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Patient preferences for shared decisions: A systematic review

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Abstract

Objectives—Empirical literature on patient decision role preferences regarding treatment and screening was reviewed to summarize patients' role preferences across measures, time and patient population.

Methods—Five databases were searched from January 1980-December 2007 (1980- 2007 Ovid MEDLINE, Cochrane Database of Systematic Reviews, PsychInfo, Web of Science and PubMed (2005-2007). Eligible studies measured patient decision role preferences, described measures, presented findings as percentages or mean scores and were published in English from any country. Studies were compared by patient population, time of publication, and measure.

Results—115 studies were eligible. The majority of patients preferred sharing decisions with physicians in 63% of the studies. A time trend appeared. The majority of respondents preferred sharing decision roles in 71% of the studies from 2000 and later, compared to 50% of studies before 2000. Measures themselves, in addition to patient population influenced the preferred decision roles reported.

Conclusion—Findings appear to vary with the measure of preferred decision making used, time of the publication and characteristics of the population.

Practice implications—The role preference measure itself must be considered when interpreting patient responses to a measure or question about a patient's preference for decision roles.

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Keywords

shared decision making; patient preferences; patient decisions

1. Introduction

Health care providers have been urged to integrate patients more actively as partners in decisions [1-9] Such patient involvement is often considered to fall under a model of shared decision making where both patient and provider contribute to the decision [3]. This contrasts with a patient delegating a decision to the health care provider. When patient involvement does not occur, it may be due to a perceived lack of time or because the provider does not have the skills to involve patients in decision making [5]. The approach of involving patients in decision making has been debated due to conflicting findings about decision roles preferred by patients.[10-14] Patients who have just received a serious diagnosis and feel vulnerable may not want the responsibility of being involved in decision making. [11] **For example**, research has found that in order to cope with their cancer diagnosis, some patients may not want the information about their cancer that would be necessary for participation in decision making. [13]

To date, no comprehensive review has identified time trends, targeted health problem/ population trends, and the influence of different measures on patients' reported decision role preferences across a range of patient contexts. While earlier reviews examined a single disease group such as cancer [15], this paper compares decision role preferences in a variety of contexts by looking at a fuller range of patient populations. This review seeks to examine and summarize patients' decision role preferences across studies that have used different measures, time of publication and patient populations.

2. Methods

2.1 Data Sources and Search Strategy

This review included empirical, peer-reviewed journal articles that measured patient decision role preferences, described measures, presented findings as percentages or mean scores and were published in English from any country. Three strategies were used to identify relevant studies. First, we searched for relevant studies published between January 1980 and December 2007 using Ovid MEDLINE, Cochrane Database of Systematic Reviews, PsychInfo, Web of Science and PubMed (2005-2007). A combination of the following Medical Subject Headings (MeSH) terms and keyword terms were used for MEDLINE and adapted to the other data bases: PHYSICIAN-PATIENT RELATIONS OR (PHYSICIANS or physician$ or doctor$) AND (patient participant$ or involve$ or relation $) AND preference$. These searches were restricted to empirical literature. Second, after conducting this search we reviewed references of all potentially relevant articles to retrieve additional articles. Third, the authors consulted their extensive prior literature banks to locate any articles not identified by the literature search. The lead author, along with a second reader, reviewed abstracts for inclusion. To be included, articles had to present data to calculate: 1) the percent of patients reporting a preferred decision role, or 2) mean scores with a scale and algorithm to interpret patients' desire to delegate or to collaborate in their medical decisions.

Key information from each eligible study was abstracted into standardized summary tables that listed the sample characteristics, measure(s) used, and findings regarding respondents' decision role preferences and associated factors (ie, age, education). Articles were divided into four study population groups: 1) patients with cancer; 2) patients with other chronic illness; 3) patients undergoing invasive procedures; and 4) general population (unspecified reasons for visit or community population samples).

2.2 Measures

Patient decision role preferences are measured with an array of instruments. These include the Autonomy Preference Index (API), the Control Preferences Card Sort (CPS), the Health Opinion Survey (HOS), and the Problem Solving Decision Making Scale (PSDM). These measures vary substantially in their role preference domains, specificity, scale response categories, summary scores and how they are reported (see Table 1). We reviewed all measures in studies that met the inclusion criteria including simple dichotomous and single item measures.

2.3 Conceptual Framework for Categorizing Studies

In order to construct summary tables of patient decision role preferences across studies that used different measures and summary scores, we needed to be able to commonly categorize findings from different studies. Thus, the question examined for each study was whether or not the majority of respondents in a study wanted to delegate their decisions to physicians or instead wanted a participative role at that time. Many measures categorized respondents into these 2 specific groups. However, not all studies did this and so we implemented three rules that allowed us to compare across studies.

First, some studies used measures which divided patients into 3 groups: 1) those who wanted to delegate decisions to the physician; 2) those who wanted to share the decision; or 3) those who wanted to make the decision themselves. Flynn et al [27] distinguished between "autonomists" who wished to make decisions themselves versus "delegators" who preferred a doctor to make the decisions regardless of whether or not respondents wanted disclosure of all options. Building on this distinction , we merged the "3 group" findings into 2 groups: 1) a group who wished to delegate; 2) a group who wished to participate in decisions either by making an autonomous decision or by sharing the decision with the physician. For example, in studies using the CPS we merged the "decide myself" and "shared decisions" groups. Through this categorization we could then report whether the majority of study respondents across all studies reviewed reported they wanted to *participate* in decisions or to *delegate* decisions to the physician.

A second rule involved how to label findings for studies that reported mean scores. Patients' decision role preference summary means were reported on scales ranging from 5-100 points. For the purposes of this review, the standard algorithm for interpretation was to use the midpoint to differentiate the extent to which patients wanted to delegate decisions to a physician versus to share decisions, unless a different algorithm was explicitly indicated. When the mean was lower than the midpoint, a majority of the study's patients wished to delegate decisions to the physician. When it was above the midpoint, a majority of the study's patients wished to share or make the decisions alone.

The third rule concerned how to report mixed findings from a single study with at least 2 measures and/or at least 2 study population subgroups. While the mixed findings from these studies complicated the review, in some ways, this group of mixed-findings studies presented unique information regarding factors affecting preferences of their respondents. Holding the population constant we could analyze whether and which *measure* elicited more of a delegator role preference. Likewise, holding the measure constant we could analyze which *population* had a more delegator role preference. Accordingly, these studies were retained and are reported in the tables as a separate group labeled “mixed findings”.

3. Results

3.1 Descriptive Overview

One hundred and fifteen articles met all eligibility criteria for this review. The most frequently used measures were the CPS (44 analyses), API or API-modified (16 analyses), PSDM (6 analyses), and HOS (5 analyses). Other measures were used in a total of 49 analyses; none were evident in more than two of these study analyses. The sum of these analyses (119) exceeds 115 articles because some articles included more than one measure to analyze. Four studies compared two different existing measures of patient role preferences within a single study such as: 1) the HOS versus the PSDM [25]; 2) the API versus HOS [27-8]; and 3) the CPS versus a single dichotomous item.[29]

Across the 119 analyses, 63% (75) found that the majority of respondents wanted to participate in decisions (see Table 2). By comparison 21% (25) of the analyses found that the majority of respondents preferred to delegate decisions to a physician. Sixteen percent (19) of the analyses reported mixed findings from using two different samples with a single measure or using a single measure with hypothetical vignettes of different patient conditions as with the API. Without these latter studies with mixed findings, 75% (75) of the remaining analyses found the majority of respondents preferred to share or make their decision alone.

While more patients favored participating in decisions rather than delegating them to a physician, there is a need to disentangle what contributes to the inconsistent findings. To better understand this phenomenon, we investigated how the reported decision role preference patterns differed by three variables: 1) the health population studied, 2) how recently the study was published and 3) the instrument used to measure patients’ preferred decision role. Each is discussed separately below.

3.2 Health Population Patterns

We compared the role preference findings for four different health population groups: 1) cancer study populations; 2) invasive procedure populations; 3) other chronic condition population groups; 4) general population groups (see Table 3). More than three quarters of the studies targeting the first two population groups versus about half of the studies targeting the latter two groups preferred participating in decisions rather than delegating decisions to the physician. Seventy-seven percent of the 43 *cancer* study analyses found the majority (i.e. >50%) of their respondents wanted to participate in decisions as was the case for 78.5% of the 14 *invasive procedure* study analyses. The invasive procedure study includes a range of procedures such as dental interventions, angiograms, and other surgical procedures. In contrast about 53% of the 36 analyses from the *general population* and 46% of the 26 analyses from patients with *other chronic conditions* found the majority of their respondents wanted to participate in decisions rather than delegate decisions to the physician.

3.3 Date of Publication Patterns

When analyses were compared by the date of publication, a time trend emerged. Patients' preference for participation increased over time (see Table 4). Forty three percent of the 7 analyses published between 1974 and 1989 found a majority of patients preferred to participate in decisions, another 43% of these analyses found a majority wanted to delegate major decisions to the physician, and 14% had mixed findings for different samples or hypothetical decisions. In the following decade (1990-1999) 37 analyses were published and 51% of these found a majority of patients preferred to participate while 27% of the 37 analyses found a majority preferred to delegate decisions. In contrast, 71% of the analyses published from 2000-2007 found a majority of patients reported they preferred to participate and only 16% found a majority of patients preferred to delegate decision making, with the remaining 13% showing mixed findings.

This time trend may be due to a variety of factors including different types of patient populations or study measures. To explore this further we examined the trends for patient decision role preferences within studies for four respondent groups: *cancer* studies, *other chronic conditions* studies, *invasive procedures* studies and *general population* studies. The cancer study time analysis was particularly useful since the CPS was used heavily across time periods.

Patient preference for participating in decisions increased over time most in two health populations – cancer studies and studies with other chronic conditions. The majority of patients preferred to participate in decisions in 85% of the 27 *cancer studies* published in or after 2000 versus 62.5% of studies before 2000. This was true for 59% of *other chronic condition* studies published in 2000 or later versus 22% before 2000. The majority of patients preferred to participate in decisions in 59% of the *general population* study analyses in or after 2000 versus 43% before 2000. The *invasive procedure* studies were stable. The majority of respondents preferred to participate in decisions in 78% of studies in or after 2000 compared to 80% before 2000.

3.4 Role Preference Measure Patterns

Having examined time and health population differences, last we examined whether findings differed by role preference measure used in studies. As Table 5 summarizes, the percent of respondents who indicated they preferred to participate in decision making did vary substantially with the measure utilized.

While 75% of the 44 analyses using the CPS found the majority of respondents preferred to participate in decisions, this was much less true with the original form of the API. The API presents a variety of vignettes, often differing in seriousness. It frequently offers hypothetical situations that the patient may not have experienced. The majority of respondents reported preferring to participate in only 8% of the original 12 API study analyses. When the API was modified to include an explicit scale point for shared decision making roles, patients reported more shared decision role preference. [19, 33, 59, 66]

Since the CPS was used in 44 analyses, it was possible to examine study recency effects. The majority of respondents in these studies preferred to participate rather than delegate decisions in 86% of the studies published 2000 or later compared to 54% published before 2000.

Although the measures in the “other” category in Table 5 are diverse, an important pattern emerged for brief 1 to 2 item measures that present respondents with agree-disagree response options. Some items in these measures asked respondents how much they *agreed with sharing* major decisions. Others asked respondents how much they *agreed with delegating* major decisions to their doctor. All of the 5 study analyses that worded the statement stem positively toward shared decisions found the majority of respondents agreed with shared decision roles (ie, “After discussion with the doctor, any decision about a cancer treatment should ultimately be made by the patient.”) [35, 38, 42, 87, 106]. However, 75% of the 6 study analyses that worded the stem positively toward delegating decisions to the doctor found the majority of respondents wished to delegate their decision role (ie, “ I prefer to leave major decisions about my medical care to my doctor.”) [29, 97, 99, 105-107]

Another clear example of how reported decision role preferences are sensitive to the format and wording of question stems and response options can be seen in studies which use two contrasting measures. Two measures can show opposite patient role preference in the same sample of subjects.[29, 50-51, 106] Gattellari and Ward [29], using both the CPS and a dichotomous measure, found that 45% of men who had been classified as passive by their dichotomous measure preferred a “shared” role on the CPS. Buchanan et al. [38] found 76% of patients said decisions ultimately should be made by the patient in response to a statement that positively framed a patient's role in final decisions. Meanwhile 51% of the same sample said the doctor should have the final say in response to an item that positively framed the physician having the final decision role.

Equally important, measures that explicitly presented a shared decision response option, such as the CPS or PSDM, found a higher percentage of respondents preferred shared or autonomous decision roles. Measurement scaling differences contributed to these variations as well with some measures having only two response choices versus those having 5 response categories with the CPS.

Two-thirds of the non-hypothetical measures found a greater preference for participating in decisions, while less than half of the hypothetical studies did so. A number of studies with hypothetical scenarios reported condition severity was negatively associated with shared decision role preference, however, findings were inconsistent within the same condition and between two samples from Australia.. [17, 116]

4. Discussion

This comprehensive review compared findings between health populations studied, recency of publication and measures utilized. Several patterns emerged along with implications for both researchers and practitioners.

4.1 Study Population Patterns

First, the choice of the study population contributes to contradictory findings in the literature. When we segmented studies into different patient and population health groups, interesting differences in patterns emerged. In three quarters of the cancer studies and invasive procedure studies, the majority of patients preferred shared or autonomous decision making. In contrast, this was true for only about half of the studies with non-disease specific study populations or other chronic conditions, many of which incorporated hypothetical scenarios. It is important to note that the category of “other chronic conditions” included a broad range of conditions including diabetes, asthma, hypertension, HIV, multiple sclerosis for example. Future reviews may have more studies within subgroups of chronic conditions to enable finer comparisons between them.

4.2 Publication Recency Patterns

Second, recency of the publication was highly associated with increasing preference for shared decisions. The majority of study respondents preferred shared or autonomous decision making in 43% of studies before 1990, 51% of studies between 1990 -1999, and 71% after 1999. This trend is particularly strong for cancer studies where a majority of patients preferred to participate in decisions in 85% of the 27 *cancer studies* published in or after 2000 versus 62.5% of studies before 2000.

4.3 Measures Patterns

Clear differences occurred in patients’ reported decision role preferences depending on the measure used. This varied by the wording of the stem of the sentence as well as how explicit the shared decision option was in the measure. A much higher percent of respondents reported they preferred to share decisions if the stem of the root sentence affirmed sharing decisions. The same was true if the measure's response categories included an explicit option to share decisions.

Hypothetical vignette measures raised a number of questions given their inconsistent findings. They have the potential to provide controlled comparisons to study respondents’ reactions, but respondents may never have experienced the condition or decision situation for which they are asked to anticipate a role preference. This has been analyzed by others within a concept of “cold-to-hot” empathy gaps. This perspective posits that it may be quite difficult for a person not in a state where a decision needs to be made (cold) to imagine his or her own feelings and behavior in those (hot) states. [131]

In summary, this review suggests bias can be introduced through the selection of measures and should be carefully considered in terms of whether a measure: 1) includes an explicit response option for shared decision making as well as decision delegation; 2) positively or negatively frames delegating or sharing decisions in the root stem of a single item measure; 3) presents only hypothetical scenarios that a person may not have experienced and may not be able to anticipate their response. The validity of results is deeply weakened to the extent a measure slants patient responses through social desirability effects and framing.

4.4 Implications for Research

A challenge in evaluating tools that can be used to assess patient preference for decision making is the nonstandardized fashion in which their findings are presented, particularly with the API. While some authors provide mean scores for different vignettes, they may not give a summary score or general scale score and vice versa. (See Table 1.) Nor is the algorithm for interpreting a **tool's** scores always given. It is important for future authors to provide all scale scores, how standardized scores were derived, and the rubric for **interpretation. An important** methodological question centers on how to interpret mean scores used by several measures. The lack of psychometric data about measures weakens inferences about the reliability and validity of the **tools** used. In the future, researchers are encouraged to assist readers by systematically presenting a study measure's psychometric characteristics.

Qualitative research suggests that more work is needed to measure the construct of decision making itself. Earlier research found that patients at times are confused about what constitutes appropriate patient participation or even if they have been given a choice when a choice point was observed via coded encounter tapes. [132] Recent communication and integrative models of shared decision making offer promising approaches for helping to address this gap in key **decision making** constructs [133-135] which can assist the development of future tools and the revision of current ones.

We need to understand better how patients perceive the decision process and which decisions patients most want to share. One approach is to use trigger-stimulated recall of encounters. [136]**. We also ne**ed more longitudinal descriptive studies of how a patient's preferred role changes over time within different conditions and as health status changes. Decisions involved in calibrating ongoing or palliative regimens are equally important as initial diagnostic test or treatment decisions; however they are understudied. We may find that additional decision preference tools are needed to study these aspects of the full trajectory of care.

This literature review has limitations to note. We did not examine non-English language articles on patient decision role preferences. Nor did we examine in-patient setting studies. We also limited our analyses to quantitative studies.

4.5 Implications for Practice

Finally, we wish to consider the import of this area of study for practice. Neutral modes of assessing patient preferences are needed. Although the majority of patients wished to participate in decisions, all studies identified a subset of patients who wanted to delegate decisions. The question then is how to solicit a patient's role preference and tailor visits appropriately. While it is possible to have a previsit assessment of a patient's preferred decision role, the danger is that one's role preference could change as the visit proceeds. An alternative approach is to assess patient preferences during the visit by simply asking at natural choice points if the patient has a preference unless there have been clear cues that the patient is unable or does not want to participate at this time. A recommended model that ethicists developed for shared decision making is as follows: (1) ensure a shared understanding of the patient's illness; (2) present treatment options; (3) discuss the patient's values and lifestyle factors; (4) present a clear statement of recommended treatment options and invite patient choice [137]. By asking patients what preferences they have about a choice point, it alerts the patient that there is a choice and allows patients to participate if they wish. The majority of patients want to discuss options and receive information from physicians even though they may not wish to make the final decision.[27,106] This is consistent with the concept of patient-centered care as a partnership between practitioners and patients...”to ensure that decisions respect patients’ wants, needs and preferences and that patients have the education and support that they need to make decisions and participate in their own care.[138]

It is important to note that the nature of the decision as well as the stage of the patient-provider relationship could influence a patient's role preference. In a multiphase, qualitative study of ongoing health care relationships, Thorne and Robinson [139] found that chronically ill patients’ relationships with physicians evolve over time to a type of “guarded alliance”. Trust is at the center of this alliance, both in terms of the patient's own sense of competence and their trust in the provider's competence. As this framework suggests, the provider has the challenge to assess and adapt their information and decision making process to the patient's cues about their own self-efficacy and trust in the provider. There is no question that at some points in a relationship, a patient's own sense of competence and/or trust in their provider will lead the patient to simply prefer delegation; at those times the provider needs to respect that preference.

If we broaden the conceptualization of decision making beyond initial treatment decisions, many more opportunities exist for a range of health care professionals to invite patients’ preferences across the care process. Nearly all studies in this review report on patient preference as a “snapshot” in time rather than over time. It is key to re-examine the natural opportunities longitudinally when patient preferences can have a deep impact on quality of life, even when the decisions to the provider may seem inconsequential for clinical outcomes. For example, simple questions about the patient's preferred schedule for chemotherapy can affect a patient's quality of life in major ways by saving “good days” for family or priority work. [140]

In summary, interpreting the current literature on patients’ role preferences for decision making is challenging due to methodological variances and a limited characterization of key constructs in decision making. Despite these limitations – taken together – the studies suggest that the number of patients who prefer participation has increased over the past three decades so that the majority of patients prefer to participate in decisions during the encounter. It is in this context that researchers and clinician communication training programs can move forward our ability to identify how patient preferences and preferred decision roles can best be integrated across the full trajectory of care to improve outcomes of interest to patients and health care providers.

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Table 1

Measures of patient preference for decision-making (PPD) roles

Measure	Description	Original measure: # of dimensions and Items for each, use of vignettes or card sorts	Measurement and Presentation of Results	Modifications/ Disease Areas where scale used
Autonomy Preference Index (API) Ende et. al [16]	The API assesses patient (pt.) preference for two identified dimensions of autonomy- desire for information and desire for making medical decisions Reliability: ***Test-retest reliability:*** Decision-making scale-0.84 Information-seeking scale-0.83 Internal consistency: Cronbach's Alpha: 0.82 Validity: ***Concurrent validity:*** A correlation of 0.54 with a global item on who should take control. ***Convergent validity:*** administered the same scale to diabetic patients	1.Information seeking preference: 8 items 2.Decision-making preference: 15 items *General Decision-making: 6 items (a-f)* *a.Important medical decisions* *b.Whether to follow MD's advice, even if Pt. disagrees* *c.Care decisions when hospitalized* *d.Everyday medical problem decisions* *e.Decision whether MD should take control, when sick* *f.Frequency of check-up decision* *Clinical Vignettes: 9 items (3 item/vignette)* *Vignette 1: Mild- Upper Respiratory Tract Illness decision areas:* *a.Whether to see a doctor* *b.Whether to take a chest X-ray* *c.Whether to try a cough syrup* *Vignette 2: Moderate-Hypertension* *a.When to have next visit to check BP* *b.Whether to take time off to relax* *c.Whether to treat with drugs or diet* *Vignette 3: Severe-Myocardial Infarction* *a.How often nurses should wake Pt. to check temperature and BP* *b.Whether Pt. should have visitors aside from immediate family* c.*Whether to consult a cardiologist*	General items are measured on a 5- pt. Likert Scale: SA to SD Each Clinical Vignette is measured on a 5-point scale, where 5- patient alone, 4- mostly patient, 3- doctor and patient equally, 2- mostly the doctor and 1- doctor alone API studies present total DM score in different ways. Four types are identified: 1) 0-100 total DM score where 50 = shared; 2) 1-5 total DM score where 3 = shared; 3) 0-1 total DM score where 0.5 = shared and 4) 15-75 total DM score where 37.5 = shared. It also has four ways of presenting Vignette DM mean scores: 1) 3-15, where 7.5 =s shared, 2) 1-5 where 3 = shared, 3) 0-1 where 0.5 = shared, and 4) 0-10 where 5 = shared. Often the General Scale score is not presented at all.	.Gibson et. al [17] modified it for Asthma and developed the Asthma API. Catalan et. al [18] modified it for HIV and developed the HIV API. See table 2 for each of these studies
API Modified by Smith et al [19]	Developed a revised version of the API, offering the critique that the original version did not offer mutuality as an option for the process of participation. Reliability: ***Test-retest reliability for vignette items:*** Spearman's rho -.79-.87 Internal consistency for general items: R=.84-.91	Only the revised version uses the Decision Making Preference Scale. **General scale** has **two additional items (a2. and a3.)** added to each item, for a total of 18 items: Example for General Scale Item a: a1. Important medical decisions should be made by your doctor, not you. a2. Important medical decisions **should be made by you, not your doctor.** a3. Important medical decisions **should be made by you and your doctor together after talking it over.** Similar modifications are made for general items b-f above. Content of clinical vignette items remain the same.	Response categories of the **General Scale** remains same: 5-point Likert Scale: SA to SD Response categories of **Clinical Vignette** items were modified slightly to the use the following response categories (revisions are in bold below): ❖You alone ❖**You, after getting information from your doctor** ❖**You and your doctor after a full, mutual discussion** ❖**Your doctor, after getting information from you** ❖Your doctor alone	
Control Preferences Card Sort (CPS) Degner & Sloan [11]	The CPS assesses Pt. control preference in medical decisions from 5 cards each representing a role. The respondent is	Cards were presented in pairs, subject indicated which of the 2 cards was closest to their preferred role.	The order of 5 card preferences generate ordinal scores to reflect degree of control Pt. wanted in decision-making. Results	CPS revisions include: ❖treating each card role as a response category listed in a

Measure	Description	Original measure: # of dimensions and Items for each, use of vignettes or card sorts	Measurement and Presentation of Results	Modifications/ Disease Areas where scale used
	presented with successive paired comparisons of the cards to derive the respondent's order of most to least preferred roles. Studies suggested that preferences formed a unidimensional scale. **Validity:** Construct validity is based on the grounded theory approach that generated the categories. **Reliability:** Unfolding analysis found scale met Coombs' criterion of 50% plus 1 patients falling on the hypothesized dimension. Cancer patients, as hoped, had only 1 of possible 60 scales that could emerge from the n=5 stimuli met scaling criterion.20 (Degner, 1998)	*"I prefer to make the decision about which treatment I will receive."* *"I prefer to make the final decision about my treatment after seriously considering my doctor's opinion."* *"I prefer that my doctor and I share responsibility for deciding which treatment is best for me."* *"I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion."* *"I prefer to leave all decisions regarding treatment to my doctor."*	typically presented as percent of people who prefer: "Active roles", "Collaborative roles", or "Passive roles". Traditionally, the first two roles are categorized as passive, the middle role is categorized as shared, and the last two roles are categorized as preferring active roles.	single item stem asking what decision role Pt. prefers ❖treating each card role as 5 different item stems with response categories such as SA to SD ❖recategorizing the 5 responses to enlarge the shared decision-making category Hermansen et al.. [20]^{0}..Protiere [21]; .Salkeld et al. [22].
Health Opinion Survey (HOS) Krantz, Baum & Wideman[[23]	The HOS assesses two dimensions: desire for information and behavioral involvement. **Reliability:** Kuder Richardson =.74-.76 Test-retest - .59-.74 **Validity:** Patient behaviors and other questionnaires	16 item questionnaire with two sub-scales: *Information subscale* focuses on what the patient usually does to seek information *Behavioral involvement* sub-scale focuses on what the patient's desire is to participate in self-care. For the purposes of the current review, we focused on the data about the *behavioral involvement* subscale.	Scoring is binary - either agree or disagree. Information scores range from 0-7. Behavioral involvement scores range from 0-9. Higher scores indicate favorable attitudes toward informed or self-directed treatment.	
Problem Solving Decision-Making Scale (PSDM) Deber et al [24]	The PSDM scale measures patient preferences for decision-making for 4 problem-solving and 2 decision-making tasks using 3 clinical vignettes. **Reliability:** Internal consistency: Cronbach's Alpha: Range 0.71 to 0.90 for 1 vignette to 3 vignettes **Validity:** Factor Analysis: 55.3% variance extracted	1.**Problem Solving (PS) dimension uses 4 tasks:** *a.Diagnosis: Decision about the likely causes of symptoms* *b.Treatment options: Decision about what the treatment options* *c.Risks and Benefits: Decision about the risks and benefits for each treatment option* *d.Probabilities of risks and benefits: Decision about the likelihood of risks and benefits* **2.Decision-making (DM) dimension uses 2 tasks:** *a.Utility: Decision about the acceptability of risks and benefits* *b.Decision: Decision about the treatment option, given the information about risks and benefits* These PS and DM tasks are presented for the following vignettes. Vignette 1- Morbidity vignette Vignette 2: Mortality vignette Vignette 3- Quality of Life vignette	The 6 tasks (4 PS tasks and 2 DM tasks) are measured on a 5- point scale, where 5-patient alone, 4- mostly patient, 3-doctor and patient equally, 2-mostly the doctor and 1- doctor alone for each vignette. Typically, for each vignette, mean scores on the 5-point scale for each task are presented. For individual tasks, percentage patients reporting preference for decision-making are reported. Some articles report means and others report percents. On a 5-point scale any score around 3 can be considered patient preference for shared decision-making	Meana et al.[25] and Stewart et. Al [26] used the PSDM scale for their studies without using the vignettes.

Table 2

[a] Respondents' decision role preferences across all study analyses (N=119 analyses in115 studies[a])

In 63% (75) of analyses the majority preferred to *participate in decisions*[b]	**In 21% (25) of analyses the majority preferred to *delegate decisions***	**In 16% (19) of analyses MIXED vignettes or samples[c] had MIXED findings**
[19], [21], [24a], [25-27a,b], [29a], [30-96]	[10], [14], [24b], [28a, 28b], [29b], [97-115]	[11], [16-18], [22], [116-129]

[a] Each cell contains the citation number of relevant studies in the reference list of this paper. Four studies compared two different measures so while there are 115 studies, there are 119 analyses of different measures. See for example Nease, 1995.

[b] The term *participate in decisions* refers to patients who either wanted to share decisions or to make them alone.

[c] The Mixed Findings Category indicates studies using a single measure with mixed findings due to using different subsamples (for example different countries or regions) or due to using a single measure with different vignettes (such as the API) or 2 or more items in a non-vignette single measure.

Table 3

Health population patterns (N=119 analyses in 115 studies)

Health Population	**Majority preferred to participate**	**Majority preferred to delegate**	**MIXED vignettes/ samples had MIXED findings**
Cancer (43 Analyses)	**77% (33 analyses)** [21], [32], [34-42], [45], [47-51], [54-55], [58], [62-64], [69-70], [76], [80], [83-84], [88], [91], [93], [95]	**14% (6 analyses)** [10], [14], [100-101], [111], [114]	**9% (4 analyses)** [11], [22] [117], [123]
Other Chronic Conditions (26 Analyses)	**46% (12 analyses)** [30-31],[56-57], [59-60], [75], [78], [86-87], [89-90]	**31% (8 analyses)** [28a, b], [97], [102-103], [108-9], [115]	**23% (6 analyses)** [17-8], [116], [119], [121], [124]
Invasive Procedures (14 Analyses)	**78.5% (11 analyses)** [24-26], [43], [65],[71-73], [79], [85], [96]	**14% (2 analyses)** [24],[104]	**7% (1 analysis)** [128]
General Population (36 Analyses)	**53% (19 analyses)** [19], [27a,b], [29a], [33], [44],[46], [52-53], [61], [66-68], [74], [77], [81-2], [92], [94]	**25% (9 analyses)** [29b], [98-99], [105-107], [110], [112-113]	**22% (8 analyses)** [16], [118], [120], [122], [125-127],[129]

Table 4

Recency of publication patterns (N=119 analyses in115 studies)

Year Study Published	Majority preferred to participate	Majority preferred to delegate	MIXED vignettes or samples had MIXED findings
1974 -1989 (7 analyses)	**43% (3 Analyses)** [35], [42], [90]	**43% (3 Analyses)** [14], [108], ,[112]	**14% (1Analysis)** [16]
1990 -1999 (37 analyses)	**51% (19 Analyses)** [19], [24a], [25] [33-34], [38], [41], [47], [49], [51-52], [58], [65-6], [71], [77], [81], [83], [87]	**27% (10 Analyses)** [10], [24], [28a,b], [98],[100], [102] , [107], [111], [113]	**22% (8 Analyses)** [11], [18], [17], [117-120], [129]
2000 -2007 (75 analyses)	**71% (53 Analyses)** [21], [26-[27a, b], [29a], [30-32], [36-37], [39-40], [43-46], [48], [50], [53-57], [59-64], [67-70], [72-6], [78-80], [82], [84-86], [88-89], [91-96]	**16% (12 Analyses)** [29b], [97], [99], [101], [103-106], [109-110], [114-115]	**13% (10 Analyses)** [22], [116], [121-128]

Table 5

Measure patterns (N=119 analyses in115 studies)

Measure Used In Analyses	**Majority preferred to participate**	**Majority preferred to delegate**	**MIXED vignettes or samples got MIXED findings**
API (12 Analyses)	**8% (1 Analysis)** [27]	**17% (2 Analyses)** [102], [28]	**75% (9 Analyses)** [16-18], [116], [119-121], [126],[129]
API-Modified (4 Analyses)	**100% (4 Analyses)** [19], [33], [59], [66]		
CPS (44 Analyses)	**75% (33 Analyses)** [21], [29a] [32], [34], [36-37], [40-41], [43-51] [53-55], [58], [60], [62-63], [69-70], [76], [80], [83],[89], [93], [95-6]	**14% (6 Analyses)** [10], [14] [100-101], [111], [114]	**11% (5 Analyses)** [11], [22], [117], [122-123]
DPMD (2 Analyses)	**100% (2 Analyses)** [56-57]		
HOS (5 Analyses)	**20% (1 Analysis)** [27]	**80% (4 Analyses)** [24], [28], [108], [110]	
PPOS (2 Analyses,)	**100% (2 Analyses)** [67-68]		
PSDM (5 Analyses)	**80% (4 Analyses)** [24-25], [77], [85]		**20% (1 Analysis)** [124]
Other (45 Analyses)	**62% (28 Analyses)** [26]?,[30-31], [35], [38-39], [42], [52], [61], [64-65], [71-75], [78-79],[81-82], [84], [86-88], [90-92], [94]	**29% (13 Analyses)** [29b], [97-99], [103-107], [109], [112-113], [115]	**9% (4 Analyses)** [118], [125], [127-128]