kreps and colleagues⁴⁸ (Figure 2.1). In their model of pathways in which clinician-patient communication can lead to better health, Street and colleagues posit that while communication between clinicians and patients, including SDM, can lead to improved health outcomes directly, in most cases communication affects health indirectly through proximal and intermediate outcomes. As proposed by Kreps and colleagues in their Transformation Model of Communication and Health Outcomes,⁴⁸ we change the categorization

of outcomes from a temporal classification to a conceptual classification. This latter model asserts that patient outcomes should be categorized by their impact on the individual across three categories: cognitive, behavioral, and physiological. Cognitive outcomes include knowledge, attitudinal, and affective/emotional effects. Behavioral outcomes include both adherence to recommended treatments and adoption of health behaviors. Physiological outcomes (which we have broadened to label as health outcomes) include quality of life, self-rated health, and biological measures of health (e.g. blood pressure).⁴⁸



Adapted from Street et al. (2009) and Kreps et al. (1994)

Figure 2.1: Conceptual framework linking SDM to patient outcomes.

Inclusion and Exclusion Criteria

Studies were included in this review if they empirically (1) measured SDM in the context of a patient-clinician interaction, and (2) evaluated the relationship between SDM and at least one patient outcome. Excluded studies were those not in the context of a patient-clinician interaction, that reported only qualitative data, or that were reviews or commentaries. Also excluded were studies that evaluated the relationship between SDM and patient outcomes but did

not directly measure SDM. As such, evaluations of decision aids and other interventions which assumed that use of the decision aid led to a SDM process, but which did not explicitly measure SDM were excluded.

Search Strategy

We began with the primary search strategy outlined by Makoul and Clayman (2006) in their systematic review of the SDM literature.⁴ Specifically, in January 2013, we conducted a PubMed search for English-language articles published through December 31, 2012 with the words *shared decision making* in the title or abstract. Makoul and Clayman reasoned that this search strategy captured articles with a clear focus on shared decision making in the medical literature and that the simple approach allows for reproducibility for future studies.⁴ No start date was specified so that all studies published up through the end of 2012 would be included. The resulting abstracts were reviewed for inclusion and exclusion criteria. I read and reviewed the full text of those articles meeting the study inclusion criteria and collected any non-redundant references to SDM.

Among study eligible articles, patient outcomes were defined as observed or self-reported effects in association with a specific patient-clinician encounter or overall medical care. Because a number of eligible studies evaluated more than one patient outcome in relation to SDM, the unit of analysis for this review is a patient outcome.

Classification framework

There are multiple ways that SDM can be measured.^{4,11} A priori we expected the measurement of SDM to fall into two primary categories: patient self-reports of SDM or observer-ratings of the use of SDM (usually via structured coding of audio-recordings). Our review of the literature also revealed a third category: clinician reports of using SDM with

patients. In addition to considering the SDM measurement perspective, as indicated in the conceptual framework (Figure 2.1) we also considered the type of outcome evaluated using the three classifications proposed in the Transformation Model of Communication and Health Outcomes⁴⁸: cognitive, behavioral, or health outcome. Combined, these categorizations resulted in a 3 x 3 classification framework that was used to structure the results of the systematic review (Figure 2.2).

SDM Measurement Perspective	Patient Outcome Category		
	Cognitive	Behavioral	Health
Patient self-reported			
Clinician self-reported			
Observer rated			

Figure 2.2: Categorization framework of patient outcome categories by SDM measurement type

Assessment of the quality of studies

We used a modified version of the Systematic Appraisal of Quality in Observational Research (SAQOR) tool to assess the quality of included studies.⁴⁹ SAQOR was created for use in systematic reviews to assess the quality of observational studies. Each study was rated as adequate, inadequate, or unclear across six categories: sample, research design, quality of measures, follow-up, distorting influences (confounders), and reporting of data. A total score for each study is computed by counting the number of categories marked adequate. Thus the total quality score has a range of 0 to 6, with higher scores indicating higher quality studies. Total

scores of 5 or 6 represent high quality, scores of 3 or 4 represent moderate quality, and 0 to 2 represent low quality observational studies.⁵⁰

Results

Overview of studies

Forty-one publications,^{10,17,51-89} representing 39 unique studies, met the inclusion criteria (Figure 2.3; Table 2.1 on page 26). Thirty-four of the 41 articles meeting inclusion criteria were published in the last ten years and the earliest study meeting the inclusion criteria was published in 1989.⁵¹

The 39 studies were conducted across a variety of clinical contexts. Fourteen studies (36%) were conducted in the context of cancer care, and almost three-quarters of these (n=10) focused specifically on breast cancer treatment and surgery decisions. Other clinical contexts studied included mental health (n=5), diabetes (n=5), serious injury (n=3), heart disease (n=2), HIV (n=2), and general primary care (n=2) among others (n=6).

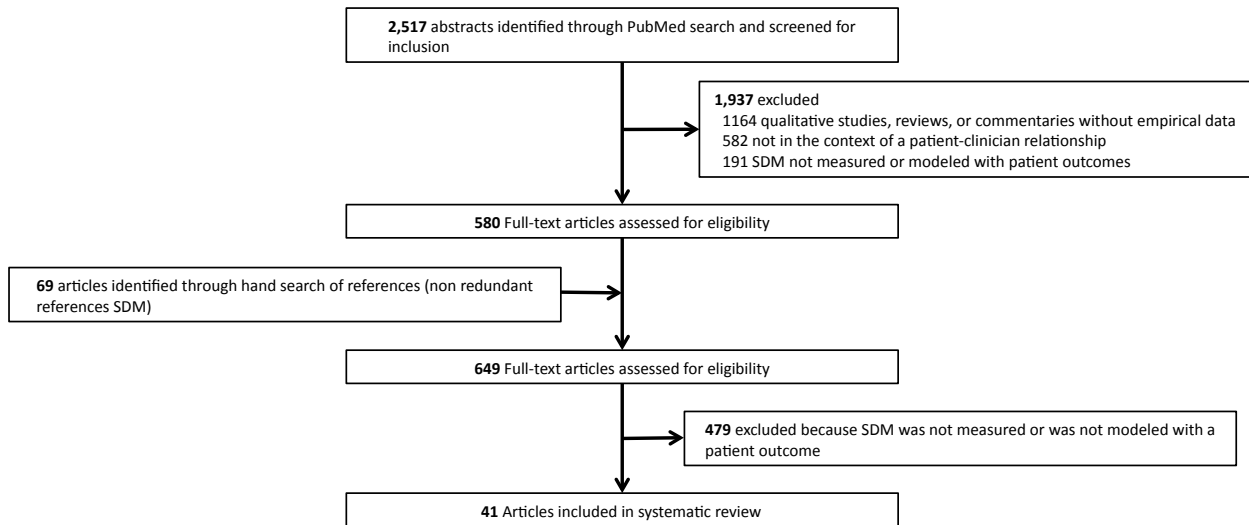


Figure 2.3: Search strategy and selection results

Quality assessment

The SAQOR quality scores ranged from 2 to 6, with a median score of 3 (Table 2.1). Across the 39 studies, six (15%) received a high quality rating, 25 (64%) moderate, and eight (21%) low. Most of the studies were either cross-sectional or prospective surveys in which data were collected either before and after, or only after, a consultation with a clinician. Nine of the 39 studies were conducted in the context of a clinical trial.^{53,58,64,65,68,70,72,77,82} Eight of these were a secondary analysis of a previous RCT.^{53,58,64,72,77,82} In these studies, the analysis either was conducted without regard to group assignment,^{77,82} group assignment was used as a predictor variable in the model,^{58,64,68,72} or the results were tested separately to see if group assignment confounded the relationship between measured SDM and patient outcomes.^{53,65} The ninth study included a patient self-report of participation in SDM, but only tested the association of patient-reported SDM with a patient outcome among those in the experimental group.⁷⁰ Thus, none of the included RCTs evaluated the association between SDM and a patient outcome with a randomized design.

SDM Measurement Perspective

Eighty-five percent of studies measured SDM from the patient's perspective (n=33), 15% (n=6) via observer rating, and two (8%) used clinician-reports to measure SDM. In two studies,^{74,81} the same patient outcome was assessed for its association with SDM from different SDM measurement perspectives and these analyses are considered separately.

Patient-reported SDM was measured in a variety of ways across studies. The most commonly used measure was a modified version of the Control Preference Scale¹² in which patients rate their perceptions about their level of involvement in decision-making (n=13 studies). The second mostly commonly used patient-reported measure of SDM was the multi-

item Patient Involvement in Care Scale,¹⁷ which was used in four studies. A variety of other single and multi-item measures of SDM were used (n=16 studies).

Five of the six studies that included observer ratings of SDM used the OPTION scale in which observers rate the communication between patient and clinician on 12 items.⁹⁰ The OPTION scale is either completed by an in-person observer in real time or is used to rate audio-recordings of patient/clinician interactions.

Clinician-reported SDM was used in two studies, both in the context of diabetes.^{81,84} One of these used a modified version of the Control Preference Scale¹² and the other used a 9-item Self-Assessment Questionnaire.⁹¹

Patient Outcomes Evaluated

The number of patient outcomes evaluated per study ranged from 1 to 7 with a total of 95 unique patient outcomes and 97 unique patient outcome-SDM measurement pairs assessed across the 39 studies (Table 2.2). Among the 97 outcome assessments, 51% (n=50) were cognitive, 28% (n=27) behavioral, and 21% (n=20) health outcomes. Half of the cognitive variables studied were around patient satisfaction (n=25). Beyond satisfaction, cognitive variables included concerns/anxieties about the illness (n=5), decisional conflict (n=4), anxiety following the consultation (n=4), confidence in the decision (n=2), and knowledge (n=2) among others. The most frequent behavioral variable assessed was around the treatment decision itself (n=10), with nine of these regarding breast cancer treatment decisions. Other behavioral variables include treatment/medication adherence (n=7), health behaviors (n=3), and others. Health outcomes included patient ratings of overall health (n=6) and quality life (n=3), depressive symptoms (n=5) and other patient-reported measures (n=2), as well as a blood pressure (n=2) and other physiological measures (n=2).

Table 2.2: Patient outcomes assessed by SDM measurement perspective and outcome category (n=97)

SDM Measurement Category	Patient Outcome Category		
	Cognitive (n=50)	Behavioral (n=27)	Health (n=20)
Patient-reported SDM	Satisfaction with care (x7) Concern/anxiety about illness (x5) Satisfaction with decision (x5) Decisional Conflict (x3) Satisfaction with consultation (x3) Anxiety after consultation (x2) Control over medical problem (x2) Health care empowerment (x2) Knowledge (x2) Satisfaction with information received (x2) Trust in physician (x2) Confidence in decision Predicted discomfort Predicted functional capacity	Decision about breast cancer treatment (x7) Medication/treatment adherence (x6) Diet Disclosure of CAM use Exercise Number of treatment strategies agreed upon Receipt of depression care Stress management behaviors Use of CAM	Pt rated health/symptoms (x6) Depressive symptoms (x5) Quality of life (x3) Anxiety Blood pressure Emotional functioning
Clinician-reported SDM	Satisfaction with provider communication	Medication adherence Receipt of dilated eye exam Receipt of hemoglobin A1c assessment Receipt of lipid assessment	Blood pressure Hemoglobin A1c Lipid level
Observer-rated SDM	Satisfaction with decision (x 4) Anxiety immediately after consultation (x 2) Satisfaction with consultation (x 2) Confidence in decision Decisional conflict Satisfaction with physician's SDM skills	Decision about breast cancer treatment (x 2) Decision about treatment for arrhythmia	

Associations between SDM and patient outcomes

As can be seen in Table 2.3, less than half (n=42; 43%) of assessments found a statistically significant and positive relationship between SDM and the patient outcome. Results varied by both the SDM measurement perspective and the category of patient outcome. When SDM was measured from the perspective of the patient, regardless of the outcome category, assessments were more likely to result in significant associations. Across all outcomes assessed, 52% were significantly and positively associated with patient-reported SDM, compared to only 21% of outcomes when SDM was observer-rated and 0% when SDM was clinician-reported. Similarly, regardless of how SDM was measured, cognitive patient outcomes were most likely to

be associated with SDM. Fifty-four percent of cognitive outcomes were positively associated with SDM, compared to 37% of behavioral, and 25% of health patient outcomes.

Three studies found negative effects of SDM on patient outcomes including an increase in decisional conflict,⁵⁸ a decrease in patient satisfaction,⁶³ and an increase in patient reports of the impact of breast cancer on their life.⁶⁷ All three were cognitive patient outcomes in the context of patient self-reports of SDM.

Table 2.3: Summary of results by SDM measurement perspective and patient outcome category

SDM Measurement Perspective	Patient Outcome Category											
	Cognitive		Behavioral		Health		Total					
	n	%	n	%	n	%	n	%	n	%		
Patient reported	Positive*	25	66%	Positive	9	45%	Positive	5	29%	Positive	39	52%
	NS*	10	26%	NS	11	55%	NS	12	71%	NS	33	44%
	Negative*	3	8%	Negative	0	0%	Negative	0	0%	Negative	3	4%
	Total measured	38		Total measured	20		Total measured	17		Total measured	75	
Clinician reported	Positive	0	0%	Positive	0	0%	Positive	0	0%	Positive	0	0%
	NS	1	100%	NS	4	100%	NS	3	100%	NS	8	100%
	Negative	0	0%	Negative	0	0%	Negative	0	0%	Negative	0	0%
	Total measured	1		Total measured	4		Total measured	3		Total measured	8	
Observer rated	Positive	2	18%	Positive	1	33%	Positive	0	--	Positive	3	21%
	NS	9	82%	NS	2	67%	NS	0	--	NS	11	79%
	Negative	0	0%	Negative	0	0%	Negative	0	--	Negative	0	0%
	Total measured	11		Total measured	3		Total measured	0		Total measured	14	
Total	Positive	27	54%	Positive	10	37%	Positive	5	25%	Positive	42	43%
	NS	20	40%	NS	17	63%	NS	15	75%	NS	52	54%
	Negative	3	6%	Negative	0	0%	Negative	0	0%	Negative	3	3%
	Total measured	50		Total measured	27		Total measured	20		Total measured	97	

- Positive refers to a significant, positive (i.e. beneficial) association between SDM and the patient outcome. NS refers to a non-significant association. Negative refers to a significant, negative (i.e. non-beneficial) association between SDM and the patient outcome

five health outcomes that were found to be associated with SDM were patient self-reported outcomes, including a one-item ratings of general health rating,⁷² discomfort,⁵¹ symptom improvement,⁵¹ general medical improvement,⁵¹ and measure of depressive symptoms rated on the Center for Epidemiologic Studies-Depression scale.⁶⁵ Among these, only depressive symptoms were measured using a multi-item, previously validated scale.⁶⁵ None of the four physiological measures assessed were associated with SDM.^{70,84}

Discussion

Relatively few empirical evaluations have been conducted between SDM and patient outcomes. We found a total of 39 unique studies, which included 97 assessments of the relationship between an empirical measure of SDM in the context of a patient-clinician interaction and a subsequent patient outcome. Cognitive outcomes were assessed most often and were primarily patient reports of satisfaction, decisional conflict, or other perceptions immediately after an interaction with a clinician. Furthermore, relative to behavioral and health outcomes, cognitive outcomes were most often found to be significantly and positively associated with SDM. While cognitive outcomes are important and represent SDM's origins as an ethical call to increase patient autonomy,^{39,92} there has been a shift towards understanding how patient-clinician communication, including SDM, may be associated with more distal behavioral and health outcomes.^{2,47,93}

Although there are strong ethical and interpersonal reasons to advocate for SDM, our findings illustrate the continued uncertainty surrounding SDM as a mechanism to improve patient outcomes. Regardless of the type of patient outcome considered or the SDM measurement employed, empirical evaluations more often than not have found no positive and statistically significant relationship between SDM and a patient outcome. The one exception is

among assessments that evaluated a cognitive patient outcome in relation to patient-reported SDM. Within these assessments, the majority (66%) found a significant and positive relationship between SDM and a subsequent patient outcome. Notably lacking were any studies that evaluated the association between observer-rated SDM and patient health outcomes. Clinician reports of SDM were also rare, with the eight such associations evaluated here coming from only two independent studies, with none found to have a significant association with a patient outcome.

Results from this review indicate that the link between SDM and health patient outcomes, in particular, has yet to be fully established. Our review highlights several important points regarding the assessment of SDM and patient health outcomes. First, health outcomes were least studied. Second, when health outcomes have been assessed in relation to SDM, the outcomes have most often been measured via patient self-report, and often with un-validated instruments. In total, only five of the 20 (25%) health outcomes evaluated were found to be associated with SDM, and four of these used single-item un-validated measures. Furthermore, we identified only four physiological measures of patient health (blood pressure, hemoglobin A1C, and lipid level) that have been evaluated for their association with SDM, and none of these evaluations identified a statistically significant relationship.^{70,84} Despite the fact that conceptual models of patient-clinician communication hypothesize that communication is most likely to have an indirect effect on patient health outcomes, the studies included here tested only for a direct effect of SDM on health outcomes. Without mediation or path analysis models designed to specifically examine indirect effects, the relationship between SDM and patient health outcomes is likely to remain elusive.

As previously reported,^{4,11} within the patient-perceived SDM measurement category a wide range of measures of patient perceptions of SDM are currently being used. While variations of the Control Preference Scale¹² are most commonly used, we found 16 different instruments used across the 33 studies that measured SDM via patient self-report. Whether the Control Preference Scale or some other instrument is used to capture patient-reported use of SDM, more often than not, items contained in these instruments do not enable an understanding of what it is about the decision-making process that leads a patient to report that it was shared. This is particularly troubling as several recent studies have found that observer ratings of SDM do not predict patient reports of having participated in a shared decision.^{19,74,94} These results, combined with our findings that when positively associated with a patient outcome it is patient-perceived SDM, and not observer-rated SDM that is important, only serve to highlight the challenge and need to understand what leads a patient to label a decision as “shared.” Without such an understanding, our ability to foster SDM processes in practice will continue to be hindered as will our ability to fully understand the impact of SDM on patient outcomes.

Notably lacking among the SDM literature are randomized trials evaluating the impact of a communication/decision-making intervention on patient outcomes that empirically measure the communication/decision-making process used. There have been many RCTs in recent years that have evaluated the effects of some type of communication or decision-making intervention on patient outcomes. These interventions most often center on a decision aid, but also include patient or clinician communication training interventions.^{95,96} These studies have rarely included an empirical measure of SDM, instead assuming SDM to have occurred based upon group assignment. Our review identified only 9 studies conducted in the context of a randomized trial,^{53,58,64,65,68,70,72,77,82} and despite the design of the parent study, none evaluated the association

of SDM and a patient outcome in the context of the randomized design. To compliment thoughtful conceptual models that hypothesize the paths between patient and clinician communication behaviors and patient outcomes (e.g.⁴⁷), well designed studies are needed that formally test whether decision-making and communication interventions lead to increase SDM, and then whether it is these increases in SDM (or something else) that are associated with health outcomes. SDM may mediate, or even moderate the relationship between communication or decision-making interventions and patient outcomes, but as of yet these relationships remain untested in the empirical literature.

Limitations

Our conceptual framework examines impact of SDM on patient outcomes across two important domains – the way in which SDM was measured and the category of patient outcome. However, there are undoubtedly other dimensions that are important to understanding the relationship between SDM and patient outcomes. For example, the clinical context in which the decision was made and the nature of the decision itself (prevention vs. acute treatment vs. chronic treatment decisions, etc.) may influence the impact of SDM on patient outcomes. Given the relatively small number of studies identified as eligible for study inclusion, we were not able to further categorize studies for this first systematic review.

We recognize that SDM (particularly patient perceptions of SDM) may not be limited to the context of one visit between a patient and clinician, but rather patient reports of SDM may be influenced by the prior relationship between the patient and clinician or by the influence of other parties in the decision.¹⁹ This is especially likely to be true in primary care and chronic disease contexts in which patients and their clinicians often make multiple decisions over the course of many visits. However, none of the studies identified here measured SDM across a long-standing

relationship, and thus we are unable to discuss how SDM may affect patient outcomes over time. Additionally, all of the studies reviewed here examined SDM in the context of a patient and clinician only, limiting our ability to examine the effects of having family members or others participate in decision-making.

Furthermore, the results and conclusions presented here may be influenced by publication biases. Although we were careful to review articles identified as eligible for inclusion for additional non-redundant references, we did not attempt to identify and include results from unpublished studies. Additionally, due to the diversity of patient outcomes assessed across studies we were not able to use meta-analysis methods. As consensus is built around the measurement of SDM and the patient outcomes most salient to SDM, future systematic reviews may be able to use a meta-analysis to formally combine and assess the evidence across studies.

Conclusion

Our review suggests that when patients report that they have participated in shared decision making, they are likely to enjoy better cognitive outcomes, such as improved satisfaction and less decisional conflict. Furthermore, patient reports are the only SDM measurement perspective found to be associated with patient health outcomes, albeit in a minority of those studies. The challenge with these findings is that we do not know what leads a patient to report a decision as shared, and thus do not know how to foster SDM and its associated benefits in practice. Thus, not only should future studies continue to address the impact of SDM across a continuum of patient outcomes and clinical settings, they should also address the methodological challenges associated with such evaluations. Patients increasingly report a desire to engage in shared decision making, and SDM remains an important tool to promote patient

autonomy and satisfaction. However, our findings indicate that the link between SDM and patient behavioral and health outcomes has yet to be fully established.

Table 2.1: Summary of included studies by SDM measurement perspective

First Author	Year	Diseases context	n	Design	SDM Measurement	Patient outcomes measured	Summary of results	Quality rating
			(patient; provider if reported)				SDM associated with: (unless noted the association was significant in the expected direction in a multivariate model)	SAQOR score and rating
Patient self-reported SDM								
Brody	1989	Primary care, various	117	Survey at baseline, 1 day, and 1 week post-consultation	1-item variant of Control Preference Scale (CPS)	Sense of personal control; concern regarding illness; satisfaction with the physician; expediting discomfort; experiencing dysfunction; symptom improvement; general medical improvement.	SDM associated with greater sense of personal control, lower post-visit levels of concern regarding illness, less discomfort, greater symptom improvement and greater improvements in overall medical condition one week after visit. No association between SDM and experiencing dysfunction one week after visit.	4 Moderate
Lerman	1990	Primary care, various	83	Cross-sectional survey after primary care visit	13-item Perceived Involvement in Care Scale (PICS)	Satisfaction with the art of care; satisfaction with the technical aspects of care; understanding about illness; reassurance regarding health status; perceived control over medical problem; predicted discomfort; predicted functional capacity	SDM associated with satisfaction with the technical aspects of care, understanding about illness, reassurance regarding health status, perceived control over medical problem, and predicted functional capacity. No association between SDM and satisfaction with the art of care or predicted discomfort.	3 Moderate
Chambers	1999	Asthma (primary care)	394	Cross-sectional survey, SDM questions are not about one specific interaction	1-item variant of CPS	Regular use of inhaled corticosteroids	SDM associated with regular use of inhaled corticosteroids as prescribed.	3 Moderate

Gattellari	2001	Cancer, various	233; 9	Audio-recorded consultation and surveys at baseline, immediately after consultation, 1 week, and 2 weeks post-consultation	1-item variant of CPS	Anxiety immediately after the consultation; anxiety 2 weeks after the consultation; satisfaction with the consultation; satisfaction with the information and emotional support received; recall of information.	SDM associated with satisfaction with the consultation and satisfaction with the information and emotional support received. No association between SDM and anxiety at either time point or recall of information.	6	High
Golin	2002	Diabetes	198	Face-to-face interviews before and after consultation	9-item Facilitation of Patient Involvement in Care Scale (FPI)	Satisfaction with the visit	SDM associated with satisfaction with the visit. In a subgroup analysis, this association was found to be true only for women.	4	Moderate
Heisler	2002	Diabetes	1431	Cross-sectional mailed survey	4-item Provider Participatory Decision-Making Style Scale (PDMstyle)	Patient-reported diabetes self-management	In separate multivariate analyses, both components of SDM are positively associated with patient-reported diabetes self-management. When both components of SDM are included in one model, only information giving remains significant.	3	Moderate
Keating	2002	Breast cancer	1081	Cross-sectional phone survey	1-item rating of decision making role developed for this study	Satisfaction with treatment information provided; satisfaction with treatment choice; receipt of breast conserving surgery (versus mastectomy)	SDM associated with satisfaction with the amount of treatment information provided. There was no association between SDM and satisfaction with treatment choice or receipt of breast conserving surgery.	3	Moderate

							No association in multivariate analysis.	
Heisler	2003	Diabetes	127; 50	Cross-sectional survey of patient and physician	1-item variant of CPS	Number of treatment strategies agreed upon by patient and provider	In a bivariate analysis, SDM is positively associated with the number of treatment strategies agreed upon by the patient and provider. After multivariate adjustment, the association was no longer significant.	4 Moderate
Legare	2003	Menopause	167	Cross-sectional survey of both the patient and physician immediately after consultation	1-item variant of CPS	Difference between physician and patient decisional conflict	SDM associated with the physician experiencing greater decisional conflict that then patient (unexpected direction).	3 Moderate
Ananian	2004	Breast cancer	181	Cross-sectional survey after decision before surgery	1-item variant of CPS	Decision about surgery (mastectomy alone or mastectomy with reconstruction); Decision about timing of reconstruction among those receiving mastectomy with breast reconstruction (immediate or delayed reconstruction)	No associations in multivariate analysis. In bivariate analysis, SDM associated with choice of having breast reconstruction .	2 Low
Lantz (Also Katz 2005; Bleicher 2008)*	2005	Breast cancer	1633	Cross-sectional mailed survey study on average 7 months after diagnosis	1-item variant of CPS	Satisfaction with surgery received; satisfaction with decision process; decisional conflict; decision about surgery (mastectomy or breast conserving surgery)	SDM associated with greater satisfaction with surgery received, greater satisfaction with the decision process, and less decisional regret. Patients who reported SDM were more likely to receive mastectomy. In a subgroup analysis, this association was only supported for white women and not for racial groups (Katz).	4 Moderate

						Satisfaction with decision 6 months after surgery; current satisfaction with decision; current breast cancer concern; current depressive symptoms	SDM (versus patient-controlled decisions) associated with lower satisfaction 6 months after surgery and lower current concern about breast cancer.	4
Nekhlyudov	2005	Breast cancer	431	Cross-sectional mailed survey study	1-item variant of CPS		No associations between SDM and current satisfaction or current depressive symptoms.	Moderate
Thapar	2005	Epilepsy	975; 115	Cross-sectional survey study; Secondary analysis of RCT	Not described beyond "patient-rated shared decision making"	Satisfaction with physician care of epilepsy	SDM associated with satisfaction with physician epilepsy care.	3 Moderate
Clever†	2006	Depression (primary care)	1706	Survey at baseline, 6, 18, and 24 months post-consultation; Secondary analysis of 4 RCTs combined	1-item rating of involvement in decision making developed for this study	Receipt of guideline concordant depression care (antidepressant medication or counseling); depressive symptoms	SDM associated with receipt of guideline concordant depression care and resolution of major depression symptoms over 18 months of follow up.	6 High
Loh	2006	Depression (primary care)	207; 30	Longitudinal survey study - data collected at initial consultation and 6-8 weeks later	6-item patient participation scale first used by Mah-Son-Hing et al. 1999	Depressive symptoms; treatment adherence	SDM associated with treatment adherence.	4 Moderate
Mandelblatt	2006	Breast cancer	718	Cross-sectional in-person survey	4-item subscale of PICS	Decision about surgery (mastectomy or breast conserving surgery); receipt of adjuvant therapy; satisfaction with care; impact of breast cancer on life	SDM associated with adjuvant treatment use, satisfaction with care, and with impact of breast cancer on life (unexpected direction).	4 Moderate
							In a subgroup analysis, SDM only associated with adjuvant treatment use among women aged 67 to 74, and not among those aged 75 and older.	4 Moderate
							No association between SDM and decision about type of surgery.	4 Moderate

Swanson†	2007	Depression (primary care)	1317	Survey at baseline, 6, 18, and 24 months post-consultation; Secondary analysis of 4 RCTs combined	3-item rating of involvement in SDM developed for this study	Satisfaction with care	SDM associated with satisfaction with care.	5 High
Mahone	2008	Serious mental illness	85	Cross-sectional survey; Secondary analysis of 4 RCTs	1-item variant of CPS	Medication adherence in the past one month; medication adherence in the past 6 months; quality of life	No associations.	3 Moderate
Deinzer	2009	Hypertension (primary care)	86; 15	Prospective controlled clinical trial	Combined Outcome Measure for Risk Communication and Treatment Decision Making Effectiveness scale (COMRADE)	Blood pressure (diastolic and systolic)	No association. In a subgroup analysis, patients with a high interest in participating in SDM who reported an increase in SDM had a decrease in diastolic and systolic blood pressure.	3 Moderate
Hawley	2009	Breast cancer	1651	Cross-sectional mailed survey	1-item variant of CPS	Receipt of mastectomy as the initial surgery treatment	No association between SDM and rates of mastectomy as the initial surgery in multivariate model. In bivariate analysis, women who reported SDM were less likely to receive mastectomy initially than those who reported a patient-based decision.	4 Moderate

Janssen	2009	Serious injury, various	90	Cross-sectional survey	4-item scale measuring SDM as part of the larger Cologne-Patient-Questionnaire (CPQ)	Self-rated health: "Would you say your health in general is excellent, very good, good, fair, or poor?"	SDM associated with better self-related health. SDM associated with decreased decision conflict.	4 Moderate
van den Bergh	2009	Prostate cancer	129	Cross-sectional mailed survey study	1-item rating of involvement in decision making developed for this study	Decisional conflict; depressive symptoms; generic anxiety; prostate cancer specific anxiety	No association between SDM and depressive symptoms, generic anxiety, or prostate cancer specific anxiety.	5 High
Burton ‡	2010	Heart disease	85	Surveyed before and after consultation. Med students observed interaction and coded using OPTION scale	13-item PICS	Confidence in the decision	SDM associated with confidence in decision.	2 Low
Ommen	2011	Injury or illness requiring hospitalization, various	2197	Secondary analysis of a cross-sectional, retrospective mailed survey study	4-item scale measuring SDM as part of the larger CPQ	Trust in physician	SDM associated with trust in physician.	3 Moderate
Glass	2012	Various	499	Secondary analysis of a cross-sectional survey study	9-item SDM-Q-9 scale	Satisfaction with decision	SDM associated with satisfaction with the decision.	4 Moderate
Johnson§	2012	HIV	254	Cross-sectional analysis from a longitudinal cohort study	1-item variant of CPS	Health care empowerment	SDM is positively associated with health care empowerment.	2 Low
Johnson§	2012	HIV	148	Cross-sectional analysis of a larger RCT	1-item variant of CPS	Health care empowerment	No association.	2 Low
Lim	2012	Breast cancer	206	Secondary analysis of a cross-sectional survey	1-item variant of CPS	Exercise, diet, stress management behaviors	SDM is positively associated with engagement in exercise. No association between SDM and diet or stress management.	2 Low

Mo	2012	Terminal cancer	93	Cross-sectional survey	2-item rating of involvement in decision making developed for this study	Physical functioning; emotional functioning; quality of life; quality of death	No associations.	3 Moderate
Schleife	2012	Breast cancer	107	Cross-sectional survey	1-item rating of involvement in decision making developed for this study	Anxiety and depression; quality of life	No associations. No association.	3 Moderate
Schoenthaler‡	2012	Diabetes	608;41	Cross-sectional mailed survey of patients and physicians and review of electronic health record	13-item PICS	Medication adherence	In an additional analysis there was a significant interaction effect between social support and SDM so that the association between patient perceptions of SDM and medication adherence was stronger as social support increased.	4 Moderate
Thum	2012	Serious injury, various	91	Cross-sectional analysis of a larger RCT	3-item scale measuring SDM as part of the larger CPQ	Trust in physician	SDM associated with trust in physician.	3 Moderate
Wallen	2012	Rheumatic disease	109	Cross-sectional survey study	3-item rating of involvement in SDM as part of the larger Complementary and Alternative Medicine Use in Arthritis (I-CAMP) questionnaire	Use of complementary and alternative medicine (CAM); disclosure of use of CAM to provider	SDM associated with use of CAM and disclosure of use of CAM to provider.	2 Low
Clinician self-reported SDM								

						Satisfaction with provider communication; receipt of dilated eye exams; assessment of A1c; assessment of lipids; elevated A1c; elevated lipids; elevated systolic blood pressure		4	
Heisler	2009	Diabetes	4198; 1217	Cross-sectional mailed survey and medical record review	1-item variant of CPS	No associations.		Moderate	
								4	
Schoenthaler‡	2012	Diabetes	608;41	Cross-sectional mailed survey of patients and physicians and review of electronic health record	9-item Self-Assessment Questionnaire	Medication adherence	No association.	Moderate	
Observer rated SDM									
					OPTION scale (codes for 12 physician communication behaviors), consultation was audio recorded and coded			2	
Goossensen	2007	Mental Illness	61;8	Audio-recorded visits with post-consultation surveys		Satisfaction with involvement in decision	No association.	Low	
								2	
Burton‡	2010	Heart disease	85	Surveyed before and after consultation. Med students observed interaction and coded using OPTION scale	OPTION scale, consultation was observed and coded	Confidence in the decision	No association.	Low	
								5	
Singh	2010	Cancer, various	63	Audio-recorded visits with pre- and post-consultation surveys	Coding system containing 20 physician communication behaviors developed for this study	Satisfaction with consultation; anxiety	No associations.	High	

Politi	2011	Breast surgery - both prevention and cancer treatment	57	Patient visits were observed and rated on the OPTION scale, patients completed 2 surveys (immediately after consultation and 1-2 weeks late via phone)	OPTION scale, consultation was observed and coded	1. Decision satisfaction; treatment decision consistent with recommendation from physician; aggressiveness of treatment chosen	No associations.	3 Moderate
Smith (Also Butow 2010)	2011	Breast cancer	55	Audio-recorded visits with pre-consultation surveys and then follow up mailed surveys at 2 weeks and 4 months post-consultation	OPTION scale, consultation was audio recorded and coded	Post-consultation anxiety; decisional conflict; satisfaction with the consultation; satisfaction with the physician's SDM skills; satisfaction with decision (after 2 weeks); satisfaction with the decision (after 4 months)	SDM positively associated with satisfaction with the decision after 4 months and satisfaction with the physician's SDM skills. No association between SDM and post-consultation anxiety, decisional conflict, satisfaction with the consultation, or satisfaction with decision after 2 weeks.	5 High
Langseth	2012	Heart disease	49; 2	Audio-recorded visits with post-consultation surveys	OPTION scale, consultation was audio recorded and coded	Treatment decision (invasive or non-invasive)	SDM associated with choice of non-invasive treatment.	2 Low

* In two cases, the results from one study were published separately in two articles, but the patient outcomes evaluated as well as the measurement of SDM used overlapped entirely [Butow and Smith; Bleicher and Katz]. The results for each of these pairs of publications are considered only once in the context of this review.

† Two publications [Clever and Swanson] are secondary analyses of the same sample, but use different measures of SDM modeled with different outcomes. Each unique SDM measurement and patient outcome assessment is listed separately here and throughout the review.

‡ Two studies measured SDM from multiple perspectives. Each unique SDM measurement and patient outcome assessment is listed separately here and throughout the review.

§ Johnson et al., 2012 report the results from two separate studies in one publication. Each study is listed separately here and throughout the review.

Chapter 3: The complexities of understanding patient perceptions of shared decision making

Abstract

Introduction: Shared decision making (SDM) has been advocated as an optimal approach to making health care decisions, both on ethical grounds and increasingly as a means to improve patient outcomes. However it is not clear how patients perceive SDM and what leads patients to label a decision as shared.

Methods: In-depth, qualitative interviews were conducted with 23 patients who recently attended a non-follow up primary care appointment. Patients were asked about the meaning of SDM and about specific recent decisions that they labeled as shared. Interviews were coded using a qualitative content analysis approach.

Results: Patients' conceptual definition of SDM included four components of an interactive exchange prior to making the decision: both doctor and patient share information, both actively listen to one another, patients advocate for themselves, and physicians make personalized recommendations. Additionally, a long-term trusting relationship helps to foster SDM. In contrast, when asked about why a specific, recent SDM was labeled as shared patients described interactions that ranged from very simple recommendations through complex interactions. Common among all decisions labeled as shared was that the patient and physician ultimately agreed on the decision.

Conclusions: It seems there is no one-size-fits all process that leads patients to perceive a decision as being shared. Rather, the outcome of "agreement" may be more important than the actual decision making process used to reach that agreement when patients label a recent decision as shared.

Introduction

Increasingly, clinicians are being encouraged to employ a shared decision making (SDM) process with patients. Both the National Cancer Institute and the U.S. Preventive Services Task Force, among other organizations, have advocated for the use of SDM.^{2,3} SDM has been suggested as an optimal approach to making health care decisions,¹ first on ethical grounds and increasingly as a means to improve patient outcomes.⁹⁷⁻⁹⁹

Despite this increasing attention, what exactly constitutes a shared decision making process is not always clear. Among the academic literature, the most commonly cited definition of SDM is that developed by Charles and colleagues.^{4,5} This definition includes four key characteristics, all of which must be present for a decision-making process to be labeled shared: at least two participants (patient and physician) are involved in all phases; both parties share information; both parties express treatment preferences; and agreement is reached.^{5,100} But there are a variety of ways that SDM has been measured, including patient self-reports of having participated in SDM, physician self-reports, and structured coding of patient-physician communication.^{11,101} Among these, only patient-self reports of SDM have been consistently associated with patient outcomes, including greater patient satisfaction, less decisional conflict, and medication adherence.¹⁰¹

Across studies, the most common way of measuring patient perceptions of SDM is using a modification of the Degner et al. (1997) Control Preferences Scale.^{12,101} This scale asks patients to rate their role in making a specific decision among five choices: (1) I made the final decision, (2) I made the final decision after seriously considering my doctor's opinion, (3) My doctor and I shared the responsibility for deciding, (4) My doctor made the final decision but

seriously considered my opinion, and (5) My doctor made the final decision. Option 3 is typically considered a shared decision, and has been associated with patient outcomes including symptom improvement in primary care patients,⁵¹ medication adherence,⁵² and satisfaction with the consultation,³⁷ among others. The single-item instrument for ascertaining patient perceptions of SDM leaves the process in a black box without out a clear understanding of what SDM means to patients.

Furthermore, studies have repeatedly found that patient perceptions of shared decisions differ from both observer ratings of SDM,^{19,94,102,103} and physician perceptions of SDM.^{23,104} Thus in order to attain the benefits of SDM in practice, a greater understanding of the patient perspective on SDM is needed. We know of only two studies that have directly explored the meaning of SDM to patients.^{21,22} While these studies highlighted important differences between patient perceptions of shared decision making and published definitions of SDM, they were not designed to understand what needs to have happened in a specific decision making context for a patient to label it as a shared decision. Thus, while it is known that patient reports of SDM are what drive the link between SDM and outcomes,¹⁰¹ it is unclear whether patient perceptions of SDM about a specific, recent decision are related to their perceptions or ideals about SDM.

The aims of this qualitative study are: (1) to develop a conceptual model of patient-defined SDM, (2) to compare this conceptual definition with patient descriptions of a specific, decision-making process they labeled as shared on the modified Control Preference Scale and, (3) to contrast patient perceptions with Charles et al.'s theoretical model of SDM.

Methods

Study setting and participant recruitment

Participants were recruited from an academic and safety net health system in Virginia. The health system's electronic scheduling system was queried to identify adults aged 50 to 75 years with a non-follow-up primary care visit in the general internal medicine or family medicine out-patient clinic scheduled in the next month. Among these age-eligible patients, the electronic medical record was queried for those who were due for colorectal cancer screening as specified by the U.S. Preventive Services Task Force.²⁴ These patients were mailed a letter of study introduction two weeks prior to their scheduled appointment. Within one week after their scheduled appointment, patients who had not declined participation were contacted via telephone by the principal investigator (LAS). At that time, eligibility was confirmed and among those eligible and agreeing to participate, verbal consent was obtained. Recruitment continued until theoretical saturation was met.¹⁰⁵ All aspects of the study were approved by the Virginia Commonwealth University internal review board.

Data collection

Study participation entailed completion of one telephone interview lasting approximately 45 minutes. The interviews were conducted by the principal investigator (LAS) using a semi-structured interview guide. (See Box 3.1 for specific questions from the interview guide used in this analysis; see Appendix A for full interview guide.) Participants were first asked to recall and describe any decisions made in their most recent primary care appointment. They were then asked to indicate how the decision was made using the modified Control Preferences Scale,¹² and to describe what during the visit led them to perceive that the decision was made this way. Following these questions, participants were asked about the meaning of SDM more broadly,

with the question, “Now, thinking more generally, this doesn’t have to be about your recent visit with [your doctor]: What does the phrase “My doctor and I shared responsibility in deciding,” mean to you?” Finally, participants were asked about their perceptions of the patient and physician responsibilities in a SDM process. All interviews were audio-recorded.

Box 3.1: Selected questions from semi-structured interview guide

1. Let’s start by talking about some of the topics that you and Dr. __ discussed during your most recent visit. Please tell me what topics you discussed.
2. Were any decisions made about any of these topics? Which ones?
3. I’d like to hear more about the decision about <topic>? How was that decision made?
4. Now I am going to read you 5 choices for how the decision was made. There are no right or wrong ways to make the decision, so none of these choices are better or worse.
5. When it came to making the decision about <topic>, which of these would you say would best describe how the decision was made?
 - a. I made the final decision.
 - b. I made the final decision after seriously considering my doctor’s opinion.
 - c. My doctor and I shared the responsibility for deciding.
 - d. My doctor made the final decision after seriously considered my opinion.
 - e. My doctor made the final decision.
6. What makes you feel that the decision about <topic> was <type of decision chosen in Question 4>?
 - a. What specific things happened during the visit that made you feel that <type of decision chosen in Q4>?
 - b. What specific things did your doctor do or say that made you feel this way?
 - c. What specific things did you do or say that made you feel this way?
 - d. If someone were to have audio-recorded or video-recorded your visit with Dr. X, how would they have known from the audio or video that the decision was <type of decision choices in Q4>?
7. Now, thinking more generally, this doesn’t have to be about your recent visit with Dr. X. What does the phrase “My doctor and I shared responsibility in deciding” mean to you?
8. What things must you, as a patient, do during the conversation for you to consider a health care decision to be shared between you and the doctor?
9. What things must the doctor do during the conversation for you to consider a health care decision to be shared between you and the doctor?

Data analysis

Prior to analysis, all audio-recordings were transcribed. A qualitative content analysis approach was used to analyze interview data. Coding and analysis occurred concurrently with subsequent interviews and proceeded in three phases: immersion, reduction, and interpretation. ¹⁰⁶ During immersion, audio-recordings were listened to and transcripts read several times to identify emerging themes. The reduction phase consisted of creating initial codes, developing a coding scheme, and coding the interviews using ATLAS.ti. Coding consisted of both a priori codes informed by prior literature on SDM and inductive codes using the patients' own words about SDM. The principal investigator developed a preliminary coding scheme early in the analysis process and, in discussion with the coauthor, revised it using an iterative process as new relevant themes arose (see Appendix B for full list of codes). Once the conceptual model of patient-defined SDM was developed, the patient descriptions of decisions made during their recent primary care visit were coded with the same codes to allow for comparison of responses. The interpretation phase consisted of reorganizing the data into categories that help address the research questions and drawing conclusions from the data. ¹⁰⁶ Memos were kept throughout the process to document the decisions made and help with interpretation. ¹⁰⁵

Results

Sample characteristics

A total of 60 patients were identified as potentially eligible, mailed a letter of study introduction, and called to assess willingness and eligibility. Among these, 21 were not reachable by phone, 14 declined participation, and two wished to participate but were ineligible due to not attending their recently scheduled primary care visit. In total, 23 patients were

interviewed. Table 3.1 provides the characteristics of each patient in the sample. Patient participants were primarily female (61%) and Caucasian (74%). The mean participant age was 63 years (SD = 10.4).

Table 3.1: Sample characteristics

ID	Age	Sex	Race*	Clinic*	Number decisions made	Context of decisions identified by patients
1	68	Female	C	GIM	2	Colonoscopy, Bone Density Scan
2	58	Female	AA	GIM	2	Elevated cholesterol, high blood pressure
3	57	Female	C	GIM	2	Mammography, elevated cholesterol
4	54	Female	AA	GIM	0	
5	53	Female	C	GIM	1	Hormone replacement therapy
6	70	Male	C	GIM	0	
7	60	Female	C	GIM	1	Insomnia treatment
8	58	Female	C	GIM	1	Referral to GI specialist
9	51	Male	C	GIM	1	Colonoscopy
10	53	Male	AA	FM	1	Dryness of nose
11	51	Male	AA	FM	1	Referral for sleep study
12	71	Female	C	GIM	2	Colonoscopy, referral to orthopedics
13	55	Male	AA	GIM	3	Routine blood work, back pain, HIV testing
14	57	Male	C	GIM	1	Shingles vaccine
15	61	Female	C	GIM	1	Bloodwork for liver function
16	77	Male	C	GIM	2	Pain medication, referral to allergist
17	66	Female	C	GIM	1	High blood pressure
18	66	Female	C	GIM	3	Hormone replacement therapy, abdominal ultrasound, referral for genetic counseling
19	61	Female	C	GIM	1	Colonoscopy
20	60	Male	AA	GIM	1	Referral to specialist for poor circulation
21	66	Female	C	GIM	3	Foot injury, arthritis treatment, routine blood work
22	67	Female	C	GIM	2	Diet planning, hormone replacement therapy
23	74	Male	C	GIM	1	PSA

*Race is abbreviated as AA for African American and C for Caucasian. Clinic refers to the type of practice that the patient attended for their most recent primary care appointment and is abbreviated as GIM for general internal medicine and FM for family medicine.

Patients' conceptual definition of shared decision making

When asked about the meaning of shared decision making in general, respondents described two key phases of SDM: an interactive exchange and making the decision. The interactive exchange phase consisted of four interdependent components: sharing information, active listening, patient self-advocacy, and a personalized physician recommendation (Figure 3.1). Additionally, a cross-cutting theme emerged that spanned across the phases of SDM and, which patients describe as being essential: the need for a trusting relationship that extends beyond a single encounter. No differences were noted in patient conceptual definitions of SDM by patient age or race. The following section describes these phases and related themes of patient perceptions of SDM.

Phase 1: An interactive exchange

All patients described SDM as a collaborative process in which both the patient and physician are active participants. Patients described four iterative components that make up the interactive exchange phase of shared decision making: a mutual exchange of information, active listening, patient self-advocacy, and the physician making a personalized recommendation.

Component 1: Mutual exchange of information

Patients nearly unanimously brought up the importance of a mutual exchange of information in which the patient shares any relevant concerns or problems and the physician shares medical and treatment information. This interactive information exchange process included “input from both sides” (Pt18). Patients described specific roles for both themselves and for physicians in the exchange of information.

First, patients are responsible to describe their symptoms and health concerns to their physician, so that their physician had the basic knowledge to begin forming a recommendation.

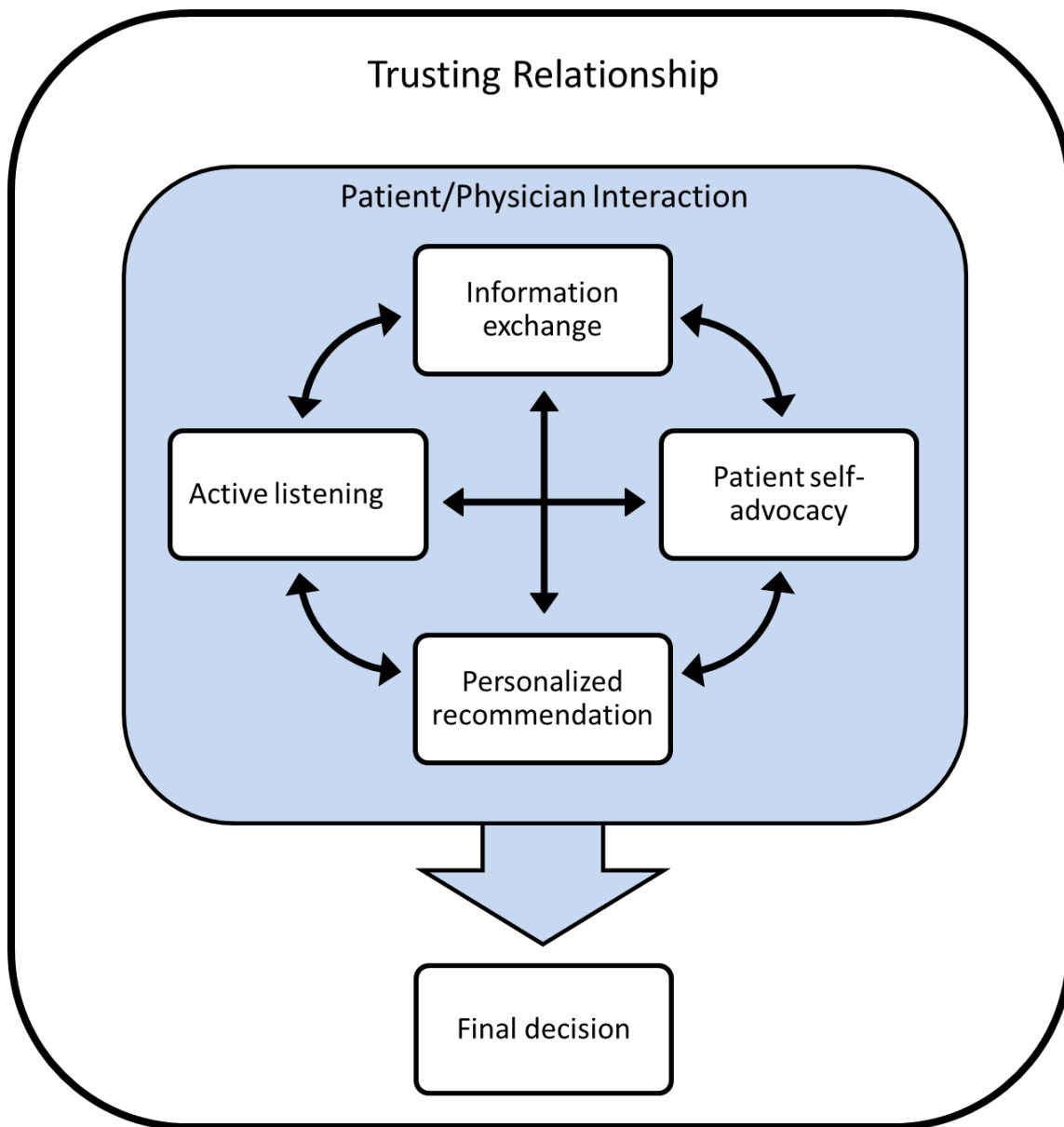


Figure 3.1: Patients’ conceptual definition of SDM

For example, one patient said, “They can’t read your mind. If you don’t go in on your visit and tell them everything that’s going on for whatever your problem happens to be, they can’t really help you,” (Pt22). Beyond simply describing symptoms, patients acknowledged a need to be

completely open with their physician about anything that might affect their health, even if the topic is uncomfortable. Many patients brought up the concept of “honesty”, noting its importance in reaching the best possible decision. One patient described this with, “The patient needs to have shared everything that's going on that might possibly be contributory to whatever's happening, whether that's casual drug use or whatever... I think you'd have to have made the decision to be open and honest with the physician,” (Pt17). Another said, “You (need to) be honest with the doctor. Just like a priest. You can tell the doctor everything. And you should, because they cannot treat you to your best advantage if they don't know everything.” (Pt 8)

Patients acknowledged that physicians also have the responsibility to share information. Specifically, according to patients, physicians should share any relevant medical information and treatment options, taking the time to clearly explain in language that is understandable to patients. One patient described this, saying that it is important, “that your doctor tell you what's going' on, explain your options to you,” (Pt13). Another described the importance of the physician taking the time, “to explain what I had, to explain the medication. So, I knew exactly what it was for, how to use it,” (Pt 10).

Component 2: Active listening by both parties

In addition to sharing information, many patients specifically described listening as an important component of SDM. Patients were clear in their beliefs that both physicians and patients bring their own specific expertise to the interaction. Physicians bring medical expertise and training while patients have unique knowledge about their own body and symptoms. Thus, acknowledging the physician's medical expertise, patients stated that they should listen and be open minded about what the physician says.

“I have to be very open and honest to her and I also have to be open minded enough, and I know that this is hard sometimes for me, open minded enough that if she recommends

something that's a little unusual that I really need to seriously consider that because I know she's doing what she feels is best for me.” (Pt8)

Likewise, patients stated that physicians should also take the time to listen to and understand patients. This takes the form of an interactive conversation rather than the physician simply providing medical information. Patients described two ways that they understood physicians to be listening to them. First, when a physician makes time to talk with a patient on a more personal level, this helps the patient to be assured that the physician sees them as an individual person with unique circumstances and needs. Patients desired to see this type of active listening throughout the visit, not only during the discussion about the particular decision at hand.

“I think they just have to be very open and not rush and talk so fast and talk in ‘doctor-ese’ that you don't understand them-that if they can just look at you and-like you're a person and not patient number 93.” (Pt15)

Second, patients wanted physicians to respect the expertise that they bring to the visit. To do this, physicians should carefully listen to patients, solicit their thoughts and concerns, and take time to answer questions before forming a recommendation.

“The doctor has the training and the knowledge and everything, but I feel that the doctor needs to listen to the patient, listen to what they're saying. The doctor sees you for half hour, 15 minute appointments or whatever... you live with yourself” (Pt2)

Component 3: Patient self-advocacy

Patients described a responsibility to advocate for themselves throughout the SDM process. This may consist of asking questions if clarification is needed, guiding the conversation if the physician gets off track, sharing opinions, and speaking up if there are hesitations or disagreements. As one patient stated, “if you don't feel right about something; don't be afraid to challenge that doctor to get the information that you really want to have,” (Pt 4). Similarly, another said, “If you have a doubt, talk about it. Be prepared with questions. If it's something

serious, have your questions down. Don't be afraid,” (Pt7). Like active listening, patients described the importance of these self-advocacy behaviors not only during the decision-making process, but also extending to all parts of the visit. By engaging in this way, patients viewed themselves as actively contributing to the formation of the best possible decision.

Component 4: Physician makes a personalized recommendation

Most patients seemed to take it for granted that physicians should provide a recommendation for action, whether for treatment or no treatment, during the discussion. However, they had specific thoughts about how these recommendations should be made. First, patients wanted to feel the physician knew and understood them before making the recommendation. As one patient put it, “I don't want doctors telling me what's best for me without me knowing that they understand what's best for me from my point of view,” (Pt7).

In order for patients to feel confident that these recommendations are based on the individual patient and their unique situation, rather than relying only on what the physician typically recommends, patients reported that physicians must take the time to explain the reasoning behind their recommendations. For example, one patient said they'd like physicians to “explain the reason for a certain procedure or an appointment with a specialist or whatever. It's helpful to me, and I think it would be for most patients, to understand why something is being suggested,” (Pt 12). Patients want to understand both the benefits of the treatment or procedure in general as well as why it is specifically recommended for them. Additionally, the words that physicians use to make the recommendations to patients affect patients' perceptions of SDM. Patients stated that they want physicians to make suggestions or give options, not demands or ultimatums. One patient gave an example of how this type of personalized recommendation might play out in practice:

“The doctor has to be willing to defer somewhat what might be convenient for him or something that he’s more comfortable doing... I just think there has to be a lot of interaction and dialog rather than just dictating orders to patients. Like we’re going to put you in the hospital tomorrow and we’re going to do this and we’re going to do that. Let’s slow down here a minute and let’s talk about this. How about if I put this off for a month? What’s the consequence of doing that? How about we don’t put me in the hospital at all? The patient’s got to be active. Being active, the doctor’s got to be receptive to that and willing to work-willing to take the time that’s necessary to explain if he has strong views about why that idea is the best one.”(Pt14)

Phase 2: Making the decision

Following the collaborative exchange between the patient and physician in which information was shared and a personalized recommendation was provided, patients then said that a decision is made that is in the best interest of the patient. Patients generally described one of two perspectives about how the decision was made. About half of the patients (n=11) described decision making as mutual between the patient and physician. One patient described the decision-making process with, “You and your doctor talk over all the options and come up with a shared thought about what’s the right way to do it,” (Pt1). Another said, “Well, for me that means that we thoroughly talk about any issues, concerns that I have and he has, and that we come to some agreement around treatment or non-treatment or whatever we’re going to do.” (Pt6)

The other half of patients (n=12), however, stated that ultimately the patient always decides, even in a SDM process. These patients acknowledged that the patient has to take final responsibility, even if they shared in the communication process leading to the decision. One patient said, “It’s a collaborative thing, but I mean I clearly feel that it’s my decision. I also assume that my doctors share that assumption... but yeah I’m the decision maker” (Pt16).

Another patient described the distinction between a shared process and the final decision with,

“I’m thinking sharing, that’s the way it should be. I mean they can give you their opinion, but it’s something that you’ve got to live with. I mean, I know you’re going to

them because they went to school for many years or whatever, but ultimately it's still your life and your body.” (Pt20)

Crosscutting Theme: Trusting relationship built over time

Patients also pointed to the importance of a strong rapport when describing SDM.

Prominent among this was the need for the patient to trust that the physician knows them and understands their health care needs and preferences. As described by patients, the building of this trust is not confined to the communication around a particular decision itself, but is built over time and extends beyond a single visit. As one patient stated,

I think you just have to find a doctor you trust, not because he's the best doctor out there and somebody else recommended him. That's nice, but what's the sense of having the best doctor out there if you don't have trust in him and you can't talk to them, you know? (Pt 7)

A trusting relationship allows for both patient and physician to feel comfortable throughout the collaborative exchange to speak up if they are uncomfortable, and for a high quality, personalized decision to be made. One patient described how this trusting relationship with his physician helps him to make high quality decisions.

It's wonderful that I have a strong relationship with [my doctor] because I think those are the kinds of relationships that are hard to come by these days in medical care. I think he's especially good at making sure that I'm comfortable with decisions. There have been occasions where he's sensed that I have some concerns, and he's gone ahead and referred me when I suspect that he's been fairly sure about his decisions, but he wants to make certain that I'm comfortable, and he's comfortable too. (Pt6)

Decision-making processes that patient label as shared

Patients were also asked to describe any decisions that they made in their recent primary care appointment. A total of 33 unique decisions were described across the 23 interviews. The reported number of decisions made during the recent primary care visit ranged from zero to three, with a median of one decision per visit. The context of the decisions was varied and included decisions about adding or changing medications (n=11), ordering diagnostic tests (n=

9), referrals to specialists (n=5), cancer screening (n=4), ordering “routine” blood work (n=2), prescribing a vaccine (n=1), or changing health behaviors (n=1). Of these 33 decisions, 15 (45%) were reported as being shared decisions on the modified Control Preference Scale¹² (option 3), 13 (40%) were reported as patient-led decisions (option 1 or 2), and 5 (15%) physician-led decisions (option 4 or 5).

Across the 15 decisions that patients labeled as shared, the level of communication between the patient and physician described by patients as having occurred varied greatly, ranging from extremely short and simple exchanges to lengthy discussions. The only commonality found across the 15 decisions that patients labeled shared was that the patient and physician ultimately came to an agreement. Further analysis revealed three general patterns of communication: simple agreement by the patient to a physician recommendation, patient pushback to a physician recommendation, and a patient-led recommendation. In this section we apply the phases and themes of patients’ conceptual definition of SDM to the patient descriptions of the specific decisions that they labeled as shared within each of the three general patterns of communication.

For a third of the decisions labeled as shared (n=5), patients described a straightforward process in which their physician made a recommendation and the patient simply agreed. In this situation, very little communication exchange seemed necessary to consider the decision to be shared. In these cases of simple agreement, the only component of the patient conceptual definition of SDM that was reported was a physician recommendation. However, even these recommendations did not meet the full requirements of a personalized recommendation where the physician explained both why the procedure is suggested in general and for the individual patient in particular. Rather, patients described very straightforward recommendations without

an active exchange of information. Below are two of these patient descriptions of decisions labeled as shared that included only simple interactions:

“She just said, if I hadn’t had [a bone density scan] in three years, and I said, oh, I know it’d been longer than three years. She said, “Well then I think you should have one,” and I said fine. That’s fine with me. So that’s a shared... She didn’t say to me, you have to have this. I mean, you know, we discussed it, and we both agreed. So that’s shared.” (Pt1)

“She said I would suggest as long as you fasted, you might as well take it [blood work for liver function] if you want. And so she was-and then when I said yes, she said that's a good idea. To me, I felt it was a mutual thing. I could have said, well, nah, let's wait until next six months and-but she said you might as well do it now.” (Pt15)

In other cases, a physician made a recommendation and the patient had questions or hesitation (n=6; 40%). After discussion, the two parties ultimately came to agreement, and this was also labeled as a SDM process. In this situation, patients described various levels of interaction that ranged from simple questions and recommendations to much more detailed discussions. These decisions most closely resembled the conceptual model of patient-defined SDM. That is, patients described some exchange of information, active listening on the part of the physician, patient self-advocacy (including questions of clarification, expressing differing opinions, and soliciting the physician’s opinion about alternative options), and all contained a physician recommendation. For example, one patient described the decision with the following:

“He said, given your history, I might like to consider medication [to lower cholesterol]... I felt that, at this point, I really don't want to take another medicine. I would like to try other methods before even considering going on medication... He listened to what I felt, my point of view or whatever. It wasn't a snap judgment, ‘Okay, your cholesterol is up and you're going to go on medication, and that's that.’ He listened and after discussion, and I said that I was reluctant to take medication at this time. He agreed, ‘Okay, we can wait and see how the other methods are working.’” (Pt2)

The third type of shared decision described by patients involved a patient bringing in a specific request for the physician (n=4; 27%). These situations differed from the conceptual SDM process described by patients, because the patient was the party who made the initial

recommendation. The communication process after the patient recommendation was typically described as being similar to those in the first category who had simple agreement with their physician. That is, very little communication exchange seemed to be necessary to label these decisions as shared.

“Well, I just I brought it up. I had been in my local pharmacy a couple months ago and I saw they were offering [the shingles vaccine] there... I’d had two scary incidents with shingles over the course of the last 20 years; both involving it appearing in my scalp and near my eyes. I wanted to-I’m very interested in getting that preventive vaccine so I don’t have another outbreak of it...He said, ‘I’ll be happy to write that prescription for you.’ I said, ‘Good, let’s give it a shot.’...I wanted to get it and he thought I needed it so it was a pretty mutual decision.” (Pt14).

Across all three of these interaction types, when asked about why a recent, specific decision was labeled as shared, the concept of a relationship of trust did not arise explicitly in the way that it did when patients described the process of SDM in general. Only one patient directly addressed trust when asked about why a specific decision was perceived as shared.

“She (was) sharing with me the medical complications of taking it or not taking it. I'm sharing with her some of the things that I know that might have influenced it. It's a give and take. I think both of us, if you would've heard that, it would've sounded like we were both being respectful of each other...Anyway, it has to do with trust that the other one is genuine-that we were jointly doing this. It's a trust issue, and I think you could hear that in the conversation.” (Pt 17).

However, for most patients, particularly those who described an interaction characterized by simple agreement with the physician, trust was not mentioned. In these conversations, however, the manner in which the patients described themselves as easily agreeing with physician recommendations implies some level of trust in the physician’s medical opinions (see descriptions of decisions above).

In summary, despite the diversity of interactions labeled as shared, two important commonalities existed. First, except where a patient brought in their own specific request for the physician, all discussions that patients labeled as shared included a physician recommendation

for treatment or non-treatment. Second, all patient-perceived shared decisions ended in agreement between the patient and physician. Furthermore, in the cases labeled as shared decisions where patients agreed quickly with the physician's recommendation, very little communication process at all was described. Thus, patient perceptions of having participated in a shared decision may be more about the outcome of agreement with a physician recommendation rather than any specific communication process.

Patient perceptions of SDM compared to Charles et al.'s theoretical model of SDM

When asked about the meaning of SDM in general, patients describe an interactive communication process that is similar to the commonly used definition of SDM developed by Charles and colleagues (1997, 1999). My findings point to the importance of active participation and a mutual exchange of information (see Table 3.2). However, in the hypothetical at least, patients state that they want physicians to listen if they have a treatment preference to express, but that expressing a preference is not a necessary component of SDM. Similarly, patients acknowledge that there are times when they may participate in a SDM *process* but ultimately not agree on the decision. Thus, patients' conceptual definition of SDM does not support the necessity of characteristics 3 and 4 (both participants sharing their treatment preferences and reaching agreement around the decision) in the Charles et al. definition in order for a decision to be considered shared. In contrast, when patients are asked to describe a specific, recent shared decision, there was no consensus about the specific communication content needed for a decision to be considered shared. Rather, patients focused on their agreement with a physician recommendation (Charles et al. characteristic 4).

Table 3.2: Comparison of patient conceptual definition of SDM to patient experiences with a recent shared decision and a theoretical definition of SDM

	Charles et al (1997, 1999)	Patient conceptual definition of SDM	Patient experiences with a recent, specific decision labeled as shared
Characteristics from Charles et al.			
Both patient and physician are actively involved	✓	✓	
Both patient and physician share information	✓	✓	
Both patient and physician share treatment preferences	✓		
Both patient and physician reach an agreement on decision	✓		✓
New communication components			
Both patient and physician actively listen to one another		✓	
Patient advocates for self throughout the visit		✓	
Physician makes a personalized recommendation		✓	
Rapport extending beyond a single encounter		✓	

In addition to these communication components, these findings contribute several new themes to patient definitions of SDM. First, when asked about their conceptual definition of SDM, patients described a desire for care that is tailored to the individual patient in their specific circumstances. In order to accomplish this, patients want to feel that the physician understands their individual needs and opinions and has used this understanding when making a recommendation among various medical options. They emphasized the importance of both patient and physician actively listening to one another and being open-minded to

recommendations outside of what they might be accustomed to doing if it is in the best interest of the individual patient. Second, patients described an important aspect of their role in SDM to be advocating for themselves. Self-advocacy includes such responsibilities as being prepared for the visit, asking hard questions, speaking up if there is hesitation, and ultimately asking for a second opinion if desired. Finally, in order for both personalized care and patient self-advocacy to be possible, patients in our study also described the importance of a trusting relationship that is built over time, and extends beyond a single encounter.

Discussion

Patient perceptions of the meaning of shared decision making about a recent, specific decision differ from their conceptual definition of SDM. When asked about SDM in general, patients described two phases: an interactive exchange and making a decision. The interactive exchange is a collaborative process that includes four interdependent components: sharing of information, active listening, patient self-advocacy, and a personalized physician recommendation. On the other hand, when patients labeled a recent, specific decision as being shared, they described a variety of communication processes ranging from simple agreement with little or no discussion, through a more interactive process similar to that which would be labeled as SDM using currently accepted definitions. Common across all decisions perceived as shared was ultimate agreement between the patient and physician. Thus, while patient conceptual definitions of SDM center around interactive communication processes, patient perceptions of having participated in a shared decision may be more related to the outcome of agreement with a physician recommendation rather than any specific communication process that led to this agreement.

These findings have implications for both the measurement of SDM as well as intervention design. Results from my interviews indicate that SDM, when measured by instruments such as the modified Control Preference Scale, likely does not reflect patient perceptions about the communication process itself. Thus, if the purpose of a study is to understand patient's perceptions of a communication process, the modified Control Preference Scale may not be an appropriate tool. Degner's Control Preference Scale was designed to measure preferences for level of involvement in decision-making rather than perceptions about what actually occurred.¹² Although it is widely used in its modified form to measure perceptions of involvement, my findings indicate that it may not measure this concept well.

My findings also have implications for the measurement of SDM beyond a patient's perspective. In these interviews, patients described their own role in the information exchange and decision-making as being as active as or more active than the physician role. However, many of the most commonly used measurement tools for SDM (including the OPTION scale⁹) focus solely on physician behaviors and thus may be missing important aspects of the interaction. Similar to other recent qualitative studies,^{21,22} my findings point to the importance of relational factors within the visit on patient perceptions of SDM. However, patients in this study also emphasized the importance of relational factors beyond the current visit and described the importance of a trust between the patient and physician that is built over time. Thus, findings from this study provide support for others who have called for the measurement of SDM as part of a larger interaction and relationship rather than focus solely on the discussion specific to the current decision.¹⁰⁷

In interviews, patients spoke of the importance of advocating for oneself in order to fully participate in a SDM process. Thus there may be a need for interventions that encourage patient

self-advocacy such as asking questions, speaking up when uncomfortable, or asking for a second opinion. Past studies have shown that when patients are more active in their consultations, physicians both share more information¹⁰⁸ and adopt a more patient-centered style of communication.¹⁰⁹ Interventions to promote patient participation and self-advocacy could include communication training for either the patient or the physician. Patient interventions might include communication training that builds skills on assertiveness and question-asking. Physician interventions could provide training around creating a trusting environment that would allow patients to feel comfortable speaking up.

There are several potential explanations for my finding that patient reports of SDM about a specific, recent decision seem to be more about the outcome of agreement than the communication process experienced. First, it is plausible that the wording of the choices themselves, led patients to think of an outcome rather than a process. In these interviews I used the modified Control Preference Scale, which asks patients to respond to the following question: “When it came to making the decision about <the specific topic>, which of these would you say would best describe how the decision was made?” The option that represents SDM is, “My doctor and I shared responsibility for deciding.” “Shared” in this context may be more about shared agreement rather than a detailed collaborative (shared) process. Furthermore, if patients have an expectation that they will talk respectfully with their physician and come to agreement on a plan, and this expectation is met, patients are not likely to consider the process that led to the accomplished goal. This makes sense in light of communication theory, such as Expectancy Violations Theory,¹¹⁰ which posits that when a person’s expectations of the interaction are violated, their focus changes from the original purpose of the interaction (agreement on a treatment plan) to thinking about the source of the discrepancy (or the communication process

itself). Thus, unless a patient's implicit expectation is violated with extremely poor or disrespectful communication, the patient is not likely to think about the communication process itself, but rather stay focused on the goals of the consultation.

Despite past studies indicating that differences in preferences for level of involvement and reports of participating in SDM by age^{111,112} (Frosh & Kaplan, 1999; Levinson et al., 2004) and race,^{113,114} my study did not find any differences in patient perceptions of the meaning SDM by age or race. This may indicate that age and racial differences in reports of shared decisions lie in actual differences in occurrence rather than in differences in the way patients define SDM.

This study has several potential limitations. Patients described a diverse array of topics for which decisions were made during their primary care visits. The small sample size, while appropriate for the aims of the qualitative study, did not allow me to examine perceptions by the context of the decision or the existing relationship the patient has with the physician seen. Thus I do not know whether patient perceptions of what constitutes a shared decision might vary by decision context. Second, I sampled patients who had recently attended a non-follow up primary care appointment. Thus, this sample may represent patients who are more active in their healthcare and perceptions of SDM may differ for those who take a less active approach. Finally, while we did not find any difference in patient perceptions of SDM by age or race, we did not have access to their level of educational attainment. Future studies may want to explore whether level of education affects how patients perceive SDM in both conceptually and regarding a specific, recent decision.

Conclusion

Patient reports of making a shared decision have been linked with improved patient outcomes.¹⁰¹ However in order to foster the communication linked with these outcomes in

practice, a clear understanding of what leads a patient to label a decision as shared is needed.

This study makes an important contribution to the SDM literature by focusing specifically on the patient perspective of SDM. While SDM is often advocated on ethical grounds as a means to improve patient autonomy, the voice of the patient is notably lacking in most studies. The results presented here help to bridge this gap and allow for a better understanding of how patients conceptually define SDM as well what leads them to label a decision as shared. My findings indicate that patients have a clear idea of how they define SDM in general. Conceptually, patients describe a SDM process similar to accepted models of SDM in the literature, but with a greater emphasis on active listening and relational factors that are influenced by a relationship built over time. However, in the context of a specific, recent primary care decision, when agreement is reached about the decision, patients may perceive even relatively simple interactions as being shared decisions. Thus, it seems there is no one-size-fits all process that leads patients to perceive a decision as being shared. Rather, the outcome of “agreement” may be more important than the actual decision making process used to reach that agreement when patients label a recent decision as shared.

Chapter 4: Patient-defined shared decision making and colorectal cancer screening

Abstract

Introduction: The U.S. Preventive Services Task Force advises that physicians use a shared decision making (SDM) process when recommending preventive services, such as colorectal cancers screening. The aim of this study is to determine whether the occurrence of the four components of patient-defined SDM (exchange of information, physician active listening, patient self-advocacy, and a personalized physician recommendation) are associated with adherence to physician-recommended colorectal cancer screening, and whether this relationship is moderated by the patient's initial verbal response to the physician recommendation.

Methods: Secondary analysis of a dataset of 410 audio-recordings of primary care visits that included a physician recommendation for colorectal cancer screening. Audio-recordings were coded for the four components of patient-defined SDM as well as the patient's initial verbal response to the recommendation. Colorectal cancer screening use in the following year was available via electronic medical records.

Results: The most commonly observed component of patient-defined SDM was patient self-advocacy (76%), followed by physician exchange of information (61%), physician active listening (60%), and a personalized physician recommendation (23%). Only 35 visits (9%) contained all four patient-defined SDM components. In adjusted models, physician provision of information around the process and potential side effects of colorectal cancer screening was associated with an increase in screening. Patients who initially refused were least likely to be screened (40%), while patients who did not verbalize a response to the recommendation were most likely to be screened (70%). The screening rate among patients who initially verbally agreed with the recommendation was not different than the overall screening rate (49% vs. 55%).

Discussion: My findings point to the importance of providing all patients with information alongside a recommendation for colorectal cancer screening. Even patients who initially agree to recommendations may have questions or concerns that would benefit from an interactive discussion.

Introduction

In the United States, colorectal cancer is the third leading cause of cancer death for both men and women. Despite being a preventable cancer if polyps are discovered and removed early, approximately 40% of people for whom screening is recommended remain unscreened.²⁵ Having a physician recommendation for screening is one of the best predictors of colorectal cancer screening (CRCS) use.¹¹⁵ When making these types of preventive service recommendations, the U.S. Preventive Services Task Force (USPSTF) advises that physicians use a shared decision making (SDM) process. Patients who report good communication with their physician, including involvement in shared decision making, are more likely to be adherent to colorectal cancer screening recommendations.³⁴

Until recently it was not clear what patients actually meant when they endorsed a decision as being shared, making it difficult to advocate for specific communication practices that promote adherence to colorectal cancer screening. Results from three recent qualitative studies, however, enable a better understanding of the communication processes that patients label as “shared”.^{21,22,116} Collectively these studies find that patients value an interactive process in which the patient and physician share information and through which the patient feels listened to and understood before making a medical decision. Furthermore, the results from Shay (2013) highlight differences in the way patients define SDM by a patient’s initial level of agreement with the physician’s recommendation.¹¹⁶ That is, when a patient agrees with a physician’s recommendation, a less complex interaction may be needed for the patient to perceive the decision as shared relative to when the patient initially disagrees or has some hesitancy towards the physician’s recommendation. Thus to promote adherence to physician-recommended colorectal cancer screening in practice, it may be important to understand not only which specific

patient-physician communication components effect screening use, but whether the impact of these components differs by the patient's initial reaction to the colorectal cancer screening recommendation.

The current study uses the model of patient-defined SDM developed by Shay (2013) to determine whether and which components of SDM are associated with adherence to physician-recommended colorectal cancer screening and whether the relationship between these components and adherence to colorectal cancer screening is moderated by the patient's initial reaction to the physician recommendation.

Methods

Conceptual framework

The conceptual framework informing the study design and variable selection was adapted from two existing models (Figure 4.1). The Communication Model of SDM posits that patient/provider communication is transactional, involving two engaged participants, and acknowledges that decisions are influenced by both pre-existing individual patient and physician characteristics and the communication climate in which the decision takes place.¹¹⁷ Second, the model of patient-defined SDM developed by Shay (2013) involves an interactive exchange between the patient and physician that is made up of four interdependent components: physician exchange of information specific to the decision at hand, physician active listening throughout the visit, patient self-advocacy throughout the visit, and personalized physician recommendation.

Data Sources

Data for the current analysis come from an observational study of patient-physician communication in the context of colorectal cancer screening.^{19,103,118} For that study, 64 primary care physicians and 500 of their patients in an integrated health system in southeast Michigan

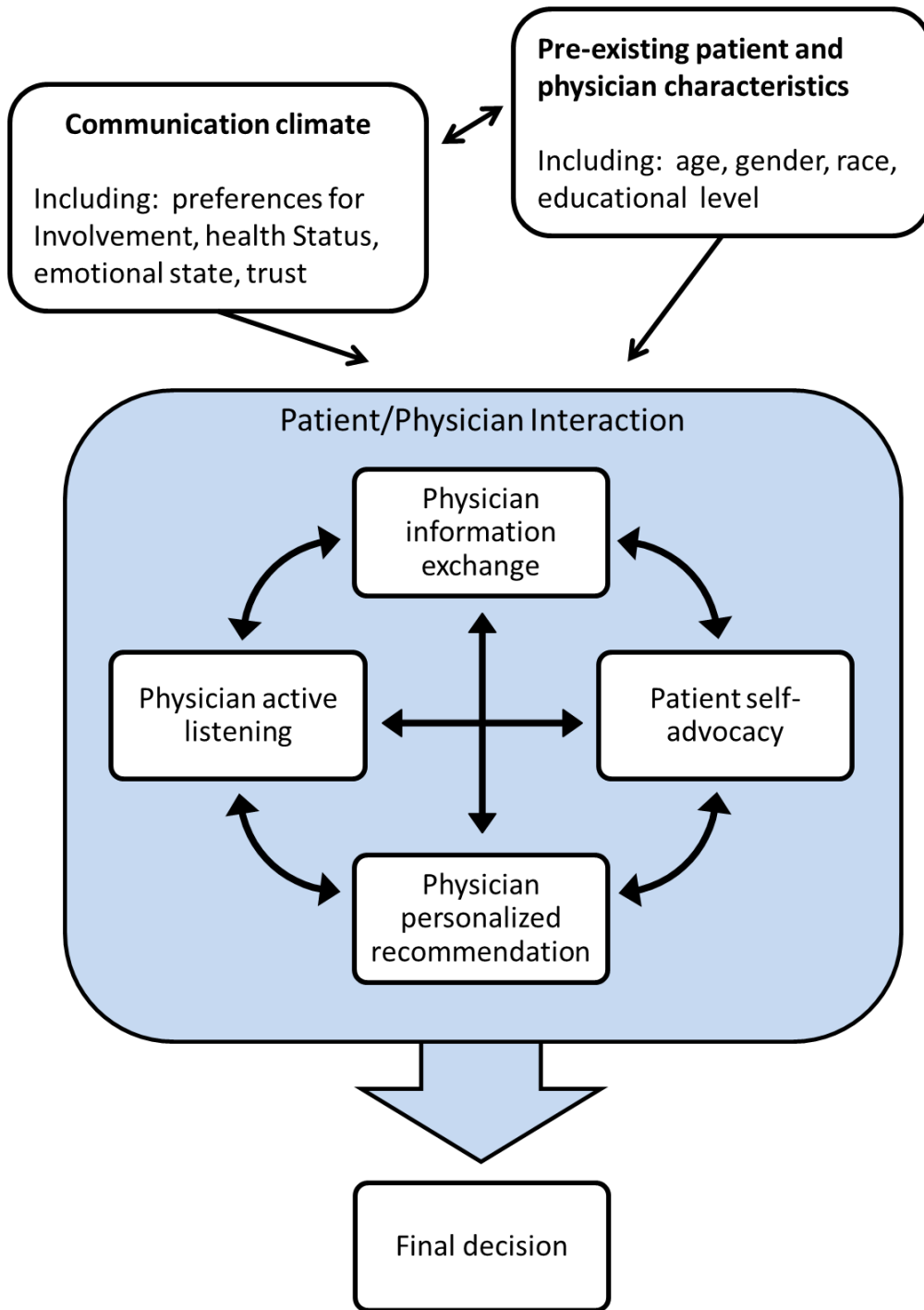


Figure 4.1 Conceptual framework adapted from Siminoff & Step (2005) and Shay (2013)

were enrolled between February 2007 and 2009. Eligible physicians included salaried family and internal medicine physicians on staff with a large integrated health system. Eligible patients were aged 50 to 80 years, insured via the health system affiliated HMO, and due for colorectal screening at the time of their scheduled period health exam with a study participating physician. Details of the recruitment and enrollment processes have been published elsewhere.^{19,103,118}

Data were collected via pre-visit patient surveys, audio-recordings of the office visits, health system records, and the electronic medical record. Research assistants administered pre-visit surveys via the telephone at the time of recruitment that included measures of socio-demographic characteristics, patient preferences for role in decision-making, and patient perceptions of their physician (among those who had previously seen the same physician). Patient and physician communication during the office visit was captured via a small digital recording device. All audio-recordings were transcribed prior to coding. Physician characteristics, including age, gender, race, and medical specialty (family or general internal medicine) were obtained from health system records. All aspects of the current research protocol were approved by Virginia Commonwealth University's Institutional Review Board.

Dependent variable: adherence to physician-recommended colorectal cancer screening

The primary outcome in this study is adherence to physician-recommended colorectal cancer screening in the 12 months following the audio-recorded visit. Screening use was identified via service codes in the electronic medical record for all screening modalities that were recommended by the USPSTF at the time of the study, including fecal occult blood test, colonoscopy, flexible sigmoidoscopy, or double contrast barium enema.²⁴ Patients were considered to have been adherent to physician-recommended colorectal cancer screening if, per

the electronic medical record, they received at least one of these procedures in the year following their recorded visit.

Explanatory variables: patient-defined SDM and patient's initial reaction to colorectal cancer screening recommendation

For this study I am primarily interested in how the components of patient-defined SDM are associated with adherence to physician-recommended colorectal cancer screening and how these associations might be moderated by the patient's initial response to a physician recommendation for screening. Thus, each of the visit transcripts was coded for the four components of patient-defined SDM (as depicted in Figure 4.1) and for the patient's first verbal indication of their response to a recommendation for colorectal cancer screening.

Each of the components of patient-defined SDM was coded as either present or absent. Physician sharing of information was coded present if the physician provided information about the process or side effects of any of the four recommended colorectal cancer screening modalities (colonoscopy, sigmoidoscopy, fecal occult blood test, or barium enema). Physicians were considered to have used active listening if they responded to patient comments using prompted partnership building or supportive.¹¹⁹ Patient self-advocacy behaviors included asking questions, expressing concerns, or using assertive responses.¹¹⁹ Physicians were considered to have given a personalized recommendation, if he or she provided both general reasoning as to why colorectal cancer screening is recommended (e.g., early detection, removal of polyps, disease is asymptomatic, etc.) and a verbal assessment of the individual patient's eligibility for screening (i.e., due to age, family history, length of time since last screening, or a reference to the electronic medical record).

Additionally, each transcript was coded for the patient's initial verbal response to the physician's initial recommendation for colorectal cancer screening. Responses were coded as either: agreement; hesitation; refusal; or no verbal response. Patients who initially agreed were those who brought up the topic of colorectal cancer screening themselves, volunteered willingness, or answered affirmatively when asked directly about their willingness to be screened (e.g. "I will. I'm going to do it," or "Oh I know I should."). Patient responses that were coded as hesitant were those in which the patient's first reaction was to ask questions about the screening (e.g. questions about pain, sedation, need for screening) or those that expressed a barrier to or concern about screening (e.g. "I don't have a ride," or "My mother had it and it was very painful."). Initial refusal was coded when a patient volunteered their unwillingness to be screened or who answered in the negative when asked directly about willingness to be screened (e.g. "I just don't want to do it." or "I feel that I'm healthy and don't need it."). Finally, some patients did not provide a verbal response to the physician recommendation, or only responded using noncommittal language such as "mm hmm" or "uh huh". These were coded as no verbal response.

Coding for the communication elements that made up the four components of patient-defined SDM was done as part of the parent study.^{19,103,118} Interrater reliability for these variables was measured with Cohen's Kappa and ranged from 0.56 to 1.00. Patient's initial response to the recommendation was coded specifically for the current study; the principal investigator (LAS) conducted this coding. Interrater reliability was assessed by having a random selection of 10% of the recordings (n=41) coded by a research assistant. Cohen's Kappa for patient initial response category was 0.74.

Control variables: patient characteristics, physician characteristics, and communication climate factors

The choice of control variables was influenced by my conceptual framework (Figure 4.1). Pre-existing patient and physician characteristics included patient and physician age, gender, and race (black, white, and other) as well as patient educational attainment (less than a high school diploma, high school diploma, some college, college degree or more) and physician specialty (general internal medicine and family medicine). Pre-existing communication climate factors included patient preference for level of involvement in cancer screening decisions,¹² non-adherence to a previous recommendation for colorectal cancer screening, patient self-reported health status,¹²⁰ patient reported depressive symptoms,¹²¹ and patient reports of trust in their physician prior to the recorded visit.¹²²

Statistical analysis

Data were first considered descriptively. Unadjusted logistic regression was used to determine whether there were differences in the occurrence of the four patient-defined SDM components by patient initial response to a physician recommendation for colorectal cancer screening. Next, simple logistic regression models were used to evaluate whether each of the components of patient-defined SDM was associated with colorectal cancer screening use and whether screening use differed by the patient's initial response to a screening recommendation. A multiple logistic regression model was then fit to determine the relationship between colorectal cancer screening receipt, and the components of patient-defined SDM and the patient's initial response to screening controlling for pre-existing patient and physician characteristics and communication climate factors. Finally, interaction terms were added to test whether the patient's initial response to a screening recommendation moderated the effect of the

components of patient-defined SDM on colorectal cancer screening use. Effects coding, or mean deviant coding, was used in modeling the categorical predictor variables. In contrast to standard dummy coding, effects coding allows for assessment of the true main effects in models that include multiple categorical predictors or interaction terms,^{123,124} and for the comparison of each subset of the data to the overall mean (i.e. average screening rate).^{123,125} All models were fit in MPlus with a logistic fit function using all available data. Standard error estimates that corrected for the non-independence of observations were attained during estimation for all analyses to control for the clustering of patients by physician.

Results

Sample characteristics

A total of 500 patients consented to participate in the parent study. Ninety of these cases were excluded from the current analysis for the following reasons: missing or inaudible audio recording (n=15); no discussion relating to colorectal cancer screening (n=29); already had screening scheduled at the time of the recorded visit (n=29); office visit discussion indicated patient not due for screening (n=12); pre-survey data was not available (n=3); screening only discussed in the context of an ongoing workup for symptoms (n=1); or physician did not recommend colorectal cancer screening due to current diagnosis of lung cancer (n=1). Thus, the sample for the current analysis includes 410 patient visits among 64 physicians. Pre-existing patient and physician characteristics and communication climate factors are depicted in Table 4.1.

Table 4.1 Pre-existing patient, physician, and communication climate characteristics

Patient characteristics (n=415)	%
Age (years), mean (SD)	58.7 (7.9)
Female	64
Race	
African-American	27
White	66
Other	7
Education	
Less than high school diploma	4
High school diploma	24
Some college or more	72

Physician characteristics (n=64)	%
Age (years), mean (SD)	48.3 (8.7)
Female	56
Race	
African-American	17
Asian/Pacific Islander	20
White	48
Other	14
Specialty	
Family medicine	30
General internal medicine	70

Communication climate factors	%
Patient preference for involvement in decision-making	
Patient-led	20
Shared	69
Physician-led	11
Patient health status*, mean (SD)	3.5 (0.9)
Patient depressive symptoms	17
Patient reports of trust in physician*, mean (SD)	5.3 (2.7)
Adherence to prior recommendation for colorectal cancer screening	31

- Patient health status was measured in a pre-visit survey with the question, “In general how would you rate your overall health,” on a scale of 1 to 5 with 5 representing excellent health. Trust in physician was measured in a pre-visit survey with the statement, “I trust this doctor’s judgment about my medical care.” Patients rated their agreement on a scale of 1 to 7 with 7 representing “strongly agree”.

Patient initial response to recommendation and occurrence of patient-defined SDM components

Across the 410 visits, the most common initial response to a physician recommendation of colorectal cancer screening was some type of hesitation or pushback from the patient (43%; Table 4.2). Another 22% of patients were observed to verbally agree with the recommendation, while about 10% initially refused. For the remaining quarter of patients, there was no verbal indication of their response to the physician recommendation. The most commonly observed patient-defined SDM component was patient self-advocacy, which occurred in over three-quarters of the visits. More than half of the visits contained an exchange of information around colorectal cancer screening (61%) and physician active listening (60%). A personalized physician recommendation for colorectal cancer screening was observed in less than a quarter of visits (23%). In total, only 35 visits (9%) contained all four components of patient-defined SDM.

There were significant differences in the occurrence of two of the patient-defined SDM components by initial response category (Table 4.2). Specifically, patients who verbalized hesitancy about screening were more likely to receive information about process or potential side effects of colorectal cancer screening than patients overall (75% vs. 61%; OR: 2.14 95% CI: 1.58, 2.88), while those who agreed or who did not disclose their response were less likely to have received screening information (For agree: 47% vs. 61%; OR = 0.64; 95% CI: 0.44, 0.92; For no verbal response: 47% vs. 61% OR: 0.63; 95% CI: 0.47, 0.86). Second, physicians were more likely to have practiced active listening with patients who initially refused the recommendation than with patients overall (70% vs. 60%; OR: 1.53; 95% CI: 1.00, 2.34), and were less likely to actively listen to those who did not verbally respond (51% vs. 60%; OR: 0.67;

95% CI: 0.49, 0.91). Neither receipt of a personalized physician recommendation nor patient self-advocacy varied significantly by the patient's initial response to the recommendation for screening, but those who verbalized initial hesitancy about the recommendation were most likely to receive all four components of patient-defined SDM (14% vs. 9%; OR: 2.32; 95% CI: 1.30, 4.11).

Table 4.2 Occurrence of SDM components overall and by patient initial verbal response to recommendation for colorectal cancer screening

Patient-defined SDM components	Total % (n)	Patient's initial verbal response				Overall significance p-value*
		Agree % (n)	Hesitant % (n)	Refuse % (n)	No verbal response % (n)	
Physician-driven components						
Exchange of information	61% (250)	47% (43)	75% (132)	63% (25)	47% (50)	< 0.001
Physician active listening	60% (244)	56% (50)	65% (113)	70% (28)	51% (53)	0.01
Personalized recommendation	23% (95)	19% (17)	27% (48)	18% (7)	22% (23)	0.11
Patient-driven component						
Patient self-advocacy	76% (310)	72% (65)	78% (137)	88% (35)	70% (73)	0.29
All 4 components present	9% (35)	3% (3)	14% (24)	8% (3)	5% (5)	0.03
Total		22% (90)	43% (175)	10% (40)	25% (105)	

* P-values represent overall difference in receipt of SDM component by initial response type using a Wald test for overall significance. Significant differences between groups are presented in the text.

Relationship between patient-defined SDM components and colorectal cancer screening

Overall, 55% of the sample went on to be screened for colorectal cancer in the year following their recorded visit. In bivariate analyses, none of the four components of patient-defined SDM individually were significantly associated with colorectal cancer screening adherence, nor was receipt of all four components (data not shown). However, there were significant differences in screening rates by the patient's initial verbal response to the physician recommendation for colorectal cancer screening. Specifically patients who initially refused were less likely than the overall sample to be screened (40% vs. 55%; OR: 0.59; 95% CI: 0.35, 0.98), while those who did not provide a verbal indication of their response were more likely to be screened (70% vs. 55%; OR: 2.00; 95% CI: 1.37, 2.93). In both the unadjusted and adjusted main effects models, only patients who did not provide an initial verbal response to the screening recommendation were significantly more likely to be screened than other patients (Table 4.3, Models 1 and 2, see page 77).

Interaction between patient-defined SDM components and patient's initial response to recommendation

Table 4.4 descriptively displays the percentage of patients who were adherent to their physician's colorectal cancer screening recommendation by the patient's initial response category and receipt of the SDM components. When the interactions between each of the patient-defined SDM components and the patient's initial response to the recommendation are added to the model (Table 4.3, Model 3), patients who did not provide an initial response to the screening recommendation remain more likely to be screened (OR: 2.13; 95% CI: 1.30, 3.48), and those who initially refuse the recommendation remain less likely to be screened (OR: 0.32; 95% CI: 0.12, 0.86). Additionally, in the model that adjusted for the effects of pre-existing

patient, physician, and communication climate characteristics (Table 4.3, Model 4), patients who receive information from their physician about the colorectal cancer screening process or its potential side effects are more likely to be screened than those who do not (OR: 1.78; 95% CI: 1.02, 3.10). None of the interaction terms reached significance in either the unadjusted or adjusted model.

Table 4.4 Percent adherent to CRCS recommendation by initial response category and receipt of SDM components

	Total screened	Patient's initial verbal response			
		Agree	Hesitant	Refuse	No verbal response
Patient-defined SDM components	%	%	%	%	%
Physician-driven components					
Exchange of information	55%	51%	55%	48%	78%
Physician active listening	56%	56%	55%	40%	68%
Personalized recommendation	56%	47%	63%	43%	70%
Patient-driven components					
Patient self-advocacy	53%	43%	53%	43%	69%
All 4 components present	66%	67%	71%	33%	60%
Total % screened by initial response	55%	49%	54%	40%	70%

Discussion

While results here do not provide strong evidence for the effect of patient-defined SDM on adherence to physician-recommended colorectal cancer screening, I did find that, controlling for other communication factors, patients who received information about the process or potential side effects of colorectal screening were more likely to be adherent to their physician's

recommendation for screening. Additionally, I found significant differences in both screening rates and receipt of the components of patient-defined SDM by the patient's initial verbal response to their physician's recommendation for CRC screening. This implies that physicians tailor their conversation to the patient's initial verbalized level of agreement with their recommendation. Furthermore, while, expectedly, patients who initially refused the recommendation were those least likely to be screened, it was not patients who expressed initial agreement with the recommendation, but those who offered no response, who were most likely to be screened.

In this sample, patient-defined shared decision making in the context of colorectal cancer screening was not provided consistently across patients. While all visits contained a physician recommendation for screening, almost 40% of did not include information about the screening process or its possible side effects. Furthermore, a personalized recommendation, in which the physician explained why colorectal cancer screening is important in general and for that patient in particular, was only observed in fewer than one-quarter of visits. In total, only 9% of visits included all four components of patient-defined SDM, and this was most likely to occur in patients who expressed hesitancy, but even then only 14% experienced all four elements of patient-defined SDM. These results support other studies that have found that, in the context of colorectal cancer screening, shared and informed decision making rarely occurs in practice.^{126,127} Thus, evaluating the impact of SDM on colorectal cancer screening in practice remains problematic.

My results have implications for primary care practice. First, primary care physicians should be cautious about assuming that they can tell whether a patient intends to be screened or not based on the patient's initial, verbal reaction to their recommendation for screening. Results

here indicate that the majority of patients who initially offer a statement of agreement to a physician recommendation to be screened for colorectal cancer do not actually do so within the following year. On the other hand, less than a third who offer no responses at all to their physician's screening recommendation remain unscreened one year later. Thus, it would seem important to engage patients in further discussion regardless of their initial response, providing patients additional opportunities to express their intents and concerns.

Second, over half of the patients in this sample verbalized some kind of hesitation or pushback against colorectal cancer screening. As previously reported, in this sample¹¹⁸ and elsewhere across the nation,¹²⁷ physicians are increasingly recommending colonoscopy for CRC screening without offering alternatives. When physicians hear hesitancy about colonoscopy, they should assess whether this hesitancy is for screening in general versus specifically for colonoscopy. Patients who are resistant to colonoscopies may be more open to the idea of a fecal occult blood test.¹²⁸ A recent trial found that patients offered a choice among modalities were more likely to be screened.¹²⁹ At the very least, physicians should provide information around the process of colorectal cancer screening to all patients along with their recommendation for screening. In this sample, those who received such information were significantly more likely to be screened regardless of their initial verbal response to their physician's recommendation for screening.

This study also has implications for future research around SDM and colorectal cancer screening. In absence of an available measure of the patient's screening intent at the beginning of the visit, I relied on the patient's initial stated level of agreement with the physician recommendation as a proxy for their initial level of agreement with the recommendation to be screened. The benefit of relying on patients' verbal responses is that this is the same information

that physicians have at the time of the visit. Thus, there is value in evaluating patients' verbalized level of agreement, despite the fact that this may not accurately represent the patient's actual feelings about the recommendation. However, because this study used audio-recordings instead of video-recordings or direct observation, I was not able to account for body language that might have provided additional information about the patients' initial reactions to the recommendation for colorectal cancer screening. In order to more fully test the model of patient-defined SDM, future studies should consider the use of video recordings and measure the patient's actual intent to be screened, both before and after the visit, and compare this with verbal responses. Second, while there has been a trend towards evaluating the effects of SDM on more distal patient outcomes like adherence^{66,69} or blood pressure,^{70,84} SDM—whether patient defined or otherwise measured—is most likely to affect proximal outcomes like satisfaction and decisional regret.¹⁰¹ While it is valuable to evaluate the effect of patient-physician communication on outcomes such as adherence or more distal health outcomes, SDM might be better advocated on the grounds of helping patients make informed and value-concordant decisions.^{45,46}

This study has several limitations. First, the availability of only one recorded visit per patient-physician dyad precludes the ability to test for the effects of SDM over time. Many of the patients in this sample have a long-standing relationship with their physician, and there may have been more active discussion around colorectal cancer screening in previous visits. I did however control for trust as expressed by the patient prior to the visit. Also, despite the fairly large sample size, the power to detect differences is limited by the clustering by physician and the large number of predictors after the interaction terms were added. Nevertheless, the stability of my findings when the patient and physician covariates were added suggests robust results.

In conclusion, further research is needed to fully establish a link between patient-defined SDM and colorectal cancer screening. However, the results presented here indicate that, regardless of a patient's initial reaction to a physician recommendation for screening, those who are provided with information about the screening process are more likely to be screened in the following year. Thus, providing information to all patients at the time of a colorectal cancer screening recommendation is critical, both to allow for more informed decision-making and for improving colorectal cancer screening rates.

Table 4.3 Factors associated with colorectal cancer screening

	<u>Model 1</u>		<u>Model 2</u>		<u>Model 3</u>		<u>Model 4</u>	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Patient-defined SDM Components								
Physician-driven components								
Exchange of information	1.41	(0.92, 2.16)	1.46	(0.93, 2.28)	1.75	(0.99, 2.70)	1.78	(1.02, 3.10)
Physician active listening	1.17	(0.78, 1.74)	1.22	(0.79, 1.90)	1.01	(0.60, 1.83)	1.14	(0.66, 1.97)
Personalized recommendation	1.16	(0.65, 2.05)	1.01	(0.57, 1.80)	0.96	(0.50, 1.65)	0.79	(0.41, 1.54)
Patient-driven component								
Patient self-advocacy	0.73	(0.43, 1.26)	0.71	(0.42, 1.21)	1.02	(0.52, 1.68)	0.99	(0.53, 1.86)
Patient's initial verbal response								
Agreement	0.87	(0.60, 1.26)	0.74	(0.50, 1.10)	1.09	(0.59, 2.02)	1.00	(0.56, 1.79)
Hesitation	0.95	(0.67, 1.34)	0.88	(0.62, 1.25)	1.33	(0.78, 2.25)	1.28	(0.74, 2.21)
Refusal	0.59	(0.34, 1.01)	0.64	(0.35, 1.15)	0.32	(0.12, 0.86)	0.31	(0.12, 0.81)
No verbal response	2.08	(1.41, 3.08)	2.41	(1.59, 3.71)	2.13	(1.30, 3.48)	2.49	(1.48, 4.21)
Interactions								
Agreement * Exchange of information					0.78	(0.51, 1.21)	0.76	(0.48, 1.21)
Hesitation * Exchange of information					0.76	(0.55, 1.05)	0.77	(0.54, 1.09)
Refusal * Exchange of information					1.39	(0.78, 2.61)	1.33	(0.72, 2.48)
No verbal response * Exchange of information					1.21	(0.78, 1.86)	1.28	(0.85, 1.94)
Agreement * Physician active listening					1.49	(1.01, 2.19)	1.32	(0.88, 1.98)
Hesitation * Physician active listening					1.09	(0.79, 1.50)	1.04	(0.73, 1.47)
Refusal * Physician active listening					0.65	(0.35, 1.21)	0.77	(0.41, 1.47)
No verbal response * Physician active listening					0.95	(0.63, 1.42)	0.95	(0.62, 1.44)
Agreement * Patient self-advocacy					0.60	(0.32, 1.13)	0.61	(0.35, 1.07)
Hesitation * Patient self-advocacy					0.86	(0.55, 1.35)	0.86	(0.54, 1.36)
Refusal * Patient self-advocacy					2.17	(0.92, 5.14)	2.15	(0.96, 4.84)
No verbal response * Patient self-advocacy					0.90	(0.56, 1.45)	0.89	(0.56, 1.40)

Table 4.3, Continued

	<u>Model 1</u>		<u>Model 2</u>		<u>Model 3</u>		<u>Model 4</u>	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Agreement * Personalized recommendation				1.00	(0.66, 1.50)	1.08	(0.68, 1.73)	
Hesitation * Personalized recommendation					1.32	(0.88, 1.96)	1.36	(0.88, 2.11)
Refusal * Personalized recommendation					0.95	(0.51, 1.74)	0.84	(0.43, 1.65)
No verbal response * Personalized recommendation					0.81	(0.47, 1.38)	0.81	(0.48, 1.37)
Pre-existing patient, physician and communication climate characteristics								
Patient sex (Female)			1.10	(0.67, 1.80)			1.08	(0.64, 1.85)
Patient age			0.97	(0.94, 1.00)			0.97	(0.94, 1.00)
Patient race			1.35	(1.00, 1.83)			1.35	(0.99, 1.83)
Patient level of education			1.30	(0.89, 1.89)			1.30	(0.90, 1.88)
Physician age			1.02	(0.99, 1.06)			1.02	(0.99, 1.06)
Physician sex (Female)			0.77	(0.44, 1.34)			0.76	(0.44, 1.31)
Physician race			1.08	(0.88, 1.33)			1.08	(0.87, 1.34)
Physician specialty (General internal medicine)			0.80	(0.49, 1.31)			0.82	(0.50, 1.35)
Preference for involvement in decision making			0.48	(0.52, 1.06)			0.76	(0.51, 1.15)
Health status			1.40	(1.09, 1.80)			1.37	(1.08, 1.75)
Depressive symptoms			0.83	(0.46, 1.48)			0.79	(0.43, 1.48)
Trust in physician prior to visit			0.97	(0.89, 1.05)			0.97	(0.90, 1.05)
Adherence to prior colorectal cancer screening recommendation			1.00	(0.57, 1.73)			0.98	(0.54, 1.76)

* Model 1 includes all four components of patient-defined SDM as well as the initial level of agreement.

Model 2 includes all variables from Model 1 and controls for pre-existing patient, physician, and communication climate characteristics.

Model 3 includes all variables from Model 1 and adds the interaction effects.

Model 4 includes all variables from Model 3 and controls for pre-existing patient, physician, and communication climate characteristics.

Chapter 5: Conclusions

The results from the three studies presented in this dissertation build on one another. First, the systematic review of the measurement of SDM and its effects on patient outcomes found that SDM is typically measured in one of three ways: via patient-self report; physician self-report; or objective rating of recorded or observed interactions between patients and clinicians. Drawing from past theoretical models,^{47,48} my review offers a novel categorization framework for examining the impact of SDM across two domains: the way in which SDM was measured and the category of patient outcomes (cognitive, behavioral, or health-related). While there has been a recent trend towards linking (or trying to link) SDM with patient outcomes,^{47,97-99} this was the first study to systematically summarize the associations between different measures of SDM and types of patient outcomes.

The systematic review had several important results that guided the direction and methodology of the subsequent studies. First, only patient reports of SDM were consistently associated with patient outcomes. Of the 97 unique patient outcomes evaluated in association with a measure of SDM, 52% of outcomes measured in conjunction with patient reports of SDM were found to have a significant and positive association, versus only 21% with observer rated, and 0% with clinician-rated SDM. This finding suggests two important points: the link between SDM and outcomes has yet to be established, and when there are significant findings only patient reports of SDM that are consistently linked with patient outcomes. Across studies using patient-reports of SDM, the most commonly used measure was a modification of the Control Preference

Scale.¹² This single item instrument asks patients to rate their involvement in a specific decision across five categories. What the instrument does not do, however, is aid in an understanding of what SDM means to patients and what needs to happen in a patient-clinician interaction for a patient to label a decision as shared. In order to foster the benefits of patient-perceived SDM in practice, we need a better understanding of what leads patients to report a decision as shared.

Building on these findings, the aims of my second study were to understand how patients define SDM in general and what leads patients to label a specific decision as shared in practice. Through in-depth qualitative interviews with 23 patients who had recently attended a primary care visit, these aims were explored. Findings from this study indicate that patients conceptually define SDM similar to academic definitions of SDM (e.g. Charles et al.⁵), with some important caveats. Specifically, patients described an interactive process that included four communication components before a decision was made: an exchange of information; active listening; patient self-advocacy; and a personalized physician recommendation. Additionally, patients reported that this process occurs in the context of a trusting relationship that is built over time. In contrast, when asked about specific decisions made at a recent primary care visit, for that decision to be labeled as shared using the modified Control Preference Scale,¹² patients described a variety of exchanges ranging from interactive to very simple. The only commonality among decisions labeled as shared by patients was that the patient and physician came to agreement. In cases where patients reported agreeing with their physician's initial recommendation, even very simple interactions were labeled as shared. Results from this study, therefore, indicated that the discussion content that is needed for a patient to label a specific medical decision as having been shared may vary by the patient's initial level of agreement to a physician's recommendation.

For my last study I used the conceptual model of SDM that I developed in study two and coded for the four components of patient-defined SDM in an existing database of audio-recorded primary care visits. In this study, I explicitly tested whether the occurrence of the components of patient-defined SDM were associated with adherence to physician-recommended colorectal cancer screening, and whether the relationship between patient-defined SDM and adherence to colorectal cancer screening was moderated by the patient's initial verbal response to the physician recommendation. This study found that, first, patient-defined SDM was not happening regularly in the context of colorectal cancer screening discussions. Second, patients who initially verbally agreed to a physician recommendation for colorectal cancer screening were not more likely to be screened, and instead it was those who provided no verbal response who were screened at the highest rates. Finally, physician provision of information about the colorectal cancer screening process was significantly associated with screening, regardless of the patient's initial response to the screening recommendation.

Taken together, the results from these three studies have implications for practice and research around shared decision making. Patient perceptions of SDM, rather than physician perceptions or observer ratings based on academic definitions of SDM, are most likely to impact patient outcomes. The three studies presented here are relatively novel in their explicit focus on the patient perspective of SDM, giving a voice to those who SDM is meant to benefit. In contrast with traditional definitions of SDM, patients emphasize the importance of a trusting relationship and other relational factors. In order to encourage patient-perceived SDM and its benefits in practice, physicians should work to facilitate trust by actively listening to patients and providing recommendations that are personalized to the patient based on their unique circumstances and preferences. Also, while a patient's initial level of agreement with a

physician recommendation may affect perceptions of SDM, physicians cannot take verbalized agreement at face value. Patients who quickly agree with recommendations may not necessarily adhere. Furthermore, all patients, including those who seem to already agree with a recommendation, could benefit from the provision of additional information, particularly in the context of colorectal cancer screening.

My findings also highlight the complexity of studying and measuring shared decision making. First, definitions of SDM overlap with several other communication processes often discussed in the literature including informed decision making, patient-centered communication, action planning, and collaborative goal setting. While the overlap of terms likely cannot be avoided, researchers should explicitly describe the communication process that they are studying, and include an operational definition of the term, so that results can be compared across studies. Second, as the findings from this dissertation demonstrate, both the meaning and the effect of SDM differ depending on the way it is measured. My systematic review revealed that the association between SDM and patient outcomes differs by measurement perspective, with patient self-reports of SDM being more likely to be associated with outcomes than other types of measures. Additionally, in the qualitative study, patient's perceptions of SDM differed by the way they were asked about SDM. Third, the study of SDM is complex because of the transactional nature of communication between patients and clinicians.¹¹⁷ The communication patterns of clinicians effect the communication patterns of patients and vice versa. Therefore, it is difficult to make any blanket statements about when SDM occurs or when it will have an effect on outcomes. Both the occurrence and impact of SDM are impacted by a myriad of factors including, but not limited to, the context and acuity of the decision being made, the prior relationship between the patient and clinician, that patient's level of initial agreement with a

physician recommendation, the match between patient and clinician communication styles and decision-making preferences, as well as other pre-existing characteristics that patients and clinicians bring to the encounter. Thus, there is no simple formula for promoting perceptions of SDM or its associated outcomes.

It is important to note that, due in part to these complexities in studying SDM, the link between SDM and patient outcomes has yet to be fully established. Relatively few studies have explicitly measured SDM in association with any patient outcome and even more rarely with more distal health outcomes. SDM is most likely to be positively associated with patient outcomes when it was measured via patient self-report and when the outcomes measured were proximal outcomes like satisfaction or decisional conflict. While this finding may not be satisfactory to those who wish to link SDM to patient health outcomes, the lack of association is not surprising. In their model of pathways linking communication to outcomes, Street and colleagues posit that the effects of SDM on health outcomes are likely to be indirect, with SDM first impacting more proximal outcomes,⁴⁷

Additionally, there is increasing recognition that SDM is a process that often occurs over the course of multiple visits.¹⁰⁷ Findings from my qualitative interviews supported this, with patient's reporting that an essential factor in SDM is a trusting relationship with the physician that is often built over time. Until now, SDM is almost always measured cross-sectionally in the context of one interaction or discussion. This may, in part, explain the lack of association between SDM and patient comes, including colorectal cancer screening adherence. That is, one discussion between a clinician and patient may not lead to improved health outcomes, but a long-standing relationship between a clinician and patient marked by patient-centered care and SDM may impact outcomes over time. Future studies should measure multiple outcomes over time so

that the pathway between communication and health outcomes, such as that proposed by Street and colleagues,⁴⁷ can be tested. For example, SDM may improve patient satisfaction, which over time may lead to trust in the physician, followed by adherence to physician recommendations and ultimately improved health.¹³⁰ Without longitudinal studies that specifically test for indirect effects in addition to direct effects, however, the link between SDM and health outcomes is likely to remain elusive.

In the meantime SDM may be better advocated on ethical grounds. Patient centered care, including SDM, is important outside of its potential effect on patient health outcomes. First, most patients want to be actively involved in the decision-making about their medical care,⁴² and SDM helps accomplish this goal. Second, SDM is historically rooted in the discipline of bioethics. One of the earliest mentions of SDM was the 1982 Report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral. This report called for a dialogue between patients and practitioners in which both voice opinions and concerns, and come to a mutually agreed upon decision. Accordingly, the report states that "ethically valid" consent should be part of a shared decision making process characterized by mutual respect and participation.³⁹ More recently, the U.S. Preventive Task Force highlighted the multiple perspectives on which SDM can be recommended. These included an ethical mandate to protect patient autonomy and self-determination, an interpersonal benefit of promoting trust in the patient-clinician relationship, and an educational gain of increasing patient knowledge about treatment options, benefits, and harms through a SDM process.³ Thus, despite only limited evidence that shared decision making improves patient outcomes, there are still important reasons to advocate for a SDM process when making healthcare decisions.

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Appendices

- A. Patient Interview Guide
- B. Final Code List for Patient Interviews
- C. Patient Initial Verbal Response to Recommendation Coding Instrument
- D. Patient Initial Verbal Response to Recommendation Coding Instructions

Appendix A

Patient Interview Guide

Introduction:

Thank you again for agreeing to participate in this interview. We are interested in learning about how patients and doctors make decisions. There are no right or wrong ways to make decisions with doctors. I am interested in hearing about your experience and opinions.

I am going to ask some questions about how you and your doctor discussed certain health decisions. Please consider what happened at your most recent visit with your doctor, Dr X, as we talk.

1. Let's start by talking about some of the topics that you and Dr. ___ discussed during your most recent visit. Please tell me what topics you discussed.

*INTERVIEWER: Prompt (if patient cannot remember any topics):
Sometimes doctors and patients talk about lifestyle choices, preventive services like cancer screening, medications, etc.*

2. Were any decisions made about any of these topics? Which ones?

Prompt with the topics raised in Q1 to see if any decisions were made about these topics.

INTERVIEWER: List all relevant topics and then review each with the patient

INTERVIEWER: If no decisions were made about topics listed, ask about a past health care decision made with a physician that included some of these topics.

3. I'd like to hear more about the decision about <topic>? How was that decision made?
4. Now I am going to read you 5 choices for how the decision was made. There are no right or wrong ways to make the decision, so none of these choices are better or worse.

When it came to making the decision about <topic>, which of these would you say would best describe how the decision was made?

- a) I made the final decision.
- b) I made the final decision after seriously considering my doctor's opinion.
- c) My doctor and I shared the responsibility for deciding.
- d) My doctor made the final decision after seriously considered my opinion.
- e) My doctor made the final decision.

5. So, you just told me that the decision about <topic> was one made by X/X. Can you tell me what makes you feel that the decision about <topic> was <type of decision chosen in Question 4>?

- What specific things happened during the visit that made you feel that <type of decision chosen in Q4>?
- What specific things did your doctor do or say that made you feel this way?
- What specific things did you do or say that made you feel this way?
- If someone were to have audio-recorded or video-recorded your visit with Dr. X, how would they have known from the audio or video that the decision was <type of decision choices in Q4>?
- Is this typical of how you usually make decisions with Dr X?

6. *IF THE RESPONSE TO Q4 WAS NOT MARKED AS SHARED (Q4 CHOICE C):* You have shared that you did not feel that the decision you made about <topic> was shared with your physician. What would have had to happen for you to say that you and your doctor shared responsibility for deciding about <topic>?

- a. What specific things would have had to happen during the visit to make you think that this decision was shared? OR
 - i. What would have been different from what actually happened for you to feel that the decision was shared?
- b. What specific things would your doctor have had to do or say?
- c. What specific things would you have had to do or say?

REPEAT QUESTIONS 3-6 ABOUT ALL DECISIONS RAISED IN Q2

7. What does the phrase “My doctor and I shared responsibility in deciding” mean to you? What kinds of things do you think of when you hear this phrase?

As you probably know, things have changed in health care and now, many patients are taking more active roles in making decisions about their health care. This is often called ‘shared decision making’. What I am interested in learning is what this means to patients.

8. What do you think of when you hear shared the words, ‘shared decision-making’ between doctors and patients? What does it mean to you?
9. What things must you, as a patient, do during the conversation for you to consider a health care decision to be shared between you and the doctor?
10. What things must the doctor do during the conversation for you to consider a health care decision to be shared between you and the doctor?
11. In your opinion, what is the difference between the options “I made the final decision after seriously considering my doctor’s opinion” and “My doctor and I shared the responsibility for deciding”?

Can you give me examples of these from your experiences?

12. In your opinion, what is the difference between the options “My doctor made the final decision after seriously considering my opinion” and “My doctor and I shared the responsibility for deciding”?

Can you give me examples of these from your experiences?

13. One of the most common definitions of shared decision-making is that four things have to happen:
 - 1) Both the doctor and the patient have to be actively involved in the decision-making process
 - 2) Both the doctor and the patient share information with each other
 - 3) Both the doctor and the patient express treatment preferences
 - 4) Both the doctor and patient agree on a decision

What do you think about this definition of shared decision-making?

Do you think both the doctor and patient have to be actively involved?
Tell me more about that...

Do you think both the doctor and patient need to share information with each other for the decision to be shared?
Tell me more about that...

Do you think that both the doctor and the patient need to take steps to build a consensus around the decision for it to be shared?
Tell me more about that...

Do you think that both the doctor and patient need to agree on a decision for it to be shared?
Tell me more about that...

Would you make any additions or changes to the definition?

If you were making up a definition of shared decision-making, what would it be?

14. Do you think that every single decision made about your health care should be a shared one between a doctor and patient?

15. Are there differences in how major and minor health decisions should be made? (examples: lab work, cancer screening (like colonoscopy), treatment decisions (surgery, cancer treatment, etc.))

16. Is there anything else that I didn't ask that is important for us to know about decision-making between doctors and patients?

Thank you so much for your time. We hope that the information you have given us will help improve decision-making for future patients.

Appendix B

Final Code List for Patient Interviews

Code Name	Description
Q1 - Topics discussed	Code for marking topics discussed in transcript
Q2 - Decisions made	Code for marking decisions made in transcript
Q3 - Description of Decision	Code for marking description of decisions made in transcript
Context	Codes for marking the context of specific decision being discussed in questions 3, 4, and 5
Context - Blood pressure tx	
Context - Blood work	
Context - Bone density scan	
Context - Cholesterol tx	
Context - Colonoscopy	
Context - Insomnia meds	
Context - Mammography	
Context - Medication	
Context - Referral for procedure	
Context - Referral to specialist	
Context - Shingles vaccine	
Context - Sleep study	
Q4	Patient response to the modified control preference scale in the context of a specific decision listed in Q3
Q4 - Degner CPS - Pt alone	I made the final decision.
Q4 - Degner CPS - Pt led	I made the final decision after seriously considering my doctor's opinion.

Q4 - Degner CPS - Shared	My doctor and I shared the responsibility for deciding.
Q4 - Degner CPS - Dr led	My doctor made the final decision after seriously considered my opinion.
Q4 - Degner CPS - Dr alone	My doctor made the final decision.

When describing a specific decision that they labeled as shared in Q4 ...

Shared type - Simple agreement	patient describes a process in which the doctor makes a recommendation, and the patient describes simply agreeing
Shared type - Pt request	patient describes a process in which the patient brings in a specific request and the physician agrees
Shared type - Pt pushback	patient describes a process in which the doctor makes a recommendation, the patient is hesitant or disagrees and pushes back, they discuss and ultimately come to agreement

Q5

When asked about a *specific decision labeled as shared...*

Q5 - Info	patient brings up the concept of sharing or exchanging information
Q5 - Info - Dr shares info	patient says the doctor shared information
Q5 - Info - Dr shares info-recommend	patient says that the doctor made a recommendation
Q5 - Info - Pt shares info - expresses concerns	patient says that he/she expressed concerns
Q5 - Info - Pt shares info - shares symptoms	patient says that he/she shared symptoms or other problems
Q5 - Listen	patient explicitly brings up the concept of listening
Q5 - Listen - Dr listens	patient explicitly says the their doctor listened
Q5 - Listen - IMPLIED	patient does not use the word "listen" but the process they describe implies listening
Q5 - Listen - Pt listens	patient explicitly says that they listened to their doctor

Q5 - Decide	patient explicitly says that a decision was made
Q5 - Decide - Agree	patient says that the patient and physician agreed on the decision
Q5 - Decide - Best for individual patient	patient says that the decision was made in the patient's best interest
Q5 - Decide - Decide together	patient says that the doctor and patient decided together
Q5 - Decide - Pt decides	patient says that they made the decision
Q5 - Rapport	patient brings up the concept of relationship or rapport

Q6 & Q7

When asked about SDM *in general*...

Q7 - Info	patient brings up the concept of sharing or exchanging information
Q7 - Info - Dr shares info	patient says that doctors should share information
Q7 - Info - Dr shares info - gives opinion	patient says that doctors should give their opinion
Q7 - Info - Dr shares info - gives options	patient says that doctors should share options
Q7 - Info - Dr shares info - recommend	patient says that doctors should make a recommendation
Q7 - Info - Dr shares info - recommend - no demand	patient says that physicians should not make demands or ultimatums when making recommendations
Q7 - Info - Pt shares info	patient says that patients should share information
Q7 - Info - Pt shares info - gives opinion	patient says that patients should share their opinion
Q7 - Info - Pt shares info - shared symptoms/problem	patient says that patients should share any relevant symptoms or problems
Q7 - Info - Pt shares info - asks questions	patient says that patients should ask questions
Q7 - Info - Pt shares info - expresses concerns	patient says that patients should express their feelings or concerns
Q7 - Listen	patient explicitly brings up the concept of listening
Q7 - Listen - Dr listens	patient explicitly says that doctors should listen to patients
Q7 - Listen - IMPLIED	patient does not use the word "listen", but listening

	is implied in the process that they describe
Q7 - Listen - Pt listens	patient explicitly says that patients should listen to doctors
Q7 - Decide	patient brings up the concept of a making a decision
Q7 - Decide - Agree	patient says that doctors and patients should come to an agreement
Q7 - Decide - Best for patient	patient says that doctors and patients should make a decision in the best interest of the patient
Q7 - Decide - Decide together	patient says that doctors and patients should decide together
Q7 - Decide - Pt decides	patient says that the patient ultimately decides
Q7 - Rapport	patient brings up the concept of relationship or rapport
Q7 - Rapport - Dr knows pt	patient says it is important for the doctor to know the patient before making recommendations
Q7 - Rapport - Honesty	patient brings up the concept of honesty
Q7 - Rapport - Respect	patient brings up the concept of respect
Q7 - Rapport - Trust	patient brings up the concept of trust
Q7 - OTHER - Accessibility	patient says that accessibility of the doctor outside of the visit is important
Q7 - OTHER - Choice	patient says that they should be offered choice
Q7 - OTHER - Pt allowed time	patient says that patients should be allowed time to make decisions
Q7 - OTHER - Pt follow-through	patient says that the patient needs to follow through with actions required by the decision
Q7 - OTHER - Pt take responsibility	patient says that patients need to take responsibility for their decisions and/or health
Q7 - OTHER - Pt understands	patient says it is important that patients understand the decision at hand

Q9

When asked what things patients must do during the conversation for it to be considered a shared decision...

Q9 - Ask for second opinion	patient says they should ask for a second opinion if needed
Q9 - Ask questions	patient says they should ask questions

Q9 - Be honest	patient explicitly listed being honest
Q9 - Be open-minded	patient says they should be -open-minded to the physician's opinion and/or recommendation
Q9 - Be prepared	patient says they should come prepared for the visit
Q9 - Direct doctors to topic of interest	patient says they should direct doctors to the topics they want to discuss
Q9 - Express opinions	patient says they should express their opinions if they have one
Q9 - Make decision	patient says they should ultimately make the decision
Q9 - Share info	patient says they should provide all relevant information
Q9 - Speak up	patient says they should speak up if uncomfortable with decision or recommendation

Q10

When asked what things doctors must do during the conversation for it to be considered a shared decision...

Q10 - Answer pt questions	patient says that doctors should answer patient questions or address concerns
Q10 - Be honest	patient explicitly says that the doctors should be honest with patients
Q10 - Be open-minded	patient says that doctors should be open-minded to patient requests and opinions, being willing to stray from usual approach
Q10 - Check for agreement	patient says that doctors should check for patient agreement and understanding
Q10 - Give information	patient says that doctors should give information to patients
Q10 - Give reasons for recommendation	patient says that doctors should check for patient agreement and understanding
Q10 - Know patient	patient says that doctors should get to know patients before making recommendations
Q10 - Listen to patient	patient says that doctors should listen to patients
Q10 - Provide options	patient says that doctors should provide patients with options

Q10 - Respect	patient says that doctors should respect the patients
Q10 - Share opinion	patient says that doctors should share their opinion with patients
Q10 - Solicit involvement	patient says that doctors should solicit patient questions, concerns, symptoms
Q10 - Take time	patient says that doctors should take the time to have a conversation with patient and not rush
Q10 - Understand patient symptoms/concerns	patient says that doctors should understand patient symptoms and concerns

Appendix C

Patient Initial Verbal Response to Recommendation Coding Instrument

Case Number: _____

Coder: _____

What was the patient's first verbal response to the physician recommendation for colorectal cancer screening?

- Agreement
- Refusal
- Hesitation
- Unclear/No verbal response

Appendix D

Patient Initial Verbal Response to Recommendation Coding Instructions

Please go through the discussion about colorectal cancer screening between the patient and physician, highlighted in yellow in the transcript.* Use the descriptions below to categorize the patient's first verbal response to the physician's recommendation for colorectal cancer screening.

*Note: Some transcripts contain dialogue between the patient and nurse, medical assistant, or others. DO NOT code this interaction. Only code the discussion between the patient and physician.

Mark the response as **agreement**, if the first verbal response is one of the following:

- Patient volunteers willingness to be screened.
- Patient brings up topic, requesting referral.
- When asked directly about willingness to be screened, patient answers affirmatively.
- Patient goes straight to asking scheduling questions, or other questions that imply agreement

Mark the response as **refusal**, if the first verbal response is one of the following

- Patient volunteers unwillingness/refusal to be screened
- When asked directly about willingness to be screened, patient answers in the negative.

Mark the response as **hesitation**, if the first verbal response is one of the following:

- Patient asks question about screening (pain, sedation, need for screening)
- Patient expresses barrier to screening without outright refusing
- Patient expresses concern (e.g. I'm scared)
- Patient makes statement that invites further physician response/questioning (e.g. I know I was supposed to do that last year but I chickened out.)

Mark the response as **unclear**, if the first verbal response is one of the following:

- Patient does not answer about willingness to screen
- Patient is not asked or does not volunteer opinion
- Patient's only verbal response is with "okay" or "mmhmm" or similar, but it is not clear that they mean this about willingness to screen

Vita

Laura Aubree Shay was born on June 29, 1981 in Odessa, Texas and is an American citizen. She graduated Cum Laude with her Bachelor of Science in Biology from Trinity University in San Antonio, Texas in 2003. She received her Master of Science in Social Work from the University of Texas, in Austin in 2005 and holds a clinical social work license (LCSW) in the state of Texas. Before beginning her doctoral studies at Virginia Commonwealth University, Aubree worked as a clinical social worker in the field of pediatric oncology. Working with the families there was her motivation for wanting to learn about how to improve communication and decision-making between patients and clinicians. While at VCU, Aubree received an F31 training grant from the National Institutes of Health (1F31AG040923-01), a Developmental Project Award from the University of Michigan (5P50CA101451-09), and was a recipient of the Elizabeth A. Fries Memorial Scholarship and the Phi Kappa Phi Honor Society Scholarship.