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ABLE to support patient financial capacity: A qualitative analysis of cost conversations in clinical encounters

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Highlights

- Patients need space for cost conversations whether or not they experience financial hardships
- Patients are eager to discuss costs and often share indirect signals of financial burdens
- High-quality responses to patient needs demonstrate a drive to know *why* patients face cost issues
- Empathic responses to patient burdens made space for broad conversations about care, including costs

ABLE to support patient financial capacity: A qualitative analysis of cost conversations in clinical encounters

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ABSTRACT

Objective: To explore how costs of care are discussed in real clinical encounters and what humanistic elements support them.

Methods: A qualitative thematic analysis of 41 purposively selected transcripts of video-recorded clinical encounters from trials run between 2007 and 2015. Videos were obtained from a corpus of 220 randomly selected videos from 8 practice-based randomized trials and 1 pre–post prospective study comparing care with and without shared decision making (SDM) tools.

Results: Our qualitative analysis identified two major themes: the first, Space Needed for Cost Conversations, describes patients' needs regarding their financial capacity. The second, Caring Responses, describes humanistic elements that patients and clinicians can bring to clinical encounters to include good quality cost conversations.

Conclusion: Our findings suggest that strengthening patient-clinician human connections**,** focusing on imbalances between patient resources and burdens, and providing space to allow potentially unexpected cost discussions to emerge may best support high quality cost conversations and tailored care plans.

Practice implications: We recommend clinicians consider 4 aspects of communication, represented by the mnemonic ABLE: Ask questions, Be kind and acknowledge emotions, Listen for indirect signals and (discuss with) Every patient. Future research should evaluate the practicality of these recommendations, along with system-level improvements to support implementation of our recommendations.

KEYWORDS:

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1. Introduction:

Over the last decade patients have experienced an increase in out-of-pocket costs to cover health care expenses [1, 2], resulting in more Americans reporting difficulty paying for care [3]. While the enactment of the Affordable Care Act in 2010 widened insurance coverage, out-of-pocket expenses continued to increase for the insured by 12% between 2014 and 2017 [4]. High out-of-pocket costs increase patient financial burdens and increase patients' perceived financial stress [5, 6]. High out-of-pocket costs can also lead to patients delaying or skipping care and cost-related medication non-adherence, such as not filling prescriptions, or taking less medication than prescribed [3, 5, 7-15]. Moreover, financial burden is related to reducing expenses on basic necessities like food, clothing, heat, or housing [10, 16, 17], cutting back on leisure activities, and using savings to defray out-of-pocket expenses [17].

Good quality cost conversations between clinicians and patients have the potential to identify and address cost issues and patient financial capacity at the point of care to better inform decision making and ensuring care fits patients' lives [18-20]. Patients persistently demonstrate eagerness to have and participate in cost conversations [3, 16, 21-26]. Yet, studies document that the incidence of cost conversations varies from 15% to 65% [27]. Beyond frequency, we also need a better understanding of *how* affordability is addressed in real conversations between clinicians and patients and what humanistic characteristics of those conversation best respond to patients' financial burdens [28].

Three important conceptual models help illustrate patient financial burdens and humanistic responses to them. First, the Cumulative Complexity Model (CuCoM) states that patients have a set of workload stemming from life and healthcare; that workload is accomplished by having enough capacity (i.e., abilities and resources) available to manage it.

[29] If patients lack the available abilities and resources to meet the demands of their healthcare and life—if their workload and capacity are not in balance—then patients may experience negative outcomes in their care. [29] More nuanced understandings of factors (i.e., burdens) related to treatment are outlined in the Burden of Treatment Theory (BOTT) (e.g., navigating patient portals, managing multiple medications, reshaping family dynamics to accommodate treatment regimens) [30]. Finally, we understand patient capacity through the detailed description outlined in the Theory of Patient Capacity (TPC), whereby patient capacity is resultant of patient interactions with their biographies, resources, environment, workload, and social network [31]. These conceptual models illustrate how financial burdens impact patients from a standpoint of *financial capacity*. We define *financial capacity* as a patient's ability to afford and address their healthcare costs, including but not limited to costs derived from insurance premiums, healthcare co-pays, medications, and other out-of-pocket costs. In other words, financial capacity sees affordability as a matter of balance with patients' lives and available resources, not as a question of the absolute costs of care.

To this end, we aim to explore both how cost is discussed between patients and clinicians in real clinical encounters and what humanistic elements (i.e., respect, compassion, empathy) support them. By addressing humanistic elements of cost conversations, we identify best practices for care that will keep a concern for the holistic well-being of the patient at the center of conversations about cost and enhance patients' capacity to manage financial burdens.

2. Methods:

2.1 Study Design

Four researchers (NE, CL, AM, KB) used qualitative research methods to analyze video-recorded clinical encounters. Videos used in our analyses were obtained during the conduct of

eight practice-based randomized clinical trials and one quasi-randomized clinical trial (pre and post) between 2007 and 2015, which aimed to assess the impact of six different shared decision-making (SDM) tools (compared to usual care) on the management of a variety of conditions including chest pain, diabetes, Graves' disease, depression, and osteoporosis, as well as cardiovascular risk prevention [32-37]. **Supplementary Table 1** describes each SDM tool and how each one addresses costs specifically; **Supplementary Table 2** provides demographic information. The Mayo Clinic Institutional Review Board approved the original trial protocols, as well as the use of these videos for secondary analyses. Written consent was obtained from all participants who participated in the trials.

2.2 Encounter Selection

We first randomly selected 220 videos from these trials to be analyzed for cost conversations; these videos were anonymized by study ID. Using Observer XT (Noldus; Wageningen, the Netherlands), CL and NE coded videos using a deductive coding scheme (based on analysis of audio recordings of cost conversations with cancer patients) [38] to identify and describe cost conversations occurring in each visit [16, 39]. Cost conversations were defined as any discussion of direct cost issues (e.g., medication costs) or indirect cost issues (e.g., discussion of patient employment) between patients, their companions, and clinicians. Quantitative findings on the incidence of cost conversations within encounters and the impact cost conversations had on decisional outcomes were reported elsewhere [39, 40]. From this data, we then purposefully selected for transcription and analysis 41 videos whose cost conversations exhibited characteristics we found significant for a robust qualitative discussion. Purposeful selection was based upon the following criteria (agreed upon by CL and NE): (1) offhand-yet-

telling comments about cost by patients, (2) patients sharing personal situations, (3) patients requesting action related to cost, (4) clinicians taking cost-related actions, (5) confusion or conflict around cost, and (6) insufficient discussion of cost (see **Table 1**). To be selected, conversations had to exhibit two or more of these criteria in order to create a sample size feasible for a rich, in-depth analysis of humanistic conversation characteristics. Cost conversations captured were both lengthy and brief as well as sometimes spontaneous and other times driven by decision aids.

2.3 Data Collection and First Phase of Analysis

In total, 1000 minutes of cost conversations, anonymized by study ID, were transcribed verbatim. We used inductive coding and a reflexive thematic analysis approach to analyze the transcripts using NVivo software Version 12 (QSR Intl Inc; Burlington, MA) [41]. Three researchers (CL, NE, and AM) first individually coded an initial set of 9 transcripts (22%) line by line. Then, they met to discuss and refine the coding scheme: new codes and sub-codes were added, and definitions were clarified.

The coding team continued to code and meet until no new codes emerged in discussion and the coders agreed saturation was reached; then, transcripts were coded independently and in duplicate (NE, CL, AM) and coders met to reach consensus on each transcript and maintain trustworthiness. After coding was complete, two investigators (CL and NE) met to develop overarching themes and select representative quotes. A third researcher (KRB) reviewed the themes to guarantee reliability and credibility and triangulated the results of our first analysis with theoretical models.

2.4 Theoretical triangulation

The second phase of analysis explored the inductively generated themes in relation to existing theories identified as relevant to the current work: the CuCoM [29], the TPC [31], and the BOTT [30]. These theories are used in our analysis to understand cost from a standpoint of *financial capacity*. Memo writing was used during this phase of analysis. Meetings with the other researchers (KRB) occurred regularly to ensure credibility; a fifth researcher (JB) reviewed the coding and analysis to ensure confirmability of the data. Disagreements were discussed among the researchers until consensus was achieved.

2.5 Researcher Reflexivity

In keeping with our reflexive approach to our thematic analysis, we see our subjectivities as researchers as resources that have productively shaped this project [41]. Of the researchers who directly contributed to coding and analyzing the data, three are qualitative researchers with training in the humanities (CL), clinical medicine (NE), and public health and nursing (KB); the fourth is an analyst with training in evidence-based practice research (AM) and the fifth is a statistician (KF) who compiled our demographics. While we have reported our findings based on an analysis of transcripts of the clinical encounters, we note that CL and NE have also each watched the videos in question multiple times.

3. Results:

Our qualitative analysis of the video encounter transcripts identified two major themes: (1) "Space Needed for Cost Conversations," which with its three subthemes described ways patients needed their financial capacity supported, and (2) "Caring Responses," which with its two subthemes described how clinicians responded to patient's needs. For quotes supporting each of these themes and their subthemes, see **Table 2**.

3.1 Space Needed for Cost Conversations

This theme described what patients needed to support their financial capacity. As outlined in the TPC, capacity is a dynamic accomplishment that can be nurtured through interactions, including those between patients and their clinicians. We observed that patients often followed the lead of their clinicians during clinical encounters; when clinicians proactively invited opportunities for cost conversations, patients brought up costs in ways that supported their financial capacity. Within this theme we observed the following subthemes: Cost is Valued Beyond Hardship, Cost as Justification for Decisions, and Indirect Signals of Cost.3.1.1 Cost is Valued Beyond Hardship

Only rarely did explicit discussions of patient financial hardship occur in encounters; nonetheless, when clinicians brought up cost-reducing strategies unprompted, patients responded positively (**Quote 1.1**). This aligns with the BOTT and CuCoM, as reducing costs would decrease patient burdens and thereby make other aspects of meeting their care more manageable. Other times patient responses were more neutral, which we interpreted as welcoming the information—or, at the very least, that they did not mind hearing it. For example, patients responded neutrally to clinicians habitually checking on insurance coverage when ordering medications (**Quotes 1.2, 1.3**). In some of the encounters supported by SDM tools, the tool prompted clinicians to initiate a cost conversation or review cost information with the patient (**Quote 1.4**).

3.1.2 Cost as Justification for Decisions

Both patients and clinicians often used cost in conversations to justify a decision and its feasibility in a patient's life (i.e., how it contributes to workload-capacity balance). Notably, it was often only *after* a decision was already agreed upon that costs were noted as the reason why a course of action did or did not make sense for a patient's life (**Quotes 1.5, 1.6, 1.7**). In other words, cost was brought up almost as a side benefit when discussing whether care would fit well

in a patient's life, and was not always explicitly discussed with patients in early stages of the decision-making process, even if the clinician had likely taken cost into account during their own decision-making (**Quotes 1.7, 1.8, 1.9, 1.10**).

3.1.3 Indirect Signals of Cost

Patients were often so eager to discuss costs that they shared financial burdens not directly related to the primary diagnosis or treatment under discussion. Sometimes these were small comments or innocuous questions (**Quotes 1.11, 1.12**). But oftentimes they shared news of financial burdens like recent changes in employment or loss of insurance coverage (**Quotes 1.13, 1.14, 1.15**). Even when invited to discuss a personal situation by a clinician, patients sometimes went further—like talking about the stress of a potential eviction, in response to a question about their job (**Quote 1.15)**. In other words, often patients seemed to put the complexities of cost and its burdens in their lives into the conversation, in the hopes that the clinician would be attuned to how it might impact care.

3.2 Caring Responses

This theme described the clinician responses to patients and their needs that we observed encouraging and improving encounter cost conversations. In other words, this theme addressed how clinicians acted to increase patient capacity and decrease their burdens (whether directly or indirectly). Our observations revealed that the most valuable support clinicians provided was not knowledge alone but a true desire to know more about the patient's capacity to manage financial burdens as well as caring humanistic responses to their suffering. Within this theme we observed the following subthemes: Curiosity for Complexity and Empathy for Patient Burdens.

3.2.1 Curiosity for Complexity

The quality of a clinician's response was often defined by their willingness to ask a patient to explain more about a cost issue. Clinicians who were curious seemed driven to understand not just what cost burdens patients faced but why. Some clinicians displayed curiosity by taking action: for example, offering to call a pharmacy to investigate pricing that seemed like it had to be a mistake (**Quote 1.16**) or brainstorming cost-reducing strategies with a patient (**Quote 1.17**). Other clinicians displayed curiosity by making efforts to understand what a patient was saying: for example, persisting in asking about a patient's capacity for pursing a diagnostic test (**Quote 1.18**) or encouraging a patient who seemed reticent to talk (**Quote 1.19**).

By contrast, a lack of curiosity—not digging deeper into the problem facing the patient—foreclosed opportunities for richer conversations about costs. In one encounter, despite directly discussing the costs of medication choices, the conversation did not lead to a richer understanding of patient capacity (**Quote 1.20**).

3.2.2 Empathy for Patient Burdens

Our observations suggested that while patients often sought or appreciated knowledge—particularly related to insurance coverage or medication prices—patients most valued empathic responses from their clinicians when discussing cost issues. Conversations went more smoothly when the clinician listened and responded with empathy (beyond a simple "oh, okay") to patient concerns around financial capacity (**Quotes 1.3, 1.6, 1.16, 1.17, 1.19, 1.21**). Empathic responses allowed clinicians to build connections with patients: like when one clinician said "we need to find out" about insurance coverage instead of 'I don't know' (**Quote 1.22**), communicating to the patient they were not alone on their journey. Another connected with their patient by sharing in a joke about "free shoes" (**Quote 1.23**).

By contrast, a lack of empathy created an obvious disconnect between patients and clinicians that felt difficult to witness as observers. In two particularly problematic examples, the clinicians either did not respond to the emotional substance of the patient's story (**Quote 1.24**) or ignored the patient's statement entirely (**Quote 1.25**).

4. Discussion and Conclusion:

4.1 Discussion:

4.1.1 Summary of Findings:

Our retrospective qualitative analysis revealed two main themes that describe what patients need (Space Needed for Cost Conversations) and how clinicians might best respond (Caring Responses) to share good quality cost conversations. Using the CuCoM, TPC, and BOTT, these results suggest it is most productive to consider cost conversations as acts of determining and understanding patients' *financial capacity*: what resources, social networks, life elements, etc. shape patients' capacity to afford their care? Can patients afford their care without creating time or resource burdens, or workload-capacity imbalances? In other words, the question is less the straightforward question, "What might this plan of care cost?" and more the complex question, "What can this individual patient afford?" Our findings demonstrate that in order to answer that question, clinicians should consider a set of best practices we present with a mnemonic ABLE: Ask questions, Be kind and acknowledge emotions, Listen for indirect signals, and (discuss with) Every patient. For a visualization of our recommendations and their connections to our themes, see **Figure 1**; for further elaboration of these recommendations for clinical practice, see **Table 3**.

4.1.2 Ask Questions

Our findings suggest that cost conversations are most fruitful when clinicians respond with curiosity, rather than accepting simple answers. Financial capacity is not a dichotomy (patients who can or cannot afford care) but a complex assessment of patients' whole lives that demands curiosity to understand. As a previous study by Riggs and Ubel suggests, whether or not patients can afford to pay medical bills does not reveal whether patients struggle to afford care [42], highlighting the relevance of engaging patients with questions about their financial capacity in encounters. Our findings suggest that issues of financial capacity are not fixed and waiting to be found but contextual and potentially discovered by patients themselves in the course of conversation.

4.1.3 Be Kind and Acknowledge Emotions

Although clinicians often (naturally) responded to patients' cost needs more easily when they had knowledge—options to provide (e.g., a less convenient but still effective generic) or information to share (e.g., whether insurance covers treatment)—knowledge doesn't build connections. Our observations demonstrate that patients most need caring, humanistic responses to the complexities of their lives. Indeed, such caring openness may best create space for patients to bring (potentially surprising) issues they deem impacting their financial capacity to the table, as our findings on indirect signals of cost demonstrate.

4.1.4 Listen for Indirect Signals

According to our findings, patients valued discussing cost highly enough to initiate cost conversations, even when the cost issues they brought up were not directly related to the main reason for their visit. Our findings account for topics of conversation that are not always directly about cost but address relevant aspects of patient capacity (e.g., effects on work, transportation burden). Indeed, the TPC recognizes that capacity is larger than resources: it also integrates an

understanding of patients' biography, environment, normalization of patient work, and social supports [31].

While "unrelated" to the direct costs of the primary diagnosis/treatment, these indirect cost issues shed light on the holistic picture of a patient's financial capacity. Moreover, the frequency with which patients brought them into the conversation suggests that patients often feel more comfortable bringing these indirect signals of their financial capacity to the table. This aligns with previous work demonstrating that patients may be hesitant to bring up costs due to embarrassment, and that clinicians must often look for clues that patients are having difficulty affording care [43]. Indeed, there are many cultural pressures around money that may potentially keep patients from *directly* discussing costs.

4.1.5 Every Patient (discuss with)

Cost matters to every patient, not only the ones experiencing financial distress. Both a previous study we conducted [39] and the literature show that cost discussions don't happen frequently, yet we know that cost still matters greatly to patients (one study demonstrating 63% of patients wanting to discuss costs with their clinicians) [24]. Patients in our study demonstrate a desire to discuss cost with their clinicians regularly, whether or not they might be labeled as experiencing financial hardships. Previous research on cost conversations has focused on who initiates cost conversations, clinicians or patients [44-47]; for instance, our team previously found that SDM tools had a significant impact on the incidence of cost conversations (and further, that clinicians initiated 84.6% of cost conversations in those SDM encounters) but that they were insufficient to support them (e.g., being less likely to address cost issues or offer potential solutions to cost concerns). Accordingly, we suggest that who initiates the conversation

is less important for ensuring a well-supported conversation than humanistic elements of care like ensuring space is provided for cost to emerge in conversation with every patient.

One barrier to implementing this recommendation is the systemic issue of time pressures [48-50]. Another barrier is a contradiction that exists in clinical practice regarding cost conversations. Some physicians report that having cost discussions during clinical encounters is part of their professional responsibility and that having cost conversations make them "good doctors" [51-53]. Other physicians report that being a "good doctor" means *not* discussing costs, as costs should not interfere with care plans [54]. Still other perspectives, like that of Edmund Pellegrino on the ethics of medical gatekeeping, emphasize that even when discussing costs clinicians must consider how they are aligned with the needs of their patients versus those of the institution or the larger system (e.g., the Choosing Wisely campaign) [55]. Underscoring the essentiality for cost conversations that meet patients' needs and addressing the conceptualization of what is to be a good doctor might help physicians to improve the quality of cost conversations.

Given the importance of the problem-solving actions we have outlined above, we propose a series of actions that build upon and follow our ABLE recommendations (see Practice Implications below).

4.1.7 Limitations and Strengths

Our study has several limitations. First, because our recordings only captured one encounter in the therapeutic relationship, we were not able to evaluate the effects of longitudinal relationships. Second, our secondary analysis of clinical encounter content precluded us from directly interviewing patients and clinicians about their perspectives on and experiences with good quality cost conversations. Third, having watched each encounter recording several times, it was difficult for our lead researchers (CL and NE) to fully separate their interpretation of

elements of the video that are not captured in the transcripts (e.g., tone of voice, body language) from their interpretation of the transcripts when conducting the analysis and writing up the results. Fourth, our method of choosing sample encounters to analyze prioritized rich detail and did not control for the quality of the cost conversation, which likely led to an oversampling of "bad" cost conversations.

However, our study also has several strengths. First, our heterogeneous sample included conditions with varying treatment lengths and costs, a variety of clinical settings, and both the use of SDM tools and usual care; this sample diversity increases the transferability of our qualitative findings. Second, to the best of our knowledge, this study is the first to describe and analyze cost conversations as recorded within real encounters; therefore, there are no biases around cost influencing patient and clinician behaviors during the encounter. Typically, cost of care conversation research has used cross-sectional survey design [56]. Third, having seen the full video recording of each encounter analyzed, our lead researchers were able to understand the context and how the codes being documented apply given that context. Fourth, although other studies have analyzed actual conversations, often using content analysis to describe quantity markers (e.g., incidence, frequency, and duration of cost conversation), our qualitative study is novel in that we can describe in depth other aspects influencing the conversation beyond economic factors.

4.2 Conclusion

Our findings describe what patients need and how clinicians might respond to share good quality and humanistic cost conversations that support patient financial capacity. We recommend clinicians consider four aspects, captured in the mnemonic ABLE: Ask questions, Be kind and acknowledge emotions, Listen for indirect signals and (discuss with) Every patient. Taken

together, our findings and recommendations suggest that strengthening patient-clinician human connections and providing space to allow (potentially unexpected) cost discussions to emerge may best support high quality cost conversations and tailored care plans.

4.3 Practice implications

Throughout our findings, cost and patient financial capacity came up in surprising ways: often, in indirect signals not directly related to the chief complaint or with patients who did not necessarily indicate they were experiencing financial duress but nonetheless wanted to discuss costs. These findings reveal the value of preparing clinicians and patients to undertake unexpected cost conversations and thereby meet patients in the real world. We suggest that there is great potential in a flexible framework (like ABLE) that supports unexpected and/or wide-ranging conversations around costs and patient financial capacity.

However, we also know that taking action to problem-solve around costs is important—in fact, we are surprised that problem-solving actions did not come up more frequently in our data. This sparseness is especially surprising given that both (1) patient requests for action related to costs and (2) clinicians taking cost-related actions were used as selection criteria for our sample of transcripts. There are several potential explanations for this finding: perhaps some clinicians have difficulty with problem-solving in the moment; perhaps a lack of knowledge about costs comes into play (e.g., we observed a lot of uncertainty around insurance coverage from both clinicians and patients); we also observed varying levels of clinician empathy in our sample of encounters. It is also possible that our sampling (which prioritized rich moments for qualitative analysis) did not lend to revealing many problem-solving actions if the conversations around them were relatively straightforward.

Based on the recommendations presented in this study, we see future practice improvements following two paths to strengthen patient-clinician conversations about cost and patient financial capacity. First, we have developed an outline (see **Table 3**) demonstrating how ABLE might be put into practice to support problem-solving actions in clinical encounters.

Second, in line with our ABLE recommendations, institutional efforts are needed to increase the positive awareness of our communication recommendations for clinicians, along with organizational support like access to recommendations-based communication training. Specifically, current communication skills training programs and undergraduate and postdoctoral programs should be improved to reinforce clinician communication competencies in different clinical settings in which cost conversations can happen. Future research should evaluate the practicality of these recommendations for clinical practice, along with system-level improvements to support the implementation of our recommendations.

CRediT author statement

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Table 1. Purposeful criteria for selecting encounters

Selection criteria	**Definition**	**Example**
Offhand-yet-telling comments about cost by patients	Patients spontaneously mentioning cost outside of a formal cost conversation during the clinical encounter.	"It's expensive [taking lots of vitamins]." "This is the year for it [imaging], I've already paid my out-of-pocket maximum."
Patients sharing personal situations	Patients sharing direct or indirect impacts that financial burdens (e.g., employment status, insurance access, family responsibilities) have on their lives.	"My criminal record has made it hard to find a job." "I was waiting on a free divorce lawyer."
Patients requesting action related to cost	Patients asking for cost-reducing strategies, information about costs (e.g., insurance coverage), or other instrumental help specific to their financial realities.	"Will you write a letter to my employer explaining that my Graves disease has made it impossible for me to keep a job right now?" "I'm just here for a second opinion because my insurance won't cover treatment here; can you write up a treatment plan I can take to my doctor at home?"
Clinicians taking cost-related actions	Clinicians providing coupons, checking the formulary, making phone calls to clarify costs, changing treatment plans to fit the patient's financial realities, or problem-solving with the patient.	"Let's discuss some free ways for you to exercise in the winter." "Let me call the pharmacy to see why your insurance denied this refill."
Confusion or conflict around cost	Conflicts between patients and clinicians (e.g., doubting, delegitimizing); situations in which clinicians or patients do not know financial information (e.g., insurance coverage, out of pocket prices, brand vs. generic prices)	E.g., clinician doesn't believe patient at first that it is possible to prescribe her a 1-year supply

Insufficient discussion of cost.	Cost issues are brought up by the patient but either ignored or insufficiently addressed by the clinician.	E.g., silence after patient shares she didn't treat her Graves disease before because her "insurance collapsed" E.g., silence after patient says that making childcare payments has kept them from seeking treatment.

Table 2. Selected representative quotes about costs and patient financial capacity from clinical encounters.

Sub-Themes	**Quote Number**	**Quote**
Theme 1: Space for Cost Conversations		
Cost is Valued Beyond Hardship	1.1	**Clinician**: Well, if they go here [to pick up medical equipment], they should get, you should get a waiver for the co-pay if they charge a co-pay for it, so. **ICAL108**: That'd be awesome.
	1.2	**Clinician**: Do you have a health plan that helps pay for the medicine, or do you pay for them out of pocket? **SC2r**: I, I do have, you know, we pay the copay and all, but then, you know, in December, I'll be 65, so that's probably all going to change. Go on Medicare, but I'll buy a supplementary insurance anyway, I'm sure. **Clinician**: Okay, see because Medicare doesn't cover, well it will in the future, maybe, you know, with that new plan, but it's kind of confusing as far as what it covers.
	1.3	**Clinician**: You know, in more life years, but your risk [of contracting shingles] is cut down by half compared to the other 73-year-olds, and your risk of neuralgia or neuritis afterwards is cut down by about half, too. So it [the shingles vaccine] makes good sense. It's something… you have Medicare D? **DCM034**: Yes. **Clinician**: D as in dog. You might want to call them and see if they cover that because we're talking about 250 smackers for that, 250 bucks. **[. . .]** **DCM034**: Is that the one that pays for my medication? **Clinician**: Yeah, yeah. Some of the plans cover, some don't. If it doesn't, you can say well, I'll wait six months and see if they are.
	1.4	**Clinician**: Okay, so is cost an important factor for you? **IIGH124**: Yeah. **Clinician**: Okay. So, if we decided to leave you on an antidepressant, and you decided that you wanted to look at the cost, the citalopram, Prozac, Paxil, and sertraline would be our best bet.
Cost as Justification for Decisions	1.5	**DMC001:** I mean, I have a secondary reason for wanting to get rid of the Cozaar. **Clinician:** Yeah, go ahead. **DMC001:** It's expensive. **Clinician:** Yeah, I see. Yeah.

		DMC001: And, and my insurance doesn‘t do a very good job of covering it.
	1.6	**GD077**: Because you got … there’s not …there’s not a chance you guys would repeat that [ultrasound] here? **Clinician**: Well, we could, but we could also look and see, you know, what’s already been done. You know, I think that just ends up being, um… it’s not, it’s sound waves, so it’s not exactly like it’s radiation exposure, but it’s another expense that sometimes people may nor may not want to have…pay for it. You know what I mean? **GD077**: Sure.
	1.7	**Clinician**: Now, some of the other ones [statins] like that can be taken any time of day because they're long, long acting, but they're also not generics, so they're more expensive, and if it gets ya to goal, I'm satisfied. **DMCO35**: Right.
	1.8	**Clinician**: I just want to look quickly. Okay, we did the … okay, so we’ve never done any imaging of your kidneys, so… **DMC031**: This is the year for it; I’ve already paid my out-of-pocket maximum. **Clinician**: Okay. Let’s do something called a kidney-ureter-bladder tomogram. It’s just like an x-ray, but they go at different levels. It’s not a CAT scan. It’s not that pricey, it’s less expensive, but it’s good.
	1.9	**Clinician**: But, ideally, you’re not going be taking a medication for this for the rest of your life. **GD084**: Yeah. **Clinician**: It’s annoying, it’s expensive, and there are side effects. **GD084**: Yeah.
	1.10	**Clinician**: Yeah, the recommendation is that, you know, all diabetics, even younger diabetics, since you said you were an old one… uh, consider taking an aspirin a day. So we mailed out… we just had them look and everybody who was diagnosed… **DCM034**: So I should start doing that? **Clinician**: Yeah, just the 81. [. . .] They come generic. They’re cheap, and it’s just one a day.
Indirect Signals of Cost	1.11	**Clinician**: Okay. And do you need any meds refilled? **HOLO15**: No, I, I think my prescriptions are good until March, aren’t they? **Clinician**: Um, I’m almost there to tell ya… okay, yeah. Good until March. **HOLO15**: And I stopped doin’ the Chantix, ‘cause the last time they said my insurance wouldn’t cover it and I was like, way more than I wanted to pay, but...

		Clinician: Okay. And you think, if you're doin' well enough... **HOLO15**: Well, I'm doin' okay without using it. It's been almost six months.
	1.12	**BLU030**: Oh, there is another thing I wanted to talk to you about. **Clinician**: Go ahead. **BLU030**: I got the phone number here. What, what do you think about Meals on Wheels? **Clinician**: I think they're good. I don't think that the meals are always extremely healthy. **BLU030**: All right. **Clinician**: But I don't know if maybe there is a way to request diabetic meals. **BLU030**: There, there is a way. They say… **Clinician**: Yeah. […] You can. I'm guessing that they probably do now because so many people have diabetes now, and I would bet that they are able to, you know.
	1.13	**IKAS043**: I can no longer talk to my son. […] I don't know how to deal with this. **Clinician**: Is there only um… uh… is this your only [living situation] option? **IKAS043**: For right now, yes. **Clinician**: Okay, and moving up [sic] with your sister, your daughter, sorry… **IKAS043**: Well… **Clinician**: Is not really an option? **IKAS043**: Yes... Yes. I'll be honest with you. They would… they… they see what's happening, but right now, my one daughter lives in Wisconsin, and I can't afford to give up the help here from Minnesota. I can't. I… I don't… until I can start collecting my widow's benefits, I'm just… I… you know… it… I… it… it just can't happen, and I know that. **Clinician**: Okay, and… you have nowhere else to live? **IKAS043**: No.
	1.14	**IGRE019**: There's so much racing through my mind, so I can't stay focused on what [inaudibile] and then with a job, you know, it's hard for… for me to find a job period. **Clinician**: Mm-hmm. **IGRE019**: Because of my background because I went to jail one time, it was one time, my first offense for fighting which, I don't know what… **Clinician**: Huh. **IGRE019**: It was like… **Clinician**: And that follows you [inaudible]…

		IGRE019: Yeah, and so, but they dropped the felony to a misdemeanor, so, which that's a good thing, but still it's like, oh, I go to the job, I tell the job and you know, I be truthfully honest. **Clinician**: Yeah.
	1.15	**Clinician**: Okay. And are you working right now? Did you get a job? **IIGH045**: I've got a part-time job. **Clinician**: Good. **IIGH045**: Uh…. **Clinician**: Well that's a start. Good start. **IIGH045**: So, I, that's the one positive I've got goin'. **Clinician**: Okay. Okay. **IIGH045**: But, I mean, my, my landlord is at his wits' end with me because I'm always late with the rent, um… **Clinician**: Okay. **IIGH045**: Ya know, he's basically threatening me with eviction… **Clinician**: Eviction. **IIGH045**: And, ya know, I, I, I… **Clinician**: All sorts of things are coming down on you right now, but… Okay. And the medication that you're taking, you have some concerns if it's helping? If it's good…
Curiosity for Complexity	1.16	**Clinician:** And then we started the metformin. **BLU030**: Right. **Clinician**: Now, metformin, in itself… **BLU030**: I, I do have, I do have a question about that too. **Clinician**: Sure. **BLU030**: Why is the pharmacy, and I don't believe it's the insurance, but right now, the pharmacy has me filling it up, instead of once a month, they've got me filling it up every other week. **Clinician**: Mm. That shouldn't be the case. Let me check and make sure. **BLU030**: And they told me, they said because of the insurance, and I don't believe it's the insurance. **Clinician**: Yeah. I'll reorder it to make sure it's correct. So, 1000 mg twice a day. Yeah, that should not be the case, that's crazy talk. It's not that expensive of a medicine.
	1.17	**Clinician**: I can give you a prescription for extra test strips if you need it. **[. . .]** **Companion**: Well you know one problem that we're having, and I don't know if it's our pharmacist or what, but now this last time, they paid for the strips in full.

		Clinician: Wow! **Companion**: They say that Medicare will. **Clinician**: Okay. **Companion**: The time before, out of $96, they paid $30, and that was it, and they're advertising… every paper's got Medicare pays for all the diabetic stuff, and they didn't. **Clinician**: Wow, I don't understand. **Companion**: And this last… **Clinician**: Talk to your pharmacist and say what is going on 'cuz he should know or she. **Companion**: He's hopeless. **Clinician**: Oh. **Companion**: I mean he goes and says we don't, uh… you see we have to pay him in full, and then Medicare has to reimburse us because he won't take the assignment. **Clinician**: Could you change to a different pharmacy? **Companion**: Well, I'm just considering to go to another town, and if worse comes to worse, have him mail the medication. **Clinician**: You could even like go… I'm not promoting the Mayo Pharmacy, but I know that you can have 'em mail it to you, and if you like dropped it off today, uh, you know, in the Subway level, you could talk to them about it, and I know they would be consistent about whether it pays or it doesn't pay. That's the nice thing. **DMC016**: Well, at least we had to pay it first, then they'd paid it, but otherwise, they're almost a dollar a piece for a strip. **Clinician**: I know they're expensive. It's up to you but…
	1.18	**Clinician**: Okay, so... So, so tell me again. You don't wanna have your cholesterol test, because you're putting way too much money into your teeth? **DMC078**: Right, but I, I will do it if I have to, but I've, is it off anywhere? **Clinician**: Um, your last LDL cholesterol was... a year ago it was 95. I need to check it once a year at least just to see where we're at.
	1.19	**Clinician**: So, after that one, what would be the next issue? **IIGH045**: Um… cost is an issue, but, um, since I'm on MnCare right now, ya know, I don't know how much longer that's gonna last with… **Clinician**: So cost is important? **IIGH045**: Yeah. **Clinician**: Let's look at that. I think that's important. This is the least cost, this is the more cost. You were on sertraline, so it was one of the, the less. Not the, ya know, cheapest,

		whereas, uh, paroxetine or fluoxetine or Celexa might have worked, might have been a little cheaper. We tried a couple of those, but they didn't work. **IIGH045**: Yeah, they're, yeah… **Clinician**: Side effects. **IIGH045**: Yeah, the shocking… **Clinician**: Yes, yes. **IIGH045**: Feeling. **Clinician**: And then the, some of these others, like Lexapro, um, Pristique, Cymbalta, Effexor, Wellbutrin are much more expensive. So, it looks like sertraline is in that realm.
	1.20 (*problematic example*)	**Clinician**: Okay, you're also on Seroquel. I think for the purposes of this discussion, we're gonna mainly go through Cymbalta. So, um, issues that I want you to look at are, um, which one of these things that I hold up seem to me, be the most important issue in your decision as to what medicine you would like to have, okay? **IIGH157**: Right now I can tell ya already… cost. **Clinician**: Cost. Okay. So if you look at drugs that cost a lot of money, I think you've been on citalopram in the past. **IIGH157**: Don't even know what that is. **Clinician**: 'Kay, that's an antidepressant. Here, gimme a moment… **IIGH157**: Okay. **Clinician**: Right. Okay, you were on Zoloft. So here, here are drugs that are available for depression—citalopram. This is a form, uh, this is Lexapro, it's kind of a cousin of citalopram. This is Prozac, okay? And notice the cost factor. The one you're on is right here. **IIGH157**: Yeah. **Clinician**: See where the cost is? **IIGH157**: Mm-hmm. **Clinician**: Okay? So you have the option. I could switch you to one, any, and Zoloft is right here. I could switch you to any of these if you wanted to try it. Now, if you asked me are they better or worse than the other one? No, I think they all have a pretty good track record of working. **IIGH157**: Okay. **Clinician**: Okay. The one thing about Cymbalta is it relieves pain better… **IIGH157**: Mm-hmm. **Clinician**: So if you're taking Cymbalta because you're having back pain or other issues, the other drugs don't necessarily relieve pain as well. **IIGH157**: Yeah. **Clinician**: Okay?

		IIGH157: See, I do have a lot of back problems. **Clinician**: Right, and Cymbalta might help that. **IIGH157**: Mm-hmm. **Clinician**: So, but you're right. The cost is .. **IIGH157**: Well, I tell ya what, I didn't realize how well the Cymbalta works until after I go off it. **Clinician**: Right. So that's, so again, you have to look, if cost is a big factor, you can see it is as expensive as anything else. **IIGH157**: I'd say let's stay where we're at right now, for a while, well you guys been givin' me… um… **Clinician**: We can get ya samples, too.
Empathic Conversations	1.21	**Clinician**: You've been seeing the eye doctor regularly? **INT001**: No. **Clinician**: Okay. **INT001**: I can't afford to, I mean, I got laid off. It was, so, it was, you know, I was, I had actually had, um, I had planned on doing it, but then all of a sudden I realized, you know, it's either that or eat, so. **Clinician**: That's a tough decision.
	1.22	**DMC078**: Okay then, I'll try it [a new diabetes medication]. It, but how much does it cost? **Clinician**: It's, urn, depending on your insurance, alright, pretty good insurance penetration. Pretty good insurance coverage for it, um, but I don't know about your particular insurance, but we need to find out. **DMC078**: It's Merck-Medco. **Clinician**: I think that should be alright. I've got another patient with Merck that got coverage.
	1.23	**Clinician**: Well, here, these cards are a system that they are trying out to just kind of show, put it all on paper, as to what we're, what we're looking at here, you know. So for instance, these are just the idea of a daily routine. Well, the insulin I'm talking about would be a long-acting one, you'd only take it once a day, you know. **FHC013**: Yeah, that ain't bad. **Clinician**: To start out with, to make sure, you know what, you..., maybe all you need is a low-dose Lantus insulin and it just, the goal is it wouldn't drop you too much, and it would just give you kind of a continuous insulin in your body. **FHC013**: Yeah, and if I get insulin, I get free shoes. **Clinician**: Yeah, this is true. This is true. **FHC013**: It's a nice way to look at it. **Clinician**: I know, I know, but, I guess there's always the silver lining...

		FHC013: We got those shoes at home with the, the arches that are from Good Feet, and they told us it we get into insulin, uh, they'll actually give you the shoes through your Medicaid/Medicare. **Clinician**: Mm-hmm. That's actually true, that's actually true. **FHC013**: Yeah, well, we paid like 300 bucks each at us, and we got the cheaper pairs 'cause we couldn't afford 600 each. **Clinician**: Hmm. **FHC013**: But boy, that did make a difference. I never had no hip pains after I did that.
	1.24 (*problematic example*)	**GD053P**: Yeah, I've had it for a while. **Clinician**: Oh, you've had the thyroid... **GD053P**: But I've never had any treatment for it because one thing, when I did find out that I had thyroids, after that my insurance, it went collapsed, and I didn't have any more insurance, so the only thing I ever did was get the little, I think they took some… whatever they did. They scanned it, a CT scan or something of my thyroid, so whatever it was. **Clinician**: An ultrasound maybe? **GD053P**: Maybe that. [. . .] **Clinician**: Mm-hmm. So they did blood tests, right? **GD053P**: Yeah. **Clinician**: And they told you that your thyroid was overactive? **GD053P**: Hyper, yeah. **Clinician**: But was it severe? Probably not much, or… **GD053P**: I don't know. **Clinician**: Okay. And so what happened? So then you just kind of got lost? **GD053P**: Yeah, kind of because I still have the… **Clinician**: Because you didn't have insurance? **GD053P**: My insurance just kind of went. **Clinician**: Okay. **GD053P**: I didn't have any insurance, so. **Clinician**: So no insurance, no continued to check up, we don't know anything until now. Is that sort of... **GD053P**: Well yeah, pretty much. **Clinician**: So what happened now? So tell me where you went to see your primary?
	1.25 (*problematic example*)	**Clinician**: Well, just have a seat here please. So you were in Texas too? **GD034 Companion**: Yes, and uh… over there she didn't get treatment because she didn't have insurance. Uh… because

		my work wouldn't give her insurance because were weren't… we're not married or nothing. So I mean, they were charging me [overlapping voices] a lot. **Clinician**: It's a very large goiter, isn't it.

Table 3. From ABLE to Problem-Solving Actions: Suggestions for Clinical Practice

ABLE Recommendations	Examples of Associated Problem-Solving Actions
Ask questions	Insurance: • Do you have insurance coverage, or do you pay out-of-pocket for your medications? • What kind of insurance do you have? What are your copays like? • Have you reached your deductible yet this year? Care: • Have you had any trouble receiving care for (or treating) this condition? • Do you have other medical expenses we need to consider? • What is most important to you when choosing a treatment option? Basic curiosity: • How are things? • So, what happened with that? • That [difficulty you mention] doesn't sound right; have you tried talking to [resource like a pharmacy]?
Be Kind and Acknowledge **Emotions**	• That must have been hard. • How did that make you feel? • Let's navigate this decision together. • I'm sorry that was difficult in the past. Is it still a problem you face today?
Listen for Indirect Signals	Listen for patients to bring up life situations related to: • Work (e.g., schedules; productivity; maintaining steady employment; searching for a new job) • Family situations (e.g., divorces and childcare support; caregiving expenses)

	• Basic needs (e.g., issues with housing, car, food, etc.; being on public assistance) • Background/vulnerabilities (e.g., immigration; incarceration; substance abuse) • Other chronic conditions (i.e., ongoing medical expenses)
Every Patient (discuss with)	• Create opportunities to discuss costs before a decision is made • Share cost-saving strategies, vouchers, and programs • Discuss patients' values and preferences • Discuss options (e.g., medication choices; a wait-and-see approach) • Show interest in patients' lives (see "Be Kind and Acknowledge Emotions" and "Listen for Indirect Signals" above)

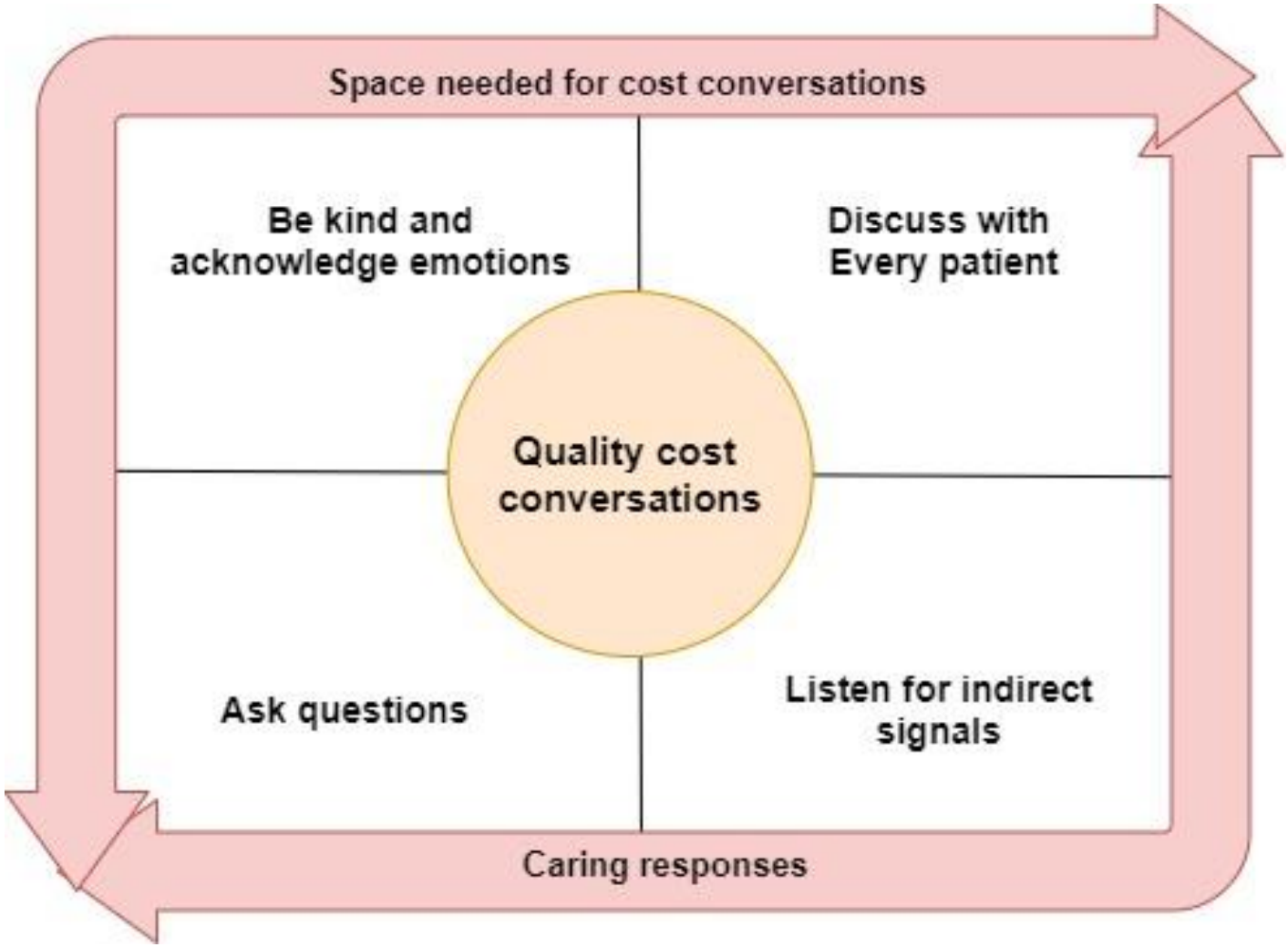


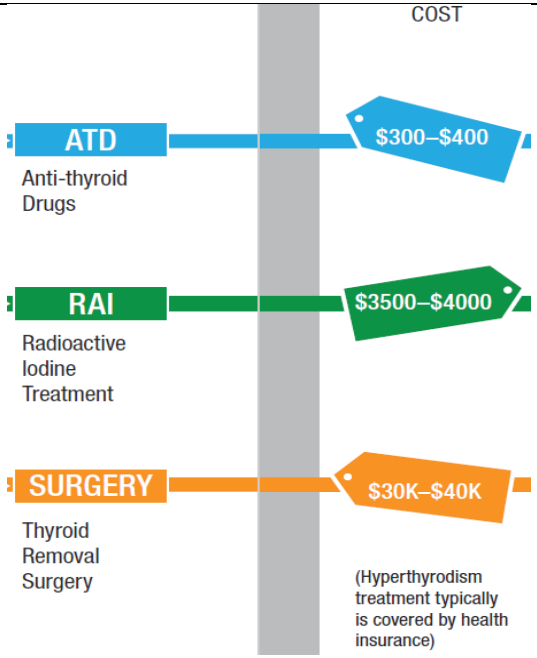
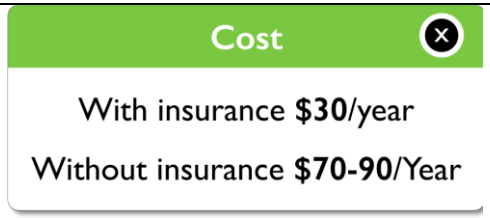
Figure 1. Representation of our ABLE recommendations and their connection to our two main themes.

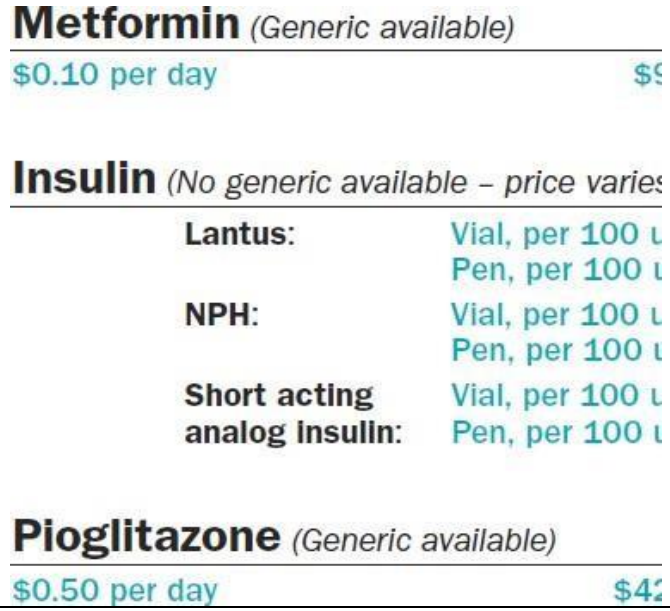
Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☐The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Supplementary Table 1: Description of the decision aids cost components

Title	Description	Aspect of Cost in tool	Screenshot of a section of the tool
Graves' Disease Choice	Intended for patients/clinicians treatment option's discussions (anti- thyroid drugs, radioactive iodine treatment, thyroidremoval survey) for Graves' Disease	Describes the estimate cost of anti-thyroid drugs, radioactive iodine, and thyroid removal surgery.	
Osteo I and II	Intended for patients/clinicians discussions about the use of bisphosphonates forthe treatment of osteoporosis	Estimate cost of bisphosphonates with andwithout insurance (paperversion and electronicversion)	

iADAPT	Intended for patients/clinicians discussions about medication for the treatment of depression	Estimate out-of-pocket cost(without insurance) of eachmedication for comparativereference	
TRICEP	For patients/clinicians discussing the use of diabetes medication for the treatment of diabetes	Estimate cost of diabetes medications	

Supplementary Table 2: Demographics by study arm

	Control (N=13)	DA (N=28)	Total (N=41)
Study, n (%)			
Diabetes	7 (53.8%)	6 (21.4%)	13 (31.7%)
Graves	2 (15.4%)	8 (28.6%)	10 (24.4%)
IADAPT	2 (15.4%)	12 (42.9%)	14 (34.1%)
Osteo	1 (7.7%)	0 (0.0%)	1 (2.4%)
Statin	1 (7.7%)	2 (7.1%)	3 (7.3%)
Age			
N	13	28	41
Mean (SD)	57.1 (16.64)	50.1 (13.80)	52.3 (14.91)
Median	61.0	48.0	52.0
Range	29.0, 81.0	26.0, 79.0	26.0, 81.0
Gender, n (%)			
Female	8 (61.5%)	13 (46.4%)	21 (51.2%)
Male	5 (38.5%)	15 (53.6%)	20 (48.8%)
Race, n (%)			
Black	0 (0.0%)	5 (19.2%)	5 (12.8%)
Other	1 (7.7%)	0 (0.0%)	1 (2.6%)
White	12 (92.3%)	21 (80.8%)	33 (84.6%)
Missing	0	2	2
Ethnicity, n (%)			
Hispanic, Latino or Spanish origin	2 (50.0%)	1 (5.0%)	3 (12.5%)
Non-Hispanic origin	2 (50.0%)	19 (95.0%)	21 (87.5%)
Missing	9	8	17
Education, n (%)			
Less than college education level	5 (38.5%)	9 (32.1%)	14 (34.1%)
Some college or more	8 (61.5%)	19 (67.9%)	27 (65.9%)
Income, n (%)			
<$40K	6 (75.0%)	8 (38.1%)	14 (48.3%)
>=$40K	2 (25.0%)	13 (61.9%)	15 (51.7%)
Missing	5	7	12
Married Status, n (%)			
Married	7 (63.6%)	17 (81.0%)	24 (75.0%)
Other	4 (36.4%)	4 (19.0%)	8 (25.0%)
Missing	2	7	9
Health Insurance, n (%)			
Private	2 (25.0%)	3 (50.0%)	5 (35.7%)
Medicare	5 (62.5%)	2 (33.3%)	7 (50.0%)
Medicaid	0 (0.0%)	1 (16.7%)	1 (7.1%)
Not reported	1 (12.5%)	0 (0.0%)	1 (7.1%)
Missing	5	22	27

CRediT author statement

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