What matters to patients and families: A content and process framework for clarifying preferences, concerns and values

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Abstract (275/275 max)

Background: Values clarification, or sorting out what matters to a patient or family relevant to a health decision, is a fundamental part of shared decision making. Little is known about how this process occurs. We aimed to describe how values clarification occurs in routine primary care.

Methods: Using framework analysis and an established taxonomy, two independent researchers analyzed 260 consultations in five family medicine clinics across Quebec. Two questions guided our analyses: 1) What categories exist regarding what matters to patients? 2) What patterns exist in discussions of what matters to patients?

Results: 1) Five distinct categories of what matters to patients were apparent: preferences, concerns, treatment-specific values, life goals or philosophies, and broader contextual or sociocultural values. Preferences and concerns were the matters most commonly raised. 2) Diverse patterns of values clarification emerged based on three analytical questions: Who initiates the discussion about what matters to patients? When? What information is discussed? The most frequent pattern was clinicians soliciting patients' concerns and preferences during the information-gathering phase. The second most common pattern was similar, except that patients' spontaneously raised what matters to them.

Limitations: The study was descriptive and based on audio-recorded visits. We did not interview patients and clinicians to elicit their perspectives.

Conclusions: There are five distinct categories of information that matters to patients as well as clear patterns of how values clarification occurs in routine primary care consultations. Clinicians could be sensitive to these categories when engaging in the process of values clarification, and may wish to pay particular attention to the opening minutes of a consultation. This study provides a structure for future identification of best practices in values clarification.

Main Text

Introduction

Shared decision making, evidence-based medicine, and informed decision making all require the incorporation of what matters to patients into health decisions [1–3]. Within shared decision making, the crucial process of sorting out what matters to patients relevant to health decisions is referred to as values clarification [4].

Little evidence exists about how values clarification occurs, nor about how it ought to occur. Although prescriptive work suggests particular approaches as to how and when health professionals should discuss or elicit values and preference [5,6] such prescriptions have minimal empirical support, little is known about how this actually occurs in practice, and the concepts of values and preferences as articulated in the shared decision making literature have been critiqued as being underdeveloped, unclear, and reductionist [7,8].

In this study, we aimed to develop an analytical framework to describe how the process of values clarification occurs in routine primary care—what is discussed and how it is discussed. We define the process of values clarification based on Witteman and colleagues' definition: values clarification is “the process of sorting out what matters to an individual relevant to a given health decision,” [9] with the adaptation that in some cases, rather than only mattering to a sole individual, what matters may also matter to others, such as family members. With this definition in mind, our specific research questions were: What (1) categories and (2) patterns exist in discussions of what matters to patients and families during routine primary care clinical encounters?

Methods

Study design and context

Data for the study are drawn from a project designed to document and explore current risk communication and values clarification practices in primary care. Data were collected at 5 university-affiliated family medicine clinics across the province of Quebec, Canada. The clinics were chosen to provide geographic, socio-demographic and linguistic variation while ensuring feasibility for an observational study. Full details are described elsewhere [10].

Participants, recruitment, and data collection

Participants were primary care health professionals (family physicians, family medicine residents, nurses, nurse practitioners, dietitians, other allied health care providers) and patients who had appointments during the study period. Children, partners, parents or guardians accompanying patients during the consultation were invited to participate. Excluded from the study were unaccompanied minors aged 14 years or less, patients who had been identified by

health-care professionals as not being able to provide informed consent, and anyone not comfortable completing forms either in English or French. All participants provided written consent.

Prior to patient recruitment, health professionals who consented to participate and have their medical consultations audio-recorded provided written informed consent and completed a brief questionnaire about their socio-demographic characteristics. Participating patients and the people accompanying them also provided written informed consent and completed self-administered written questionnaires. All consultations were then unobtrusively audio-recorded and transcribed verbatim in their original language.

Previously-described quantitative analyses of 238 consultations from the overall project dataset [10] required completed post-visit questionnaires. For our study, because we analyzed audio recordings only, we included all eligible consultations between a patient and a primary care health professional treating them. Data for the present study therefore consisted of audio recordings of 260 patients consulting 72 health care professionals.

Ethics

The study was approved by three research ethics committees: 1) Research Ethics Committees of the Integrated University Health and Social Services Centre of the National Capital (CIUSSS-Capitale Nationale) #2013-2014-31 2) Research Centre of the CHU de Québec-Université Laval #2014-1769, C13-08-1769-21, and 3) the Jewish General Hospital, Montreal #CODIM-MBM-13-134.

Analyses

Two researchers (RR, SCD) independently analyzed the data via framework analysis in an Excel spreadsheet, referring back to full transcripts and using both deductive and inductive analysis. We developed and applied our analytical framework through regular meetings between two (RR, SCD) or three (RR, SCD, HW) authors during which we identified and resolved differences, reaching consensus through discussion. The following questions guided the development of the coding framework: (1) What categories exist in discussions of what matters to patients and families during clinical encounters? (2) What patterns exist in discussions of what matters to patients and families during clinical encounters? (2a) Who initiates the discussion about what matters to patients and families? (2b) When does this information enter the conversation? (2c) After this information has entered the conversation, is it discussed in a single sequence or in a series of sequences? (2d) After this information has entered the conversation, is it explored, validated, or ignored? (2e) What happens to this information after it has been explored; i.e. is it integrated in the decision, addressed, or ignored? The coding structure is presented below and Appendix 1 provides sample coded extracts (the extracts in French were translated to English).

To answer the first question, we used a mixed approach to coding, by coding deductively according to pre-identified categories from previous literature [11], and also coding inductively to remain open to emerging codes.

For the second research question, we proceeded by first identifying sequences where patients and clinicians discussed something that mattered to the patient and families. Then we coded these sequences to describe the process of values clarification according to our five pre-identified guiding questions. Each matter discussed between patients and clinicians was assigned a single code within each guiding question. A frequency analysis was then conducted on each code. Next, to identify emerging patterns of values clarification, we sorted the data along four columns, specifically, how it enters (who initiates the discussion and how?), when it enters (when during the consultation is it initiated?), to what extent is it explored, then what happens (what happens after the values are explored?).

Results

Overall characteristics of the participants

In total, we analysed 260 consultations that were broadly reflective of the variety of consultations in primary care in Quebec. **Table 1** provides a summary of participant characteristics.

Table 1. Participant socio-demographics

		Patients (n=260)	Health professionals (n= 72)
Site (i.e., clinic)	1: n (%)	53 (20.4)	15 (20.8)
	2: n (%)	56 (21.5)	18 (25.0)
	3: n (%)	64 (24.6)	12 (16.7)
	4: n (%)	43 (16.6)	12 (16.7)
	5: n (%)	44 (16.9)	15 (20.8)
Gender	Women (all): n (%)	198 (76.2)	48 (66.7)
	Physicians	-	25 (52.1)
	Residents	-	16 (33.3)
	Nurses and dietitians	-	7 (14.6)
	Men (all): n (%)	62 (23.8)	23 (31.9)

	Physicians	-	14 (60.9)
	Residents	-	9 (39.1)
	Nurses and dietitian	-	0 (0)
	Missing data		1 (1.4)
Age	All: Median (IQR)	39 (30)	33 (28.0-42.5)
	Physicians	-	40 (34-51)
	Residents	-	27 (26-31)
	Nurses and dietitians	-	30 (29-32)
Level of education	Lower level	104 (40)	-
	None or some elementary school	2 (0.8)	-
	Elementary school	22 (8.5)	-
	Secondary school diploma	49 (18.9)	-
	Secondary school vocational diploma	31 (11.9)	-
	Medium level: n (%) CEGEP*	50 (19.2)	-
	Higher level: n (%)	101 (38.9)	-
	Bachelor's degree	68 (26.2)	-
	Master's degree	24 (9.2)	-
	Doctoral/Professional degree	9 (3.5)	-
	Missing data: n (%)	5 (1.9)	-
Types of health professionals	Physicians: n (%)	-	39 (54.2)
	Residents: n (%)	-	25 (34.7)
	Nurses and dietitian: n (%)	-	7 (9.7)
	Missing data: n (%)	-	1 (1.4)

Originally from	Province of Quebec: n (%)	207 (79.6)	59 (81.9)
	Other province in Canada: n (%)	9 (3.5)	4 (5.6)
	Other country: n (%)	41 (15.8)	8 (11.1)
	Missing data: n (%)	3 (1.1)	1 (1.4)
Number of years in the province of Quebec	Median (IQR)	34 (31)	32 (26.0-43.3)
Numbers of years of practice	All: Median (IQR)	-	5 (1.5-16.2)
	Physicians	-	12 (5.0-23.5)
	Residents	-	1.5 (0.5-2.0)
	Nurses and dietitians	-	6.5 (5.0-9.5)
Numbers of years in the clinic	Median (IQR)	-	3 (1.0-8.0)
Languages spoken**	French: n (%)	247 (96.1)	69 (95.8)
	English: n (%)	124 (51.9)	63 (90.0)
Visible minorities Defined in Canadian statistics as "persons, other than aboriginal peoples, who are non-Caucasian in race or non-white in color"	n (%)	31 (11.9)	4 (5.6)
	Missing data: n (%)	7 (2.7)	1 (1.4)
People with disabilities Defined as "physical, cognitive, intellectual, mental, sensory or developmental impairment"	n (%)	10 (3.9)	0 (0.0)
	Missing data: n (%)	3 (1.2)	1 (1.4)

IQR = interquartile range

**Spoken well, very well or fluently. Values are not mutually exclusive.

What is it that matters to patients and families?

A median of 7 things that mattered to patients and families came up per consultation (interquartile range 5 to 10, full range 1 to 23.) Things that matter to patients and families were

organized according to five distinct categories based on our analyses and previous literature: a) preferences, b) concerns, c) treatment-specific values, d) life goals and philosophies or e) broader contextual or sociocultural values. Table 2 provides definitions of these.

Table 2. Five distinct categories of what matters to patients and families

Category	Definition
Preferences	A greater liking for one option over one or more alternatives (based on Witteman and colleagues [9])
Concerns	Concerns about changes in health status, symptoms, or other aspects of health and well-being (based on Zimmerman and colleagues [12])
Life goals and philosophies	Concrete goals in life that might influence the patient's decision making (e.g., optimising their performance at work, financial concerns, wish to have a baby, etc.), and worldviews or ethical beliefs about what is good or morally desirable (e.g., not being a burden to family, avoiding suffering) (based on Lee and colleagues [11])
Treatment-specific values	Beliefs, feelings, or perceptions regarding attributes of a treatment option (based on Lee and colleagues [11] and Witteman and colleagues [9])
Broader contextual or sociocultural values	Contextual values that exist beyond the individual (e.g. family, religious or cultural values) and that influence what matters to people (based on Lee and colleagues [11])

Among all things that matter to patients and families, the two categories that were most commonly discussed were preferences and concerns, followed by life goals or philosophies, treatment-specific values, and finally, broader contextual or sociocultural values.

What are the patterns of values clarification in the consultations?

Overall, findings show that clinicians initiate the majority of discussions about what matters to patients and families. This information mostly enters the conversation during the information-gathering phase (see Table 3 for definition). Preferences and concerns are the matters raised most often, and this information is mostly discussed in a single sequence. Typically, the clinician explores this information, and if a decision is made, this information is integrated in the decision. If no decision is made, this information is at least addressed. Table 3 shows the final coding structure, definitions, and frequencies of each code across all matters discussed within all consultations.

Table 3. Summary of codes in response to the five guiding questions

Code (percentage of all matters discussed represented by this code)	Code Description
Who initiates the discussion about what matters to patients and families? (Question 2a in guiding questions)	
Suggested by clinician (29%)*	<p>Situations in which only one option is presented (similarly to clinician close-ended), however, in these situations, the patient is presented a single option but has the latitude to comment, question, explore, refute or present alternatives.</p> <p>For example, a patient presents with hypoglycemia and the clinician says: I would suggest referring you to a nutritionist now, since your hypoglycemia is not controlled.</p>
Invited by clinician-open-ended (29%)**	<p>Situations in which the patient is presented a range of options, and these options are presented as being more open; the clinician does not point to one option in particular. There is space for the patient to express preferences, values or concerns regarding various options.</p> <p>For example, when the patient expresses wanting to stop smoking, the clinician may present several options (e.g., the patch, gum, etc.) and then ask the patient to comment on the potential options.</p>
Volunteered by patient (21%)	<p>Situations in which the patient volunteers certain information or topics, without having been invited to.</p> <p>For example, the patient may change the topic of conversation by spontaneously raising a different concern.</p>
Invited by clinician-close-ended (13%)	<p>Situations in which the clinician directs the patient toward one option and does not invite further exploration; the patient does not have the opportunity to add or change the options (apart from saying yes or no to that option).</p> <p>For example, clinician suggests routine blood tests or follow-ups: We will do a blood test to check your iron level, ok?</p>
Requested by patient (8%)	<p>Situations in which the patient makes a request to the clinician.</p> <p>For example, patient may ask for a prescription renewal.</p>
When is the discussion initiated? (Question 2b in guiding questions)	
Information gathering phase (57%)	When the clinician collects information about the patient's subjective experience with the condition or concern, summarizes information (e.g., lab test results), or during interview or physical examination.

Explaining and planning phase (23%)	When the clinician informs the patient about the nature of the problem and potential treatment or management options.
Opening phase (13%)	When the patient and clinician are getting acquainted and trying to establish the reason(s) for consultation.
Closing phase (7%)	When the clinician has finished explaining and decisions have been made, the patient and clinician plan the next steps (e.g. follow-up appointment) and say good-bye.
Is this information discussed in a single sequence or in a series of sequences? (Question 2c in guiding questions)	
Single sequence (65%)	The information is clarified and explained in one phase of the interview – may be in a long or a short sequence.
Series of sequences (35%)	The information is clarified and explained in more than one phase of the interview – may be in long or short series of sequences.
Not clarified (<1%)	The information is stated, but nothing happens afterwards – it is not clarified.
After this information has entered the discussion, are matters explored, validated or ignored? (Question 2d in guiding questions)	
Explored (76%)	After the values, preferences or concerns have entered the conversation, the clinician recognizes them and engages in a discussion to clarify or learn more about this information, or generally interacts with the patient concerning the expressed information. In brief, the values, preferences or concerns do not go unrecognized, and the clinician finds a way to come back to this information.
Validated (16%)	After the values, preferences or concerns have entered the conversation, the clinician recognizes them, but does not interact in detail with the patient. The clinician verifies, in a closed-ended way, that he or she understands the patients' values, preferences or concerns.
Not explored (8%)	After the values, preferences or concerns have entered the conversation, this information falls through the cracks, as the clinician does not pick up on it, or does not come back to this information. This includes rare occasions in which patients are quite independent at clarifying their values, so much that the clinician does not necessarily need to come back to this information.
If matters are explored, are they integrated in the decision or at least addressed? (Question 2e in guiding questions)	
Addressed (38%)	Situations in which a decision does not necessarily need to be made (e.g., mother's concern about the size of her baby's head), but the

	concern was explored and addressed (e.g., clinician reassures patient after having explored the concern).
Integrated in the decision (25%)	The information is integrated in the patient's decision or the action taken by the clinician.
Addressed and later acted on (12%)	Situations in which a concern was raised and discussed. However, in contrast with "addressed", the discussion about the concern was then followed by a discussion about an intervention (e.g., need for more physical activity) or treatment (e.g., blood tests).
Not addressed (1%)	The information is ignored and not incorporated in decisions.
Not applicable (not explored or validated only) (24%)	If values, concerns, and preferences were not explored, then this code was not applicable.

*Listed first because frequency was 29.2% **Listed second because frequency was 28.9%

In spite of great variation in how what matters to patients and families was discussed, three broad patterns of values clarification appeared more frequently than others. As shown in Table 4, these patterns can be distinguished by who initiates the discussion and the nature of what is discussed. In all three patterns, the discussion is initiated in the information-gathering phase, matters are explored and integrated into the decision or at least addressed.

Table 4. Summary of the three most common patterns of values clarification.

	"Early inquiry by clinician"	"Early evocation by patient/family"	"Early suggestion by clinician"
Who initiates the discussion? (question 2a)	Invited by clinician; open-ended	Volunteered by patient/family	Suggested by clinician
When is it initiated? (question 2b)	Information gathering phase		
What categories of what matters are discussed? (question 2c)	Concerns; Life goals; Treatment-specific values; Preferences	Mostly concerns; some preferences and treatment-specific values	Mostly preferences
Are matters explored, validated or ignored? (question 2d)	Explored		
If matters are explored, are they integrated in the decision or at least addressed? (question 2e)	Integrated or at least addressed		

The most frequent pattern, “Early inquiry by clinician,” consisted of the clinician soliciting the patient’s or family member’s input during the information-gathering phase, in an open-ended manner. This pattern is the one that elicited the widest diversity of what matters to patients and families, as they responded by expressing their concerns, preferences, life goals or philosophies, or treatment-specific values. This information was then explored by the clinician and integrated in the decision. If no decision was made, the clinician at least informed or reassured the patient and family member.

In the second most frequent pattern, “Early evocation by patient/family,” the patient or a family member spontaneously raised what mattered to them during the information-gathering phase. Such matters were mostly concerns (e.g., a question about a treatment, procedure, health concern, or medication), although patients and families also offered some preferences and treatment-specific values. Once the discussion about a concern was initiated, the clinician explored this concern and addressed it. If a decision was made, the concern was integrated in the decision.

In the third most frequent pattern, “Early suggestion by clinician,” clinicians initiated discussions by suggesting an option during the information-gathering phase. The vast majority of discussions in this pattern pertain to preferences for medication, procedures, referrals, or diagnostic tests. After the patient or family member had expressed their preferences, this preference was then explored and integrated in the decision.

Other patterns varied from the three most common patterns most often because they were initiated at other times during the consultation or because they were more specific patient or family member requests for medications or interventions. For instance, among the most frequent other patterns, one consisted of clinicians eliciting patient or family member preferences and concerns earlier in the consultation; specifically, in the opening phase. Another such pattern saw clinicians eliciting preferences and concerns later during explaining and planning phases. A third other pattern consisted of the patient or family member initiating the discussion about their preferences by specifically requesting a medication, procedure, treatment, or referral during the information-gathering phase.

Discussion

Principal findings

In this study, we aimed to explore and describe how values clarification occur in primary care. The study was guided by two research questions: 1) What distinct categories exist regarding what matters to patients and families? 2) What patterns exist in discussions of what matters to patients and families?

In response to the first research question, we identified five distinct categories of what matters to patients and families discussed in primary care. Building on previous definitions and

frameworks identified by Zimmermann and colleagues [12], Lee and colleagues [11], Witteman and colleagues [9], Lim and colleagues [8], and Pilote and colleagues [13], we developed a practical, applicable framework of what matters to patients and families, grounded in the realities of routine consultations across a wide spectrum of clinical contexts. The framework developed in this study suggests that there are five distinct categories of information that are important to consider in the process of values clarification, namely, preferences, concerns, and three levels of values: life goals and philosophies, treatment-specific values, and broader contextual values.

Our data-driven findings align with a taxonomy of values proposed by clinicians based on their clinical experience and expertise. Armstrong and Mullins[14] proposed four categories of patients' values. Our category, 'Life goals and philosophies' aligns with their category, "global values," defined as, "core personal values existing beyond specific decisions, including value traits and life priorities." 'Treatment-specific values' aligns with "decisional values," defined as those relating, "directly to the decision needing to be made," such as the efficacy, convenience and cost of a potential treatment. 'Broader contextual or sociocultural values' align with "external values", which refers to considering family and cultural values in one's decisions. They also proposed a fourth category, "situational values," as "those that are tied to a specific context and modify global and decisional values." Because our study examined discussions of what matters during a single encounter, not longitudinally, we did not include transient or changing values as a separate category; however, such situational issues drove discussions that we categorized as 'Concerns' in our framework.

This framework addresses a previously-identified conceptual gap by aiming to clarify and define what is meant by 'values' in values clarification. Indeed, previous authors have criticized this area of research since there is confusion about how values are defined and how they are operationalized [7,8]. In some previous studies, values have been operationalized as preferences, which has been criticized for its reductionist perspective [7]. In contrast, our framework supports the need to distinguish the concepts of values and preferences, to add concerns to these two categories, and to consider three distinct categories of values. Together, these five categories should be considered when designing explicit methods for values clarification. Clinicians may also wish to be sensitive to these five categories when engaging in the process of values clarification to ensure that what matters to their patients and families is addressed.

In response to the second research question, examining the frequency of patterns among values clarification in routine primary care consultations leads us to three observations. First, clinicians initiated most of the discussions about what mattered to patients and families. This may be positive because when clinicians initiate such discussions, the issues are more likely to be addressed [15]. However, this finding may also reflect patients' lack of comfort initiating discussions about what matters to them [16]. Of note, once what mattered to patients had entered the conversation, this information was explored (not ignored) and integrated in the decision, if a decision was made. If no decision was made, then this information was at least

addressed, and the patient was at least informed or reassured. This suggests that primary care clinicians take what matters to patients seriously, and genuinely attempt to integrate it into care.

Second, when patients and families did initiate discussions, it was mostly during the information-gathering phase, and the information they volunteered related mostly to preferences, concerns, and treatment-specific values. Although life goals or philosophies and broader contextual or sociocultural values were not initiated as frequently by patients, this may reflect a lack of confidence on the part of patients that such foundational values belong in the clinical consultation [17]. This suggests that the opening minutes of the consultation and up until the physical examination provides an important opportunity to define the scope of what matters to patients.

Third, clinicians' open-ended questions elicited the widest variety of categories of what mattered to patients. In contrast, initiating discussions with a suggestion (e.g., 'I would suggest this option for you,') or a closed-ended invitation (e.g., 'I'm prescribing you this test or medication. Does that work for you?') constrained the scope of discussions. Some research further suggests that physicians' closed-ended questions may be associated with lower patient satisfaction [18]. This suggests that for clinicians to access the widest variety of information about what matters to patients, an open-ended invitation is likely the most suitable.

Our findings regarding the patterns of values clarification address gaps in knowledge about how the process of values clarification routinely occurs during consultations. Because preferences may be constructed, meaning that they may be inherently sensitive to context and may even be determined during a clinical consultation as a discussion evolves [19], by exploring patterns of values clarification and how values, concerns and preferences are discussed during a consultation, this study also offers avenues for further research on how preferences for one option over others may be constructed during the consultation.

Strength and Limitations

Our study has three main limitations. First, we worked with transcripts of clinical encounters, and did not interview clinicians nor patients and families to obtain their perspectives regarding the values clarification process and whether it adequately captured, explored and integrated what mattered to patients into the consultation and any decisions made.

Second, our five categories may be missing concepts that matter to patients but were not discussed in any of the consultations included in this study. This could have occurred due to lack of representation of cases among the 260 consultations in our study, or because of our study methods. In a study in which the authors interviewed patients with multiple chronic conditions directly (rather than observing what they discussed with their health professionals) Lim and colleagues [8] identified three additional domains of personal values that patients reported as contributing to their health and well-being. These three domains that were not identified in our study were "Relationships: connections with others (e.g., family, friends, community)," "Emotions: feelings or mood; states of being that are personal, embodied, or

experiential (e.g., accomplishment, comfort, serenity),” and, “Possessions: tangible things kept, owned, or cherished including spaces (e.g., computer, ‘55 Chevy, home, woodshop).”

Third, this study analyzed encounters in primary care, where clinicians have previously been shown to be more sensitive to patients’ agenda for the encounter [20]. Furthermore, the extent to which these practices reflect primary care patterns and norms in other places is not known.

Strengths of our study were that we analyzed a large dataset across diverse geographic regions, different clinics, clinicians from different health professions, and a diversity of patients, families, and primary care topics, increasing the robustness of our findings. Other strengths of this study include its rigorous coding and analysis by two independent researchers, and the depth of information gathered during analyses, allowing for a detailed description of what matters to patients that is discussed during a consultation. The findings may be useful for clinical practice and future research.

Conclusions

There are five distinct categories of information that matters to patients and families in primary-care: preferences, concerns, life goals or philosophies, treatment-specific values, and broader contextual or sociocultural values. Clinicians should be sensitive to these five categories when engaging in the process of values clarification. Various patterns of values clarification emerged in routine primary care consultations. These patterns can be differentiated according to who initiates the discussion, when the discussion is initiated, and what type of information is discussed. This study provides a structure for future analyses and identification of best practices in values clarification. Future research should also examine potential differences in the process of values clarification between different contexts of care; for example, speciality care versus primary care, and among different populations of health professionals, patients, and families.

APPENDICES

Appendix 1. Sample extracts

Pattern: “Early inquiry by clinician”

For example, in a routine pregnancy consultation, while gathering information and taking the patient’s blood pressure, the clinician initiates the discussion about birth preferences. When the patient expresses her preferences, the clinician explores this preference and addresses it, by providing advice.

Clinician: Did you have an epidural last time?

Patient: Yeah. Yeah.

Clinician: What did you want for this labor?

Patient: I don’t know if... it was quick... if I don’t need it.

Clinician: And if you... if you’re thinking of doing without the epidural... um... it’s good to start... um... to think about how you would manage your pain.

Patient: Oh... last time... I really did not feel any pain when I came here. When they check, they said 5 centimeters already. I didn’t feel anything. Then I began to feel a little and then, I asked for epidural because they said that if I don’t do it right away, I cannot have anymore so I just did it.

Clinician: Ok. I mean, it’s up to you. I mean, some people prefer to have the epidural at some point. If you choose to... if you want to try to go without the epidural, then it’s good to prepare mentally a little bit because... because the pain can be very intense and it keeps on coming back... so sometimes, you can do exercises with your partner...

Patient: Ah ok

Clinician: When he helps... like he does little massages in the lower back.

Patient: Ah ok.

Clinician: Sometimes there are tricks with ice so that when you have the contraction, you can roll the ice in your hand with... with the breathing... like different techniques.

Pattern: “Early evocation by patient/family”

For example, this patient consults for a gastrointestinal concern. However, while the clinician is gathering information about his symptoms, the patient spontaneously raises a concern about hearing loss. This concern is then explored and addressed.

Clinician: Ok... that works... no nausea? No vomiting?

Patient: no.

Clinician: ok.

Patient: I also noticed that... because when speak on the phone, I think I’m starting to have trouble hearing.

Clinician: oh really?

Patient: It bothers me a bit. I make an effort, I make lots of effort to... well to understand what people are telling me... my partner at home says that I raise the sound of the TV... so I thought that maybe...

Clinician: I can maybe give you... we can talk about it... when did you notice this issue for the first time?

Patient: It's been a few months. I had noticed something, but I told myself: Oh no, it's not true, I can hear well enough. There's no problem. But as more and more people tell me that I turn the volume up louder and that I noticed that I have trouble hearing on the phone, I can't really hear what people are saying on the phone... so...

Clinician: ok. And if we found out that you had trouble with your hearing and that it could be fixed with a hearing aid, would you be inclined to try it or...?

Patient: I don't think so. .

Clinician: Because we can for sure do the test to see if you have trouble with your hearing...

Patient: yeah.

Clinician: It's possible that there is a bit of a hearing loss. With age... you are still young, but it can sometimes depend on risk factors, like listening to music really loud or... but if we find a hearing loss and you don't want to try a hearing aid, maybe we can wait a bit...

Patient: ok.

Clinician: It's all up to you.

Pattern: "Early suggestion by clinician"

For example, while gathering information in a routine pregnancy consultation, the clinician suggests a treatment for the patient's reflux, explores the patient's preferences and integrates these preferences in the decision.

Clinician: Do you feel like it's enough to say... to say that you'll take a medication for it? Because sometimes, over-the-counter will help, but it doesn't last very long.

Patient: no... yeah...

Clinician: There is Zantac that is very safe. Did you take some during your previous pregnancies?

Patient: no. no.

Clinician: You could take it when you go to bed and if you see that it's still a problem, then you could take it as needed everyday.

Patient: ok. Ok.

Clinician: Would that be something that could...

Patient: I could take it and if I see that some days are worse than others... then... but for now, I was trying just with a small glass of milk. But it doesn't work. There's not much that works.

Clinician: Ok so Zantac is one tablet and it lasts for 12 hours. So you could take one in the morning and one at night, if you feel that it's still bothering you.

DECLARATIONS

Abbreviations

None

Ethics Approval, Consent to Participate and Consent for Publication

The study was approved by three research ethics committees: 1) Research Ethics Committees of the Integrated University Health and Social Services Centre of the National Capital (CIUSSS-Capitale Nationale) #2013-2014-31 2) Research Centre of the CHU de Québec-Université Laval #2014-1769, C13-08-1769-21, and 3) the Jewish General Hospital, Montreal #CODIM-MBM-13-134

Availability of Data and Materials

Raw data are not available to protect patients' privacy.

Competing Interests

None.

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Authors' Contributions

RR, SCD, HOW contributed to the design of the study. Data collection had already occurred. RR, SCD, HOW conducted data analysis and interpretation. RR and HOW drafted the first version of the article with early revision by SCD. RR, SCD, RG, HOW critically revised the article and approved the final version for submission for publication. RR and HOW had full access to all the data in the study and had final responsibility for the decision to submit for publication.

References

1. Sackett DL, Rosenberg WM, Gray JA, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. *BMJ*. 1996 Jan 13;312(7023):71–2.
2. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Soc Sci Med*. 1997 Mar 1;44(5):681–92.
3. Marteau TM, Dormandy E, Michie S. A measure of informed choice. *Health Expect*. 2001 Jun;4(2):99–108.
4. Fagerlin A, Pignone M, Abhyankar P, Col N, Feldman-Stewart D, Gavaruzzi T, Kryworuchko J, Levin CA, Pieterse AH, Reyna V, Stiggelbout A, Scherer LD, Wills C, Wittman HO. Clarifying values: an updated review. *BMC Med Inform Decis Mak*. 2013 Nov 29;13 Suppl 2:S8.
5. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, Cochran N, Frosch D, Galasiński D, Gulbrandsen P, Han PKJ, Härter M, Kinnersley P, Lloyd A, Mishra M, Perestelo-Perez L, Scholl I, Tomori K, Trevena L, Wittman HO, Van der Weijden T. A three-talk model for shared decision making: multistage consultation process. *BMJ*. 2017 Nov 6;359:j4891.
6. Lang E, Bell NR, Dickinson JA, Grad R, Kasperavicius D, Moore AE, Singh H, Thériault G, Wilson BJ, Stacey D. Eliciting patient values and preferences to inform shared decision making in preventive screening. *Can Fam Physician*. 2018;64(1):28–31.
7. Charles C, Gafni A. The vexing problem of defining the meaning, role and measurement of values in treatment decision-making. *J Comp Eff Res*. 2014 Mar;3(2):197–209.
8. Lim C, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman EJ, Ralston JD. Understanding What Is Most Important to Individuals with Multiple Chronic Conditions: A Qualitative Study of Patients' Perspectives. *J Gen Intern Med*. 2017 Dec;32(12):1278–84.
9. Wittman HO, Scherer LD, Gavaruzzi T, Pieterse AH, Fuhrel-Forbis A, Chipenda Dansokho S, Exe N, Kahn VC, Feldman-Stewart D, Col NF, Turgeon AF, Fagerlin A. Design Features of Explicit Values Clarification Methods: A Systematic Review. *Med Decis Making*. 2016 May;36(4):453–71.
10. Diendéré G, Dansokho SC, Rocque R, Julien A-S, Légaré F, Côté L, Mahmoudi S, Jacob P, Casais NA, Pilote L, Grad R, Giguère AMC, Wittman HO. How often do both core competencies of shared decision making occur in family medicine teaching clinics? *Can Fam Physician*. 2019 Feb;65(2):e64–75.
11. Lee YK, Low WY, Ng CJ. Exploring patient values in medical decision making: a qualitative study. *PLoS One*. 2013 Nov 25;8(11):e80051.
12. Zimmermann C, Del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. *Psychol Bull*. 2007 May;133(3):438–63.

13. Pilote L, Côté L, Chipenda-Dansokho S, Brouillard É, Giguère AMC, Légaré F, Grad R, Wittman HO. Talking about Treatment Benefits, Harms, and What Matters to Patients in Radiation Oncology: An Observational Study (in press). *BMC Med Inform Decis Mak*.
14. Armstrong MJ, Mullins CD. Value Assessment at the Point of Care: Incorporating Patient Values throughout Care Delivery and a Draft Taxonomy of Patient Values. *Value Health*. 2017 Feb;20(2):292–5.
15. Schwartz A, Weiner SJ, Binns-Calvey A, Weaver FM. Providers contextualise care more often when they discover patient context by asking: meta-analysis of three primary data sets. *BMJ Qual Saf*. 2016 Mar;25(3):159–63.
16. Frosch DL, May SG, Rendle KAS, Tietbohl C, Elwyn G. Authoritarian physicians and patients' fear of being labeled "difficult" among key obstacles to shared decision making. *Health Aff* . 2012 May;31(5):1030–8.
17. Lim C, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman E, Ralston JD. "It just seems outside my health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. *DIS (Des Interact Syst Conf)*. 2016 Jun;2016:1172–84.
18. Han Z, Li, Corinne Koehn, Naghmeh G. Desroches, Young-OK Yum, George Deagle. Asymmetric talk. *Canadian Journal of Communication*. 2007;32:417–33.
19. Warren C, McGraw AP, Van Boven L. Values and preferences: defining preference construction. *Wiley Interdiscip Rev Cogn Sci*. 2011 Mar;2(2):193–205.
20. Singh Ospina N, Phillips KA, Rodriguez-Gutierrez R, Castaneda-Guarderas A, Gionfriddo MR, Branda ME, Montori VM. Eliciting the Patient's Agenda- Secondary Analysis of Recorded Clinical Encounters. *J Gen Intern Med*. 2019 Jan;34(1):36–40.