CONSENSUS DEFINITION OF CUES AND CONCERNS EXPRESSED BY PATIENTS IN MEDICAL CONSULTATIONS

MANUAL
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1. Definitions

Cue

A verbal or non verbal hint which suggests an underlying unpleasant emotion and would need a clarification from the health provider. Instances include:

a. Words or phrases in which the patient uses vague or unspecified words to describe his/her emotions.

b. Verbal hints to hidden concerns (emphasizing, unusual words, unusual description of symptoms, profanities, exclamations, metaphors, ambiguous words, double negations, expressions of uncertainties and hope).

c. Words or phrases which emphasise (verbally or non-verbally) physiological or cognitive correlates (regarding sleep, appetite, physical energy, excitement or motor slowing down, sexual desire, concentration) of unpleasant emotional states. Physiological correlates may be described by words such as weak, dizzy, tense, restless, low or by reports of crying whereas cognitive correlates may be described by words such poor concentration or poor memory.

d. Neutral expressions that mention issues of potential emotional importance which stand out [1] from the narrative background and refer to stressful life events and conditions.

e. A patient elicited[2] repetition of a previous neutral expression (repetitions, reverberations or echo of a neutral expression within a same turn are not included).

f. Non verbal cue:
- clear expressions of negative or unpleasant emotions (crying), or
- hint to hidden emotions (sighing, silence after provider question, frowning etc)

g. A clear and unambiguous expression of an unpleasant emotion[3] which is in the past (more than one month ago) or is referred to an unclear period of live (“I was worried about…”; “I was terrified…”).

Concern

- A clear and unambiguous expression of an unpleasant current or recent emotion[4] where the emotion is explicitly verbalized (“I worry about …”; “I am upset”), with a stated issue of importance for the patient (“*I am so worried* about my husband’s illness”; “Since the illness of my husband I feel very helpless”) or without (“I am so anxious”; “I am nervous”). Included are patient expressions confirming health provider’s explicit assumption or question about an unpleasant current or recent emotion (Health Provider: “ are you anxious?, or “you must have been shocked! ” Patient: “Yes”).

[1] This applies to: 1. non verbal emphasis of the sentence; 2. abrupt introduction of new content; 3. the patient pauses before or after the expression.
[2] For definition see paragraph 3.
[3] We consider emotion any conscious experience related to depressive or anxious mood or to a combination of Ekman and Friesen’s (1969) list of basic emotions (of which we consider here only those with a negative connotation): anger, fear, sadness, disgust, surprise in terms of shock, including also shame.
[4] Si note 3

Questions

- Given that a question may contain cues or concerns too, they should be rated according to the same rules as defined above, but they have to be distinguished as a separate category by a "Q".

1.1 Conceptual framework for the distinction between cues and concerns

- Cues and concerns require different patient-centred skills from the health provider. *Cues* as verbal or nonverbal hints to concerns require information gathering and facilitating skills to help patients express their concerns. *Concerns* may or may not demand exploration. If they do not need further exploration, they always demand, however, to be commented empathically (empathic opportunities).
- The expression of concerns facilitates the recognition of emotional distress (clinically significant or sub-threshold) in patients.
- Cues and concerns suggest a different accessibility of patients to their emotions. To be able to verbalize one's own feelings (to express a concern) in the presence of an attentive and empathic listener is a good prognostic factor and predicts better coping in the patient. Feeling understood and sustained reduces the intensity of the emotion, reinforces the relationship with the doctor, increases satisfaction and adherence to the therapeutic treatment.
- To be informed about patients' concerns favours a problem-oriented approach to treatment.
- The expression of concerns, rather than of cues, is a quality indicator of the medical consultation.

1.2 Comments to cue criteria

In the subcategories (a), (b) and (c) the wording of the phrase must suggests an underlying emotion/distress.

- In **(a)** the verbal expression attempts to describe an emotion in quite vague and unspecific words with personal reference (to the patient's own feeling, whether it grammatically is expressed as *I, you, one or it*). The challenge in coding (a)-cues is to distinguish them from explicit concerns. Examples of words coded as (a)-cues: *strange, funny, odd, not so good, so-so*, etc. Examples of words that will be coded as *concerns* : *troubled, annoyed, alone, down, helpless* and of course specific emotions such as *sad, angry* etc.
- In **(b)** the verbal expression indicates (hints to) an implicit emotion. The patient does not attempt to describe, although vaguely, his/her emotion, but uses metaphors ("I am exploding", allusions ("Its better to die"), references to circumstances ("It is all so useless") or exclamations to suggest an internal state. Included are expressions such as "I don't feel like…", "I am not prepared to…", "I can't accept that…" . If the patient says: "I feel useless", the expression is coded as a *concern*.
- In **(c)** the verbal expression indicates a physiological correlate of emotion. It is not enough just to mention the physiological domain (for instance sleep), the verbal expression has to suggest an underlying emotion by emphasizing. For instance, the expression "I do not sleep very well" may not necessarily be coded as a cue. However, if the wording contains an emphasis ("I can't sleep, doctor. I can' sleep "; "I am quite sleepless these nights") it should be coded as a cue.

- In (**g**) the emotion is explicit, as is in concern definition, but is expressed in past tense and refers to more than one month ago or to an unclear period of life. Often it is part of a narrative.

In the subcategories (d) and (e) the verbal content does not in itself indicate emotion, i.e. the words used are in that sense neutral.

- **In (d)** the verbal content is neutral and has not been mentioned before. Therefore, the challenge in coding (d)-cues is to distinguish them from non-cues. Current emotion is assumed or suspected for two reasons, which both must be present (1) because the expression in some way stands out from the narrative context and (2) because refers to potentially stressful life events or conditions. For instance, the sentence "I have cancer" is not coded as a cue if it is part of a passage in which the patient simply gives medical information. It becomes a cue if the patient gives it some sort of emphasis that makes it highlight itself from the narrative, indicating an emotion. Therefore, the context of the expression rather than the wording itself is important in coding cues according to the (d) criterion.
- In **(e)** emotion is assumed or suspected because a neutral verbal expression or a sentence is repeated by the patient, on his or her own initiative, in one of the subsequent turns. In order to be coded as cue (e) the formulation of the repeated sentence must be very similar to the previous (original) one.

In order to be coded as a non-verbal cue **(f)** the expression must not have any verbal content, but simply non-verbal behaviour as indicated by the definition. Thus, a cue is coded as non-verbal **(f)** only if the other criteria ((a) through (e)) do not apply.
The verbal cues ((a) through (e) and (g)) may of course be accompanied by a non-verbal emotional aspect, such as tone of voice or facial expression. However, in (a), (b) (c) and (g) the particular word or phrase will be sufficient to code the it as a cue, independent of any nonverbal sign of emotion. In (d) the non-verbal expression may be the aspect of the word or phrase that justifies the coding as a cue. In (e) a non-verbal accompanying expression does not make any difference to the coding.

1.3 Units of analysis

The coding of cues and concerns is based on units of analysis (for the definition see the manual "*Rationale for dividing a consultation into units of analysis*").

2. Repeated cues/concerns

A cue/concern is coded only once when repeated in a turn, whereas separate codes might occur in the same turn if they refer to different content or to different coding categories of cues (a to f) or concerns. In subsequent turns a same cue/concern is always coded.

3. Cue/concern source

Conceptual framework for the distinction between Health Provider-elicited (HPE) and patient-elicited (PE) cues and concerns

- The expression of cues and concerns solicited, explored or facilitated by the health provider (health provider-elicited), are an indicator of the space given to patients to explicate their concerns (they are expected to do so) without patient needing to break "rules" or take initiatives.
- The expression of patient-elicited cues and concerns is an indicator of patient's initiative or active struggle to direct health provider's attention to specific worries.

All types of cues/concerns can be **HPE** as well as **PE,** as indicated also in table 1.

Health Provider-elicited cues/concerns

These are:

- all cue/concerns which are coherently and logically connected with the previous health provider turn. They may be given as response to health provider's closed-ended questions ("Are you worried?"), to open-ended focusing questions independent from the width of the focus (What makes you postpone the appointment? "What are you worried about?") or to statements which have addressed the mark.

- all cue/concerns in a turn subsequent to an open-ended non focusing question (inviting, "Tell me more...") or to a facilitation (Back channelling, echoing, expressions of empathy…), even when they imply a topic change within a patient turn.

☞ Attention. If minimal expressions ("Hmm", "Yes") are accompanied by uninviting non verbal provider behaviour (annoyed tone of voice, dismissive, doing other things, turned away from the patient) reported in the transcript or visible/ audible on the videotape, the cues/concerns subsequent to these expressions have to be coded as patient elicited.

NB: When the patient completes an already started sentence in the next turn without taking into account an attempted interruption by the health provider, the cue/concern reported is counted only once, at completion of the sentence.

Examples for doctor-elicited cues/concerns

After closed-ended question:

D: Do you feel disappointed? P "*Yes I do*" (**concern HPE**) ;

After open-ended focused question:

D: How do you feel? P: "*I feel anxious*" (**concern HPE**)

D: How do you feel? P: "*so so*" (**cue a HPE**) ;

D: How is the pain. P: "*my whole chest is in a tight band, I have to take my bra off*" (**cue b HPE)**

After a statement which has addressed the mark

D: It is high blood pressure that is the problem. P: "That is worrying ..." (**concern HPE)**

After open-ended non focused question:

D: What's the problem? P: "*Everything seems useless*... (**cue b HPE)**

D: How are you going? *P:* "*I am worried about this terrible pain* (**concern HPE)**. *Last week I also lost my job"* (**cue d HPE)**

After a facilitation

D: Right! *P:* "*I am worried about the blood test* (**concern HPE)** *and I am upset about my daughters' car accident*" (**concern HPE)**

After a statement of participation or empathy

D: This situation is not easy for you… P: " No, it isn't..." (**cue b HPE)**

Patient-elicited cues/concerns

Evidence the extent to which patients hint to or to introduce concerns of their agenda which the health provider so far had neglected, or not sufficiently explored. The patient introduces such cues/concerns without having been solicited, invited or expected by the doctor to do so. These are all concerns/cues not directly connected with what was said in the previous exchange, representing or suggesting a topic change, or stressing the importance of the topic for the patient, except when they follow an open-ended non focusing question, a facilitation or statement of empathy.

Examples for patient-elicited cues/concerns

D: This is the next appointment for the chemotherapy. P: "I see... *I am so anxious..."* (**concern PE**)

D: What did Dr. X say?. P: " That it's gone beyond surgery. *But we need to treat the whole body, we need to treat the whole body* (**cue b PE**)

D: You are going to be all right. P: " *It's so disappointing to have done all these tests and that part was never really checked"* (**concern PE**)

D: Did the therapy improve your symptoms? (or "What about treatment effects?" or "The therapy I prescribed will relieve your pain"). P: "Mind you, no relief at all, nothing, nothing. (**cue b HPE)**. *My husband complains about the high treatment expenses we had and makes me feel guilty **(concern PE).***

4. Definition of current/recent importance

Conceptual framework for the distinction between expressions of current/recent concerns and mentions of past concerns

Concerns of current or recent importance (any issue, related to illness or to other stressful topic, that causes worries, creates apprehension, distress, anxiety or any other verbalized emotion to the patient) are known to be associated with emotional distress of clinical significance, therefore they are useful predictor variables. The inclusion of past concerns with uncertain current or recent importance invalidates this relationship.

Concern

- Emotion related to issue is stated in present tense.
- Emotion related to issue is stated in past tense and is still important. This can be understood from the context of the interview or by details offered by the patient ("The loss of my job last week made me very upset"). The lack of details or context information about recentness of emotion implies the classification of the expression as cue g.

Examples:

D: "Do you sleep?" P. "Not so much. *The loss of my job last week made me very upset*" (***concern PE***)

D: "How is it going?" P. "Until two weeks ago I felt very depressed" (***concern HPE)***

D: "Are you still concerned about the radiation?" P: "*Yes I am* (***concern HPE***), last *week I didn't know how to cope* (***cue a PE***)"

D: "The doctor suggested chemotherapy?" P: "Yes, he did. I was quite shocked (***cue g PE***). D: "And when was this?" P: "Three weeks ago" (***concern HPE***).

D: "The doctor suggested chemotherapy?" P: "Yes, he did. I was very frightened (***cue g PE***) D: "And when was this?" P: "Last year" D: But how do you feel now?" P: "Oh, now I am ok (***no concern***)

If a concern without time frame is followed by the same concern with information on its recentness, the first one is coded as a cue, the second as a concern.

D: "What did the doctor tell you? P: "It was last year that he told me I had cancer. I was very frightened about my future (***cue g HPE***). D: "And now how do you feel?" P: "*Still quite worried…*" (***concern HPE***)

Cue

Time frame is irrelevant for the definition of cue, being this by definition something vague that needs exploration.

5. General comment

Coding aids

Expressions should be coded as cues or concerns plus a source indicator **HPE** or **PE**.
For cues the (a) through (g) criteria should not necessarily be coded. These criteria are meant as a coding aid. However, for some research purposes and for reliability studies the (a) through (g) criteria might be specified.

Coding decision criteria

Based on the above criteria, concerns are easier to identify than cues which are more complex. Cues tend to be vague and incomplete and by definition need exploration by the doctor.

To help in coding cues we suggest the following criteria:

- When in doubt between a cue or a concern, consider if the emotion has been clearly verbalized or made explicit in the preceding turn of the health provider. If this is the case, code as concern, otherwise as cue.
- When doubtful whether concern or cue, code as cue.
- When doubtful about cue, examine if the expression would need exploration or should be followed up. If not, skip it.
- If there are strong doubts whether the patient's expression is eligible for coding, skip it.

6. Conclusions

The core definitions of cue and concern present the minimal common denominators on which agreement was possible.

- The focal point of the core definition is the negative emotional connotation of the cue/concern expression, with the emotion hinted or fully verbalized.
- The consensus definition is not intended to substitute the cue/concern definitions adapted in the different coding or rating systems currently in use to analyse patient-provider interactions.

References

Ekman, P. & Friesen, W. V (1969). The repertoire of nonverbal behavior: Categories, origins, usage, and encoding. *Semiotica*, *1*, 49-98

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Summary table

EXPRESSION	DEFINITIONS	HEALTH PROVIDER ELICITED (HPE) PATIENT ELICITED (PE)
CONCERN ***Clear verbalisation of an unpleasant emotional state***	**Emotion is current or recent & issue of importance is not stated**	**HPE** *"Yes doctor, I am quite frightened"*
		PE *"·And then…I feel also very depressed"*
	Issue of recent or current importance is stated (life events, social problems, symptoms, other issues)	**HPE D:** What are you worried about? P: "*That I could loose my baby*" *P: "You are right, I am upset about the bad outcome of the treatment"* D: Are you worried for the tests outcome" P: *"Yes I do"*
		PE P: "Now the headaches are not so strong…*but I am worried about the results of the tests"*
CUE ***Expression in which the emotion is not clearly verbalized or might be present*** ***The criteria of currency/recentness is not applicable***	a. **Words or phrases in which the patient uses vague or unspecified words to describe his/her emotions** **b. Verbal hints to hidden concerns (emphasizing, unusual words, unusual description of symptoms, profanities, metaphors, ambiguous words, double negations, exclamations, expressions of uncertainties and of hope regarding stated problems).** **c. Words or phrases which emphasise (verbally or non-verbally) physiological or cognitive correlates (regarding sleep, appetite, physical energy, concentration, excitement or motor slowing down, sexual desire) of unpleasant emotional states.** **d. Neutral words or phrases that mention issues of potential emotional importance which stand out from the narrative background and refer to stressful life events and conditions.** **e. A patient elicited repetition of a previous neutral expression (repetition, reverberations of a neutral expression within a same turn are not included).** **f. Non verbal expressions of emotion** **g. Clear expression of an unpleasant emotion, which occurred in the past (more than one month ago) or is without time frame**.	**HPE** D: How do you feel? P:*"I feel so so*"(a) D: How do you feel? *"It could be better"*·(a) D: How do you feel? P:"*I feel like a wet rag*" (b) *D:* How is the pain? *P*: "*The pain really stabs me*" (b) D: How is it going? P: "*The last two months I had only sleepless nights"*(c) D: How is your appetite? P: "*I force myself to eat* (c) D: What else? P:"*I just had this sad funeral"…*(d) D. What did Dr. … said to you? P: *Well…* (sighs)*… he told me that I have cancer* (d) D: How do you feel? P: *Silence (crying, sighing)* (f)
		PE D: How is your husband? P: He is always so nervous… *I do not feel good about him*" (a) D: Are you anxious? P: "I am (Concern), *but the worse thing is that all seems useless*"(b) D: It takes some time to get to sleep.. P: "Yeah, …And then in fact once when you are pregnant you, well, do feel very tired and just feel very exhausted*, which is not the first time as well."*(b) D: What about the waterworks? P:" That's ok. *I have this stabbing pain in my back (b)* D: Wouldn't it be useful if you had some time off? P: "I don't think I could have some time off*, cos' they're very, very…"* (b) D: How is your appetite? P: "I don't eat so much lately, *and I feel completely without energy*" (c) *P* "You know that I can't relax, yeah (pause) *Can't seem to just relax (pause*)" (c) D: Is your work tiring*? P: Besides, there is my little girl. She goes to a crèche now…* (d) P: "I worked till I started radiation" D: The weight is steady? P: It has dropped about three kilos in the last fortnight, but then mayb*e, because of the radiation…* (e) *P: "And (pause) …patient cries* (f) *P* "When the doctor told me about cancer *I was so frightened..*" (g)

Some examples as coding aid

Cues

a
I (you, one, it) feel (s)… , am (are)…(unfinished sentence)
It's a strange feeling inside
I have these moments and I say oooh..
I cannot stand it anymore
You are stressed when this happens, its stressing me out.
Its too much for me
I really felt bad
You keep on trying over and over, but it's all in vain
I cannot cope
I feel terrible
I'm feeling very vulnerable
I am distressed
It just got me
I feel very tight
It just got me right now…
What I'm not coping with is…
I feel uncomfortable
I can't go on any more

b
Metaphor, Emphasis
I feel rotten inside
I feel like a wet rag
I feel cold as ice
There is this emptiness
My mind is blank
My head is in the clouds
I am off my head
I never dreamt of it
I am the black sheep of the family
I am pushed against the wall
I feel like drowning
I just want to be far away from all
I accumulate, accumulate and explode
I have no way out
I am always under pressure
I am worn-out, but not physically
I have my nerves on edge
Everything is building up on me
It gets on top of me
This one came down really hard
This knocked me down
My future is black
Its like something sticking on me and I cannot get rid of it
My battery is empty
Thunder feelings
Things are signing me
I risk a collapse
It's hard, very hard
That was devastating
It's a daunty thing
This is really a bad moment
It's a tragedy
I hate Sundays
That is the hard part of it

Uncertainty, hope (when needing exploration)
I don't know how to find relief
I have to change my life, I don't know how
I thought how long will this go on
My mother has a tumour and I don't know what will come down on me
If I just knew how to deal with it
I can't figure it out
I don't know how to say it
I was hoping... but anyway

Allusion
I have these strange symptoms
Doctor, if you would know…
Its better to die
That's the end of all
This is not life any more
With all the problems I had in my head
Now that I know..(silence)
I always was fit at work, but now…(Silence)
It's not always easy

Not being ready to..
I just can't think, I don't want to think about
I just can't believe it
I can't accept this
I am not prepared to be pushed off again…
I am not terribly keen on
I don't want to

Profanities, *Exclamation*
O my God
Heavens (Good lord)
I don't give a damn
I curse the day I met him
The bloody pain will not stop
He is really a son of a bitch

Unusual or emphasized description of physical symptoms
When I get up if I don't sort of steady myself like that, whether I would fall over or not I don't know
The pain really stabs me
I was bent in two
My body is boiling
My head is bursting
Heavy eyes, heavy legs, heavy head
These butterflies in my eyes
I get up, there is this bloody swindle, this nausea, I seem to faint
My throat feels like strangled
My fingers are dead cold
Strange sensation in my head

c
This two weeks, I eat and eat, incredibly
Already in the morning I am dead tired
I feel like crying
I have to force myself to eat
My legs are shaking
I would need something to relieve my tension
I feel this tension inside
I cannot concentrate
I feel confused, disoriented, perplexed, bewildered, mixed up

Concentration I find, it's just not good
Crying just all time
My problem is I cannot stop eating

d
We got into trouble
unfortunately, we have a problem …
The problem is…work (wife, children, stress)
My work is very stressful
The pain came on when I went through a very stressful period at work
I have cancer, doctor …(silence)
It's good to be with friends, it helps me to forget my problems
Oh.. I am really a bit isolated
How can someone say something so rude to me!?
My wife is fed up with me

CONCERN

Clinical: My problem is anxiety, depression

Sadness: I am depressed, discouraged, demoralized, unhappy, apathetic, miserable
I am without (have lost all my) enthusiasm, self esteem
I feel hopeless, I lost all my hope
I feel useless (I am of no use any more)
Nothing is of interest to me
I (am, feel) lonely, alone, abandoned at times, helpless, let down, low

Surprise: I am quite shocked (stunned)

Fear: I am worried, concerned, anxious, nervous, bothered, upset, agitated, frightened, troubled about my health (son, work etc)…, panicky
It's concerning that I ….
I am in apprehension for

Anger: I am angry (irritated, cross, grumpy, furious, outraged)
You feel betrayed, hurt, offended, disappointed, frustrated, annoyed

Disgust: I feel disgusted, nauseated, bored, appalled
I hate

Shame: I am embarrassed, shamed, humiliated, mortified,
I feel sorry, guilty, rueful