Medical Decision Making

Developing CollaboRATE: A fast and frugal patient-reported measure of shared decision making in clinical encounters

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ARTICLE INFO

Article history:
Received 4 February 2013
Received in revised form 8 May 2013
Accepted 13 May 2013

Keywords:
Shared decision making
Measurement
Cognitive interviewing

ABSTRACT

Objective: Measuring the process of shared decision making is a challenge, which constitutes a barrier to research and implementation. The aim of the study was to report the development of CollaboRATE, brief patient-reported measure of shared decision making.

Methods: We used the following stages: (1) item formulation; (2) cognitive interviews; (3) item refinement; and (4) pilot testing of final items. Participants were over 18 years old, recruited from the public areas of the Dartmouth-Hitchcock Medical Center.

Results: The key finding of this study is that developing a brief patient-reported measure of shared decision making requires a move away from terms such as ‘decisions’, ‘options’ and ‘preferences’. Although technically correct, these terms act as barriers. They are often unfamiliar, and they also implicitly assume that patients are willing to take active roles in decision making; whereas patients are often unaware that decisions are required, or have taken place, never mind feel that they could or should have participated in them.

Conclusion: These methods have allowed us to develop a brief, patient-reported measure of shared decision making that is highly accessible to intended users.

Practice implications: The potential strength of the CollaboRATE will be the ability for completion in less than 30 s, and across a range of routine settings.

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1. Introduction

The assessment of shared decision making has given rise to a number of measurement challenges. It has been difficult to achieve valid, reliable, and scalable patient-reported measures of shared decision making, and this has become a recognized barrier to making progress in both the research and implementation of patient centered care [1]. This is an especially pressing issue for policy-makers, particularly in the USA where the quality of patient centered care and the ability of hospitals to feedback quality patient-reported outcome measures will soon impact financial remuneration for health professionals from the Centers of Medicare and Medicaid Services [2]. The absence of a measure that can fit into the workflow of routine clinical practice, enabling the standardized comparison of responses across clinics, stands in the way of these implementation efforts.

There has been considerable effort made to address this measurement challenge. Scholl [1] recently identified 29 measures of shared decision making. There are a handful of third party observer measures of shared decision making [3–6], but there has been low correlation between observed assessments of patient involvement in decision making and concurrent patient reports [7–10]. Of 22 measures that were described as being patient-reported [11–32] only four specifically assessed process aspects of shared decision making [15,31–33]. A recent addition to this list, and not in Scholl’s review, is a set of patient-reported involvement items reported by Frongillo, which the authors state need further psychometric testing [34].

Researchers have consistently reported limitations of existing measures, particularly their low content validity, and ceiling effects [1]. The lack of patient involvement in item development may have been a contributing factor to these problems. Examination of the reported development of existing measures did not indicate that qualitative methods, such as focus groups, interviews
or cognitive interviews, had been used to ensure that items could be accurately interpreted by patients, as recommended [35–37]. Tools that did use such methods were developed by Edwards [23], Farin [26], Arora [11] and Melbourne [29], who used either interviews, focus groups or cognitive interviews.

Furthermore, of the five existing patient-reported measures of shared decision making process [15,29,31,32,34], all include items that refer to a health decision or treatment options, and often, a treatment decision. As well as reducing the applicability of the measure only to those encounters where decisions are visible or made explicit, this tendency to refer to ‘decisions’ or ‘options’ may undermine the interpretability of the items (and thus, the validity of the measures) for some patients. Patients often fail to recognize that a decision has taken place in a healthcare encounter [38,39], have difficulty focusing on only one decision in the context of an extended health care experience involving multiple decisions [40], or find it challenging to nominate the agent of the health care decision [38,39].

The majority of existing patient-reported measures in this area are also relatively lengthy [1], with the exception of SURE [24]. This obstructs their use in routine practice limiting the accuracy and immediacy of data feedback that health professionals could use to assess their performance and that could alert patients to aspects of care they should expect. Indeed, the development of short or even single-item measures in related fields, such as self-reported health status, have demonstrated adequate levels of validity and reliability [41]. Despite the limited use of patient-reported feedback by health professionals, such feedback mechanisms have been shown to have a positive impact on clinical practice [42], and patient participation in medical care has also been associated with a range of positive health outcomes [43].

The dominant conceptualization of shared decision making focuses on just two key dimensions, namely: (1) health professional disclosure and patient understanding of information about health care options and outcomes and (2) the option chosen is congruent with individual patient values and preferences [44,45]. While this conceptualization has been criticized for being narrow [46], in that it overlooks the broader aspects of patient role and the relationship with the clinician, measures focusing on core dimensions of shared decision making offer a more tangible target for assessment purposes. In addition, Glass [47] found significant positive associations between these dimensions and patient satisfaction with decision making.

Our goal was to develop a patient-reported measure of the extent of shared decision making process in clinical encounters that is pragmatic as well as valid. We set out to develop a measure that was sufficiently generic that it could be applied to all clinical encounters and for all conditions, as well as brief enough for use in routine practice. The aim of this study is therefore to report the development of a fast and frugal measure of shared decision making, where we included the use of cognitive interviews to examine the validity of a provisional set of dimensions and items.

2. Methods

2.1. Study overview and population

In this article, we describe the development of CollaboRATE, a fast and frugal patient-reported measure of shared decision making, which incorporated four stages of development: item formulation, two stages of cognitive interviewing with potential end-users and pilot testing of the final set of items. Participants were men and women, over 18 years old who could read English, and were recruited from the public areas of the Dartmouth-Hitchcock Medical Center. Although some of these people may have been patients, we were not specifically seeking the views of patients attending the clinic, and we did not seek ethical approval to ask about their health problems. The Committee for the Protection of Human Subjects at the Dartmouth College Institutional Review Board approved the project (CHPS #23687). For the pilot stage, we administered the measure to patients immediately following clinic appointments.

2.2. Item formulation

Initial item formulations were based on core aspects of the principles of shared decision making [44,45,47,48], and on a detailed analysis of existing measurement challenges [1]. Given our pre-specified goal of creating a brief measure, we adopted the two core elements of share decision making described above: (i) provision of information or explanation to the patient about the relevant health issues or possible treatment options and (ii) elicitation of the patient’s preferences related to the health issues or treatment options. We then generated several versions of scale items to assess the presence or absence of these elements of care from the patient’s perspective, and these were presented to interview participants. All candidate items generated avoided the use of the term ‘decision’ for the reasons outlined above.

2.3. Study design

We conducted two stages of interviews with approximately 12 participants per stage [49]. An initial set of items were assessed in stage one. Refined items were then assessed in stage two, and further modifications made. In stage three, a final set of items was piloted with patients as they left a clinic appointment, to assess acceptability, ease of use and estimate completion times.

Cognitive interviews [36] are a recognized step of instrument development methods [35]. We wanted to know how individuals would interpret survey items designed to assess their views with regard to whether shared decision making had taken place in their encounters with providers. We specifically wanted to know whether their interpretations were aligned with the dimensions we wished to measure. Participants were given time to read a set of candidate items, with alternative forms. Preset questions and probes were used [36]. We asked, for example: “Do the words in the question make sense?”; “Is there anything you find confusing or poorly worded?” We wanted to identify concerns about unfamiliar words, e.g. “What does the term ‘healthcare provider’ mean to you?”, and to assess whether any phrases were likely to be misunderstood “What does the term ‘how much effort’ mean to you?” We also wanted to check the face validity of the item by asking the question: “In your own words, what do you think the question is asking?”

Participants were also asked about their views about potential response score anchors in stage one. We asked participants to assess the degree of ‘effort’ made by providers to achieve specified tasks and offered the following minimal-level anchors: ‘No effort’, ‘No effort at all’, ‘No effort was made’ or ‘None’, and the following maximum-level anchors: ‘Every effort’, ‘Every effort was made’, ‘A huge effort’ or ‘A massive effort’.

2.4. Data collection and analysis

We recruited individuals in public areas, and after consenting them to take part, we asked them to be interviewed in a side-room. We did not keep a note of those who declined. Interviews were conducted by two researchers (PB and SWG), audio-recorded, transcribed, and commentaries written within one day. Participant comments, concerns, misunderstandings and misinterpretations about each item were identified and compared. Coherence to our measurement goals was evaluated [36]. When no further new
Table 1
Participant characteristics<sup>a</sup>

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<tr>
<th></th>
<th>Stage 1</th>
<th>Stage 2</th>
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<td>N=30 (P28–P57)</td>
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<sup>a</sup> We numbered the participants P1–P27 and use the following label convention (P8 <45 F) to refer to participant number (P8), age (less than 45 years of age) and gender (F= female; M= male).

<sup>b</sup> Two participants self identified ethnicity as Hispanic & one participant self identified race as other. All other participants self identified as non-Hispanic & White.

<sup>c</sup> Two participants did not report education or employment.

Comments were received in the first interview stage, items and anchors were revised, prior to the second set of interviews.

3. Results

3.1. Participants

A total of 27 participants (Table 1) were interviewed in stages one and two. In stage three, 30 more individuals completed the items immediately after a clinical encounter, and provided feedback. Over 70% (40/57) of the participants had a degree level education, reflecting the demographic profile of the hospital's catchment area.

3.2. Item development and evaluation

Table 2 shows how items were initiated, modified and finalized during the study. CollaboRATE was initially conceived as a two-item survey capturing what were considered to be two core dimensions of shared decision making. After completing the first stage of interviews, it became apparent that we had conflated two dimensions when considering items for 'preference elicitation'. Interview data prompted us to recognize the need for an additional dimension, one that considered the task of 'preference integration', i.e. making sure that patient's preferences were taken into account as decisions are made. Together, we felt that these three dimensions formed the core construct of shared decision making. A new set of items covering this dimension were generated, and evaluated in the second interview stage.

3.3. Generic changes to item phrasing

Data analysis from stage one led to several changes in item construction. Initially, items included the phrasing 'how much effort do you feel your healthcare provider (e.g. doctor, nurse, midwife, pharmacist) ...', followed by a specific task. Participant reactions led us to simplify the item by using the passive form 'how much effort was made'.

The use of the word 'today' was seen as unnecessary given the intended same-day use of this patient-reported measure in the future. The plural term 'health issues', received more support than the term 'problem' as well as indicating that more than one decision might be under consideration. Participants considered the term 'problem' as "off-putting" (P8 <45 F), "cold" (P12 45–64 F), that it implied a "negative frame", and that people seek health care for a range of reasons and not just 'problem[s]'?

When asked to consider response anchors, ten of 12 participants in stage preferred the maximal-level descriptor 'every effort was made'; seven of 12 participants preferred the minimal-level descriptor 'no effort was made'. These anchors were adopted in the final version of CollaboRATE.

3.4. Development of Item 1: 'How much effort was made to help you understand your health issues?'

Participants provided feedback on the following three candidate phrases: 'explain problem', 'understand health issues', or 'pay attention to what matters most' (see Table 2). Concerns were raised about the term 'information'. Participant 7 said that it implied that the provider "[gave] you the information ... [before] sending you away" (P7 45–64 F). Participant 10 equated...
‘information’ to receiving "pamphlets, graphs and websites “rather than being engaged in a dialogue” (P10 45–64 M). Nine of 12 participants preferred the question ‘... help you understand your health issues?’ Participant 1, said “this question is asking me to judge how the provider helped me to understand” (P1 65 F). Participant 5, said, “I think 'help you understand' ... is more of a collaborative thing” (P5 45–64 F). Item 1 remained unchanged after stage two, when all participant responses (N = 15) indicated good understanding.

3.5. Development of Item 2: ‘How much effort was made to listen to the things that matter most to you about your health issues?’

3.5.1. Interview stage one: item refinement

We wanted to know which of the following terms, ‘understand’, ‘consider carefully’ or ‘pay attention’, best describes the work that providers should do when eliciting patients views, priorities or preferences. We also wanted to know which of the following terms—‘worries and concerns’, ‘matter most to you’ or ‘most important to you’—were the most acceptable phrases for inclusion in the item. Participants said that ‘people recognize listen’ more than [they recognize] ‘consider’” (P1 65 F) and remarked, “... I'm not sure what 'consider carefully' means” (P10 <45 M). Participants also preferred ‘listen’ over ‘pay attention’. Participant 9 felt that the term ‘listen’ should be used rather than ‘pay attention’ (P9 45–64 M), participant 10 stated, “you can pay attention without understanding [a patient’s preferences]” (P10 <45 M). The term ‘listen’ was introduced and the term ‘consider’ was used without the adverb ‘carefully’ in stage 2.

There was significant variation in responses to the terms ‘worries and concerns’, issues that ‘matter most to you’ or issues that are ‘most important to you’. As one participant remarked, the use of the term ‘worries and concerns’ may stimulate anxiety: “you might not even know you're worried until you leave” (P2 >65 F). More participants preferred the term ‘what matters most’: a view best summarized as follows: “I do like the second one ['what matters most to you'] more than the first phrase ['what is most important to you']. What ‘matters most to me’, ... makes me think about values and things of value. Or if you're a person who wants a more holistic approach, and [that] the provider is willing to take that approach ...” (P3 >65 M). However, lacking a clear consensus, three terms—thoughts and opinions, ‘what matters most’ as well as the more technically accurate term ‘preferences’—were retained for comparison in stage two interviews.

3.5.2. Interview stage two: item refinement

In stage two, the term ‘listen’ was preferred by the majority of participants and was adopted into the final item. When comparing terms the difference between ‘listening’ and ‘considering’ was emphasized as follows: “listen to” ... [means that the provider] has heard and thought about what I said ... but who knows if they are considering it or not ...” (P1 45 F). She added, “if they [the provider] ... reiterated what I told them, I would know they had listened to me.”

When exploring reactions to the term ‘preference’ it became clear that the term was unclear to participants: “[this term] preferences is not clear” (P13 <45 F), and “I don't know what preferences would mean in this context” (P15 45–64 M). Many interpreted ‘preference’ as referring to the chosen option rather than referring to individual priorities: “what are my preferences? ... in other words he's giving me choices” (P23 >65 M) and “...if you had a number of choices, which [one] would be the one that you prefer” (P25 45–64 M).

The term ‘what matters most’ remained the most consistently understood term in this interview stage. Reactions included statements indicating that the term was the same as the things that are “more personal” (P17 <45 F) and “at the core of my concerns ... whether it be future health problems, family, or ... how I manage at home ...” (P20 <45 F), or referred to whether “... one concern outweighed others? In making a decision, I want to see my child graduate from high school. I want to stay alive as long as I can” (P24 >65 F). Nine of 15 participants preferred the phrasing ‘what matters most’, and understood the item to mean “how concerned and how interested ... [healthcare professionals were] in what I had to say about my health issues” (P26 >65 M).

In addition, there was significant evidence in the interviews of resistance toward the adoption of decision making roles when individuals considered how they would react in clinical encounters: “... when someone ... knows more than I do, I do really need them to help me choose what is good for me” (P23 >65 M), a view also espoused by participant 22: “my preference may not be best, therefore the decision or choice by the professional/the provider is the important thing?” (P22 >65 M).

3.6. Development of item 3: ‘How much effort was made to include what matters most to you in choosing what to do next?’

As described above the need for this item emerged during our first round of interviews. Participants noted a difference between providers who listened to ‘what mattered most’ and those who took the extra step to integrate those priorities when making recommendations. Participant 7 asked, “how would I know if he [provider] understood my worries and concerns?” (P7 <45 F). In research terms, we recognized this as the difference between preference elicitation and preference integration. As one participant said, it is the difference between “understanding my concerns’ versus also “paying attention to ... what I am saying” (P10 <45 M). We therefore recognized the need to develop a new item to address the dimension of preference integration.

After brainstorming candidate items, we selected a group of possible phrases (Table 2). We asked participants to respond to the terms ‘work’, ‘involve’ or ‘include’. Participants preferred the term ‘include’ as being a better indication that a patient was being brought “into the whole process” (P25 45–64 M). For the second part of this item, we evaluated the verbs ‘deciding’ or ‘choosing’ as well as the descriptions ‘way forward’ or ‘next steps’. Although there were those that felt the verbs to be “interchangeable” (P22 >65 M) the majority of preferred the term ‘choosing’ over ‘decide’ and, again, some participants responded that they viewed decision making as being beyond their remit and that “... [a] decision seems to be more of a physician decision” (P21 45–64 F).

When considering the future-oriented phrases, participants preferred the phrase ‘what to do do next’: it was interpreted as giving a positive and immediate “... sense of direction and purpose” (P24 >65 F), whereas ‘the way forward’ was viewed as indicating a broader longer time frame, as in “the future of your treatment” (P25 45–64 M). Based on these responses, we arrived at the final item phrasing: ‘How much effort was made to include what matters most to you in choosing what to do next’? Ten of 15 participants preferred this item.

3.7. Stage three completion of the pilot survey

Thirty participants provided brief demographic details and completed the final version of CollaboRATE, responding on a scale from 1 = No effort was made, to 10 = Every effort was made, all in less than 30 s. Participants were surprised as well as relieved that the survey was so short, and were positive about the focus of the questions. As a participant said: “As many times as I have been here I have never had a question like that. I think it’s a damn good question” (P27 45–64 M).
4. Discussion and conclusion

4.1. Discussion and principal findings

The key finding of this study is the confirmation that the correct end-user interpretation of a brief patient-reported measure of shared decision making is significantly improved by including the views of lay people in the development process, leading to the avoidance of terms such as ‘decisions’ and ‘preferences’. Although technically correct, these terms are barriers because, as well as being words that are unfamiliar to patients, they also implicitly assume that patients are willing to take active roles in decision making. Decisions always occur of course, even if the action is to not to make any changes, but these decisions are often implicit. Patients are therefore unlikely to be aware that decisions are required, or have taken place, unless providers make alternative courses of action clear.

The interview data indicated that many of the participants we questioned did not consider themselves to be in ‘decision making’ roles when attending clinical encounters. We saw this as an example of the expectation dissonance already noted in the literature – that patients, by and large, do not expect to step into decision making roles, and therefore, become confused when asked questions that include terms such as ‘decisions’ that imply such roles. It was clear from the data we collected that terms such as ‘what matters most’ and ‘choosing what to do next’ are more readily understood by patients and closely align with the terms used by researchers, ‘preferences’ and ‘decisions’, respectively.

4.2. Relation to existing literature

Our need, during the initial stages of development, to add a third-item to the measure corresponds to existing conceptualizations of shared decision making, and match three items in SDM-Q-9, that best predict patient satisfaction [47]. We plan to go into more depth on how this three-item measure can be considered alongside existing measures of shared decision making in future studies.

Interpretation challenges in this area are well known. As Scholl noted [1], patients often interpret attempts to measure their presumed participation in decision making as attempts to assess satisfaction. Entwistle and others have drawn attention to the difference in how patients and researchers interpret terms such as ‘involvement’ [39,50–52]. The reluctance of patients to step into decision making roles is also well-established [39,53,54]. Examining the literature, it seems that these issues are rarely considered during the development of measures in this field.

We intend to evaluate whether the involvement of lay people and patients in the development of our items, through cognitive interviews, will provide CollaboRATE with a greater degree of content validity. In contrast, all of the patient-reported measures of shared decision making to date have either included the term ‘decision’ or referred to ‘options’ in their item phrasing [1], and therefore, for the reasons already elaborated, they run the risk that patients misinterpret or measurement goal. Rather than narrow our focus on ‘decisions’, we developed items to assess broader aspects of engagement. We found that the phrase ‘what to do next’ was correctly interpreted by patients as involving situations where key determinations are needed. However this avoided the ambiguity surrounding the use of the term ‘decision’, as well as attributing the decision making role to either patient or provider. Such findings highlight the need to develop tools that are purposefully designed for end-users.

4.3. Strengths and weaknesses of the method

The quality of measure development is often compromised by not paying attention to the steps of construct clarification and rigorous item development, particularly when completion requires end-user interpretation. Cognitive interviewing is an established technique to address this requirement [36], and because of the focus on individual responses to item phrasing, is superior to the use of focus groups methods. We also tested responses and preference to two response scales, an important yet often overlooked step in measure design [55]. A potential weakness of this work is the relative homogeneity of the participant sample, and their higher than average educational profiles. However, we noted no difference in item interpretations across the range of educational profiles but accept that further testing of these items would be required in different populations.

4.4. Conclusion

This work has used recommended qualitative methods to arrive at a brief patient-reported measure of shared decision making that we anticipate will have acceptable content validity. This was the first step of a program of work which will go on to evaluate how the measure performs in ideal and real-world settings, as well as the effect of delivery mode and the timing of data collection.

4.5. Practice implications

The potential strength of the CollaboRATE will be the ability for completion in less than 30 s, and across a range of routine settings. The possibility may arise of aggregating a large number of responses to be used as a performance metric or feedback tool at hospital, clinic or provider level. We recognize however, that it would be premature to consider these issues until we have data about the psychometric performance of this measure.

Licence

Note that the CollaboRATE Score will be subject to a Creative Commons Licence. Attribution-NonCommercial-NoDerivs 3.0 Unported. All enquiries about the Licence should be directed to glynelwyn@gmail.com.

Funding

This work was funded by the Dartmouth Center for Health Care Delivery Science, Dartmouth College, USA.

Conflict of interest

None.

Acknowledgements

We wish to acknowledge all the participants and patients who contributed to this study. We also acknowledge the staff at the Center for Shared Decision Making at Dartmouth-Hitchcock Medical Center for their support and use of their facility; Ashley Harris, Martha Travis-Cook, Dr. Susan Berg, and Dr. Dale Collins Vidal. We thank Dr. Carolyn Kerrigan and staff at the clinic for their support with the pilot testing stage of the study.

References


