Encountering Patient-Centredness: The Communication Crucible

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PREAMBLE

- Making sense of Patient-centredness (PC)
- **Conceptualising PC**
- **Operationalising (Describing/Analysing) PC**
- **Assessing PC**
- Consider these challenges from a language/interaction/communication perspective

PREAMBLE

- A word about the title
- How is PC **encountered** communicatively
- **Crucible**: a vessel in which substance are heated to very high temperatures; the hollow part at the bottom of a furnace in which melted metal collects; **a severe searching test**
- Communication as the searching test bed (the furnace) for what we mean by patient-centredness.

PATIENT-CENTREDNESS: HISTORICAL DIMENSION

- Patient-centredness is embodied in the Hippocratic Oath; it is combined with professional neutrality, integrity and judgement.

- Foucault ([1972] 1994) draws attention to the complexity of clinical practice, with its commitment to application of expert knowledge while acknowledging the patient's perspective. He cites Dumas' guidelines for the doctor:

> `Make yourself master of your patients and their affections; assuage their pains; calm their anxieties; anticipate their needs; bear with their whims; make the most of their characters and command their will, not as a cruel tyrant reigns over his slaves, but as a kind father who watches over the destiny of his children.' (Foucault 1994: 88)

PATIENT-CENTREDNESS: HISTORICAL DIMENSION

- In clinical discourse, **relations between the doctor's therapeutic role, his pedagogic role, his role as an intermediary in the diffusion of medical knowledge, and his role as a responsible representative of public health in social space**. (Foucault 1972: 53)

- The complex role-set (Merton 1957) for the doctor (educator, therapist etc)

- Carl Roger's (1951) client-centred therapy has been influential, especially in counselling and therapeutic settings.

PATIENT-CENTREDNESS: HISTORICAL DIMENSION

- With regard to psychotherapy research and practice in the 1960s, Shlien and Zimring (1966: 426) observe:

- [T]he shift from *non-directive* to *client-centred* ... is not incidental revision of nomenclature. It signifies the clarification of a perspective... *non-directive* is a negative term, a protest contra to *directive*, and misleading in that it merely suggests the absence of direction... In this shift the image of the therapist changes from that of the mirror-like, passively non-influencing listener to that of the sensitive, actively understanding human respondent... When the therapist was viewed as essentially neutral, passive, self-effacing, all therapists would be assumed to be equal, i.e., homogenous by virtue of their inactivity. When the therapist image changes, the research and theory tend to focus somewhat upon him, though still largely on the client. (emphasis in original)

PATIENT-CENTREDNESS: COMMUNICATIVE DIMENSION

- Patient-centred ideology in health care delivery is currently driven by two rather different trajectories (Sarangi 2007): one a positivistic medical model of **evidence-based medicine** (signs), the other stemming from the humanities and drawing on **narrative and discourse based medicine** (symptoms and self presentation).
- Narrative-based medicine (Greenhalgh and Hurwitz 1998) rooted in the **biopsychosocial model** (Engel 1977) and the cultural hermeneutic model, gives patients the power and agency to understand and speak about their illness experience (Good 1994).
- Lyotard (1984) distinguishes between **scientific knowledge and narrative knowledge** – the latter requires a three-fold competence: `know-how', `knowing how to speak' and `knowing how to hear'.

PATIENT-CENTREDNESS: COMMUNICATIVE DIMENSION

- Narrative is equated with patient-centredness via the empowerment of patients' lifeworld stories. Following from Habermas (1984), Mishler (1984:104) proposes a distinction between **the voice of the lifeworld** and **the voice of medicine**:
- The voice of the lifeworld refers to the patient's contextually grounded experiences of events and problems in her life. These are reports and descriptions of the world of everyday life expressed from the perspective of a natural 'attitude'.
- The timing of events and their significance are dependent on the patient's biographical situation and position in the social world. (cf. Clark and Mishler 1992: the case of the `black-eye')

DATA EXAMPLE (Presenting a seizure)

[R = Resident; P = Patient (male); transcript simplified]

01 R: Okay so you said you ha:d a- ^seizure ..... yesterday?

02 P: Uh u yesterday about ..... about eleven o'clock yeah

03 R: Hmm .. at work?

04 P: hum hum

05 R: Okay. Uh

06 P: Well I'm not really worried itz same thing you told me not getting ya- know not upset and aggravated and

07 R: hh. Hh

08 P: I couldn't have-ta uhm ..... my boss give me a car Tuesday right? .... and ..... I workin-on it was an Audi I never did brakes on an Audi before.

09 R: hh. Hh

10 P: Ya-know front wheel drive?

11 R: Yeah

DATA EXAMPLE (Presenting a seizure)

12 P: And it was a problem, ya-know and I was down all day long you know w—back like this-here. Like the car's on a lift.

13 R: Yeah

14 P: But it's two bolts ya-know ya just can't get to-em unless you get right up on the caliper and ah twas—jus can twist a little bit with a screwdriver. And I was going like (gangbust) when (I) ya see I got a black e(h)ye .hhuh

15 R: O- Oh from the ^seizure

16 P: No. from the caliper. One of em fell to ^the eye

17 R: Oh I see

DATA EXAMPLE (Presenting a seizure)

18 P: And it hit me there so ..... Tuesday night and I had this terrible headache and all. So I slept with ya-know with a ice pack ..... over-it al night to keep- tryin to keep it from swelling and all. .. And then I went back in yesterday to try to finish it up. It never took me that long before to finish up a brake job

19 R: .hh hh.

20 P: And ..... my boss hadn't got all the parts for it so I start working on another car-ya-know? That's when I ended up having the seizure.

21 R: Okay uhm .hh so: did your boss or someone else see the seizure happen?

(Clark and Mishler 1992:349)

ANALYTIC COMMENTARY

- The illness experience unfolds like a story; the patient assumes `story teller' authority.
- In terms of narrative structure (Labov), `I'm not really worried' works as abstract; orientation then follows – time, place, other persons involved, e.g. the boss; complicated action seen in dealing with the two bolts; not having the right parts; evaluation – it never took me that long before to finish up a brake job.
- R assumes the role of story recipient. Note the extended turns of P, in contrast to R's acknowledgement tokens, which recognise the relevance of the facts. There is shared understanding about the relationship between emotional upset and seizures.
- This is not just mere reporting, it involves a complex argument and presentation of self (a diligent worker); P makes identity claims, draws upon personal knowledge.

PROFESSIONALS AS MINI ETHNOGRAPHERS

- Kleinman (1988): `Master ethnographers and clinicians, though their work is quite different, nonetheless tend to share a sensibility. They both believe in **the primacy of experience**. They are more like observational scientists than experimentalists. Like the poet and the painter, they are strongly drawn to **the details of perception**'.

- (Kleinman 1988:232-233): 'The purpose of conducting the mini-ethnography is for the clinician to place himself in **the lived experience of the patient's illness**. To the extent possible, the doctor tries to understand (and even imaginatively perceive and feel) the illness experience as the patient understands, perceives, and feels it… This **experiential phenomenology** is the entrée into the world of the sick person.'

PATIENT-CENTREDNESS: COMMUNICATIVE DIMENSION

- Recommended skills in the communication skills literature invariably entail the doctor talking more, at more abstract levels and metacommunicating more (e.g., 'There are two possibilities which explain your symptoms. I'm trying to decide between two ways forward ...'; 'What I've suggested makes sense to me but if it isn't right for you, we'll need to think again' (Silverman et al 1998:121).

- Narrative-based medicine emphasises the relevance of active listening, but does not recognise the fact that there might be problems with patients' ability to produce coherent, intelligible narratives.

- Patient-centred models are measured by the number of open questions asked (Henbest and Stewart 1990) and assume that doctors can unproblematically elicit symptoms, feelings, ideas and expectations and discuss the nature of the problem and possible action.

- In a linguistically and culturally diverse patient population, talk itself may be the problem.

EXAMPLE 1 (male Francophone African speaker)

01D come and have a seat so do you mind sitting there (.) is that all right (.) it's just a bit nearer for me and the computer(.) so poor old David what's been worry- shall I take that off you

02F yeah ah since er er Sat- think it's Saturday

03D mm

04F he became er he start vomiting

05D oh dear

06F [himself] er for Saturday afternoon

07D hmm right

08F so then he had a temperature

09D right

10F and then also a fever

11D **and have you any thoughts about what might be wrong with him what were you thinking**

ANALYTIC COMMENTARY

- F gives context and symptoms but no affective or epistemic stance.
- No grading of emphasis with regard to symptoms (vomiting, temperature, fever).
- D offers an affective stance instead (‘oh dear’)
- D indicates (in text boook recipe style) that F should provide an assessment (`have you any thoughts about what might be wrong with him’).
- Cross-culturally, there may be differential expectations about expertise and doctor-patient role-relationships.

Example 2 (elderly woman of South Asian origin)

D: how are you today

P: oh: {[dc] [creaky voice] not very good}

D: not very good (.) what's happening

P: I *pain here (.) *too much (.) I can't cope you know

D: right

P: *yesterday (.) *whole day

D: right

P: and I eat (.) *three times (.) paracetamol

D: right

P: two three hours it will be *all *right and then (.) *come *pain again (.) I *can't cope (.) pain like

D: you can't cope with this pain

P: yeah very very bad (.) I don't know what's the wrong with me

D: sure how *long you have this

ANALYTIC COMMENTARY (Example 2)

- Patient acts out her trouble, taking a strong affective stance.
- Her self-report is delivered in short sharply contoured units with little distinction made prosodically between symptoms, stance and self-treatment.
- GP (also of South Asian origin) uses repetition in order to elicit more affective stance.
- GP's question about symptoms is prosodically in tune with patient's self-report and affective stance.

PATIENT-CENTREDNESS: COMMUNICATIVE DIMENSION

- **What does Patient-centredness mean in interactional and communication terms?**
- Involvement/participation (e.g. active listening)
- Shared agenda setting and aligning of expectations
- Topic management (medical, lifeworld)
- Q-A sequences (open/closed questions, who initiates Qs; interactional space for patient narratives, including Perspective Display Series [PDS])
- Offer of explanations: Packaging of information (jargon-free environment which enables understanding) and advice (which enables shared decision making and compliance)
- Occupying different role-sets: as educator, as therapist; as privy to social fairness and justice.

DIFFERENT FACES OF PATIENT-CENTREDNESS

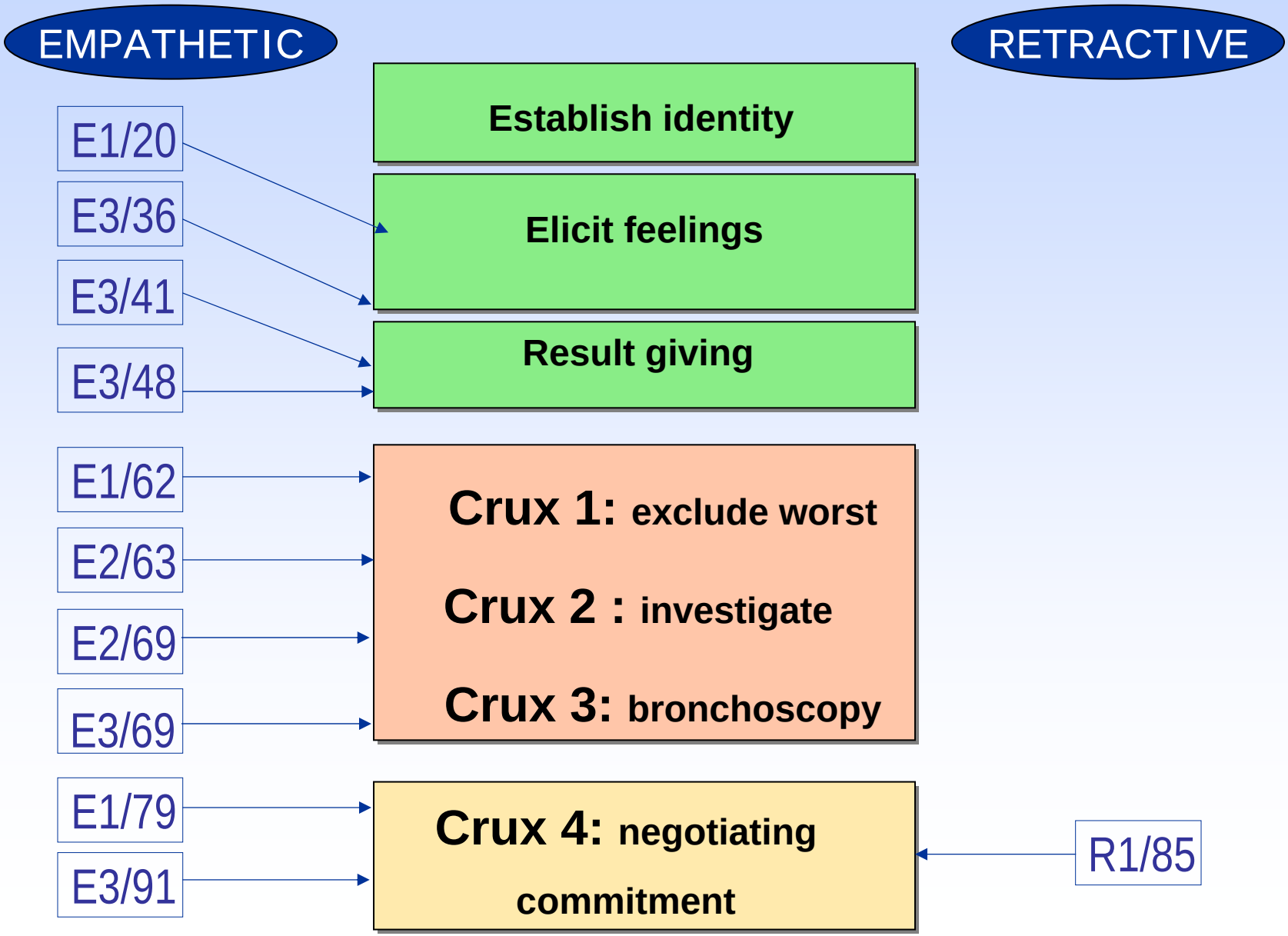
- Evidence-based medicine (orientation to professional neutrality; knowledge-led practice; functional specificity and affective neutrality)
- Narrative-based medicine (orientation to patient involvement, experiences, emotions etc.)
- PC as other-orientation (as in familial conditions in genetic counselling; counsellors speak on behalf of absent others)
- PC as self-orientation (problem formulation which acknowledges self-ownership as a basis for resolution).
- Ethics: informed consent; confidentiality; rights and obligations.

DIFFERENT FACES OF PATIENT-CENTREDNESS

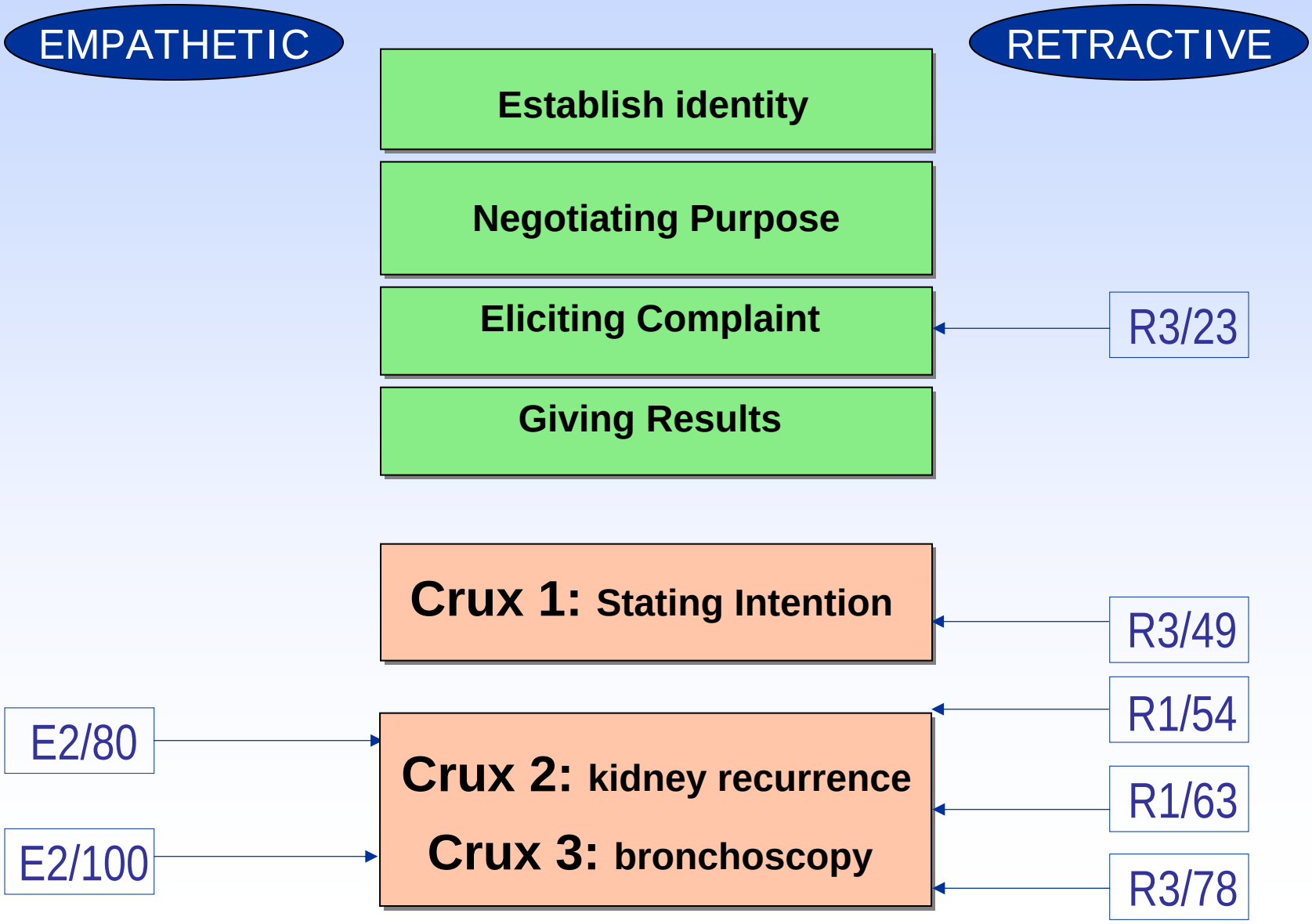
- Patient-centredness as moral philosophy (Epstein et al 2005)
- A shift in patients being understood as `unknowing bodies' to being regarded as people with autonomy, subjectivity, agency (Sullivan 2003)
- Discourse of prevention and self-governance; responsibility and accountability
- Discourse of multi-professional team-work
- Discourse of scientific research (animal testing; randomised clinical trial, hybrid embryo, stem cells etc.)
- Discourse of patient care (electronic patient records)

SOME DATA EXAMPLES

MAPPING OF PRIMARY CARE CONSULTATION (Candidate A)



MAPPING OF PRIMARY CARE CONSULTATION (Candidate B)



STYLES OF INTERACTIONAL INVOLVEMENT

- Candidates with higher scores not only use more empathetic styles of asking questions and listening (in the distributional sense), they also display their strategic orientation to an empathetic stance (in the staging/sequential sense).

ACTIVE LISTENING: STYLE OF INVOLVEMENT IN PALLIATIVE MEDICINE

DOCTOR

- Your oncologist … I wondered why you were coming to see me…..
- Who started tylex
- I see
- Thinking about what you said ….comes as a bit of a shock…do you want to tell me more
- Is it breathing too
- When did they say no treat..

PATIENT

- Hip… pain, breathless… need stronger painkillers than tylex… constipation…tried prune juice..
- GP
- Pain .. Went to B'ham…so full of hope.. Suddenly it's like no Its all come as a bit of a shock..
- I'm just not going to be OK… had hopes…don't know how long I've got…pain…need painkillers
- Yes breathless walking
- Nothing they can do

ACTIVE LISTENING: STYLE OF INVOLVEMENT IN PALLIATIVE MEDICINE

DOCTOR

- Dr B.dropped me a short note…give us an opportunity….would help me if..
- Big shock
- Problem with lungs?
- Were you warned…
- Anyone to talk to?
- [slight laugh]
- Parents? Girlfriend?
- Difficult time….
- Before problem with hip..?

PATIENT

- Cancer…pain…..chemo …..operation cancelled … …..problem in lungs
- Yes
- Cancer spread
- No
- ^^^^^^^
- No
- It was a shock

INTERPRETING INTERACTIONAL INVOLVEMENT

- The candidate with high score manages the history taking phase in a staged and strategic manner at the medical and psychosocial level, with display of adequate empathetic markers; adopts an active listening stance by allowing the patient to offer a full account of his/her concerns; recycles (rather than just repeats) relevant bits of patient information (including family concerns) in a purposive way to highlight major issues; shifts strategically between the `I', `you' and `we' mode in order to signal authority and agency on the one hand and a shared decision-making frame and reassurance on the other.

INTERPRETING INTERACTIONAL INVOLVEMENT

- The candidate with low score prevents the patient from offering a full account of his/her concerns through closed questions and premature empathetic stance; open (vague) questions tend to be used for topic shift rather than topic development; summary type and checklist type questions often lead to extracting minimal responses – indicative of doctor pursuing his/her own agenda; no particular rationale for the staging of various questions; overall tone of generality; little use of `we' pronoun to signal shared understanding and intervention.

ANTIBIOTICS (NON)PRESCRIPTION

Clinic A

Turns	Phase
1-4	Opening
5-9	Symptoms
10-14	Treatment
14-16	Symptoms
16-20	Examination
20	Diagnosis
20-28	Treatment
28-31	Symptoms
32-36	Treatment
37-39	Closing

ANTIBIOTICS (NON)PRESCRIPTION

Clinic B

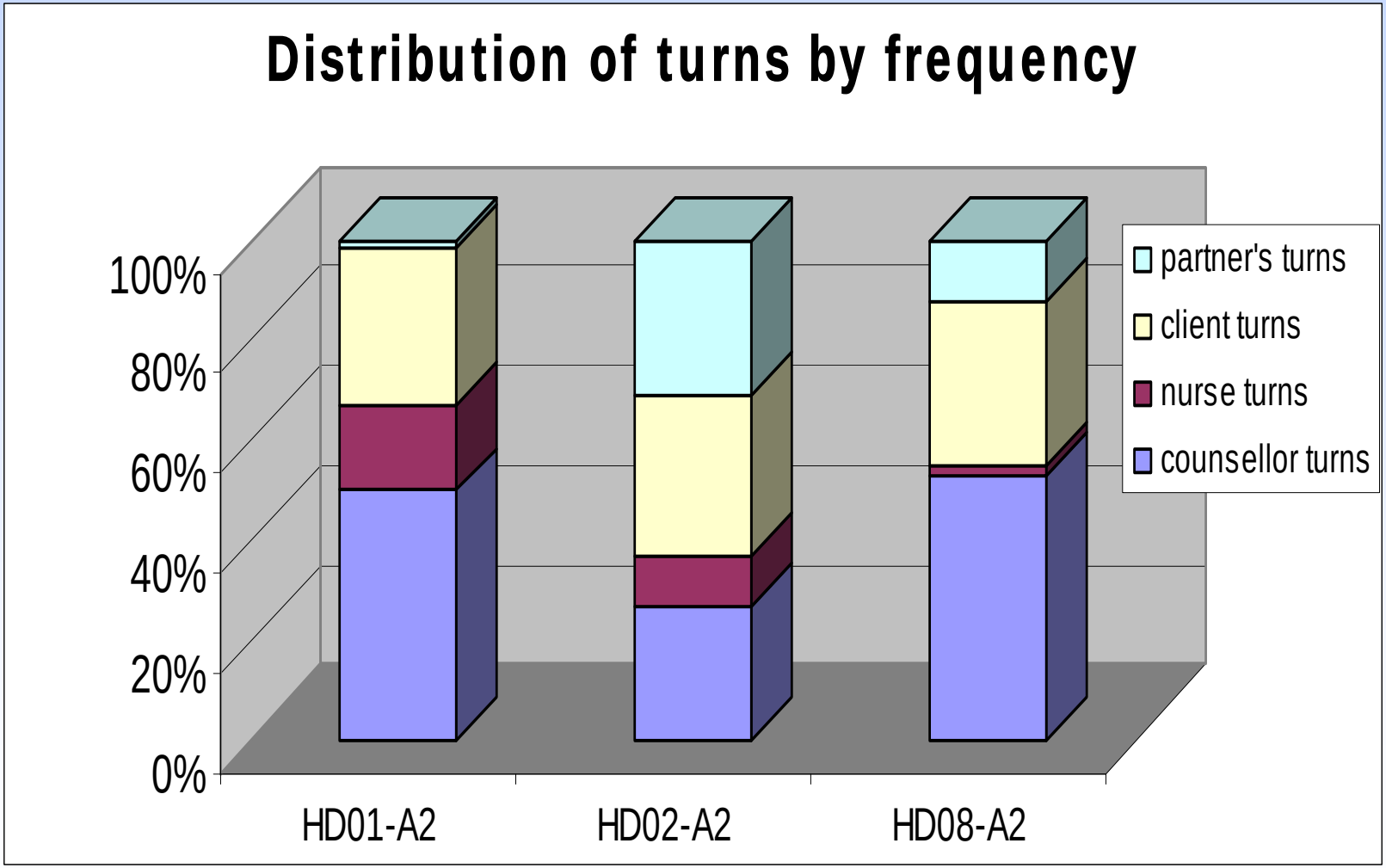
Turns	Phase
1	Opening
2-26	Symptoms
27-31	Treatment
31-40	Symptoms
41-43	Examination
44-51	Symptoms
52	Treatment
53-54	Examination
55	Causal explanation
56-58	Symptoms
Contd...	

ANTIBIOTICS (NON)PRESCRIPTION

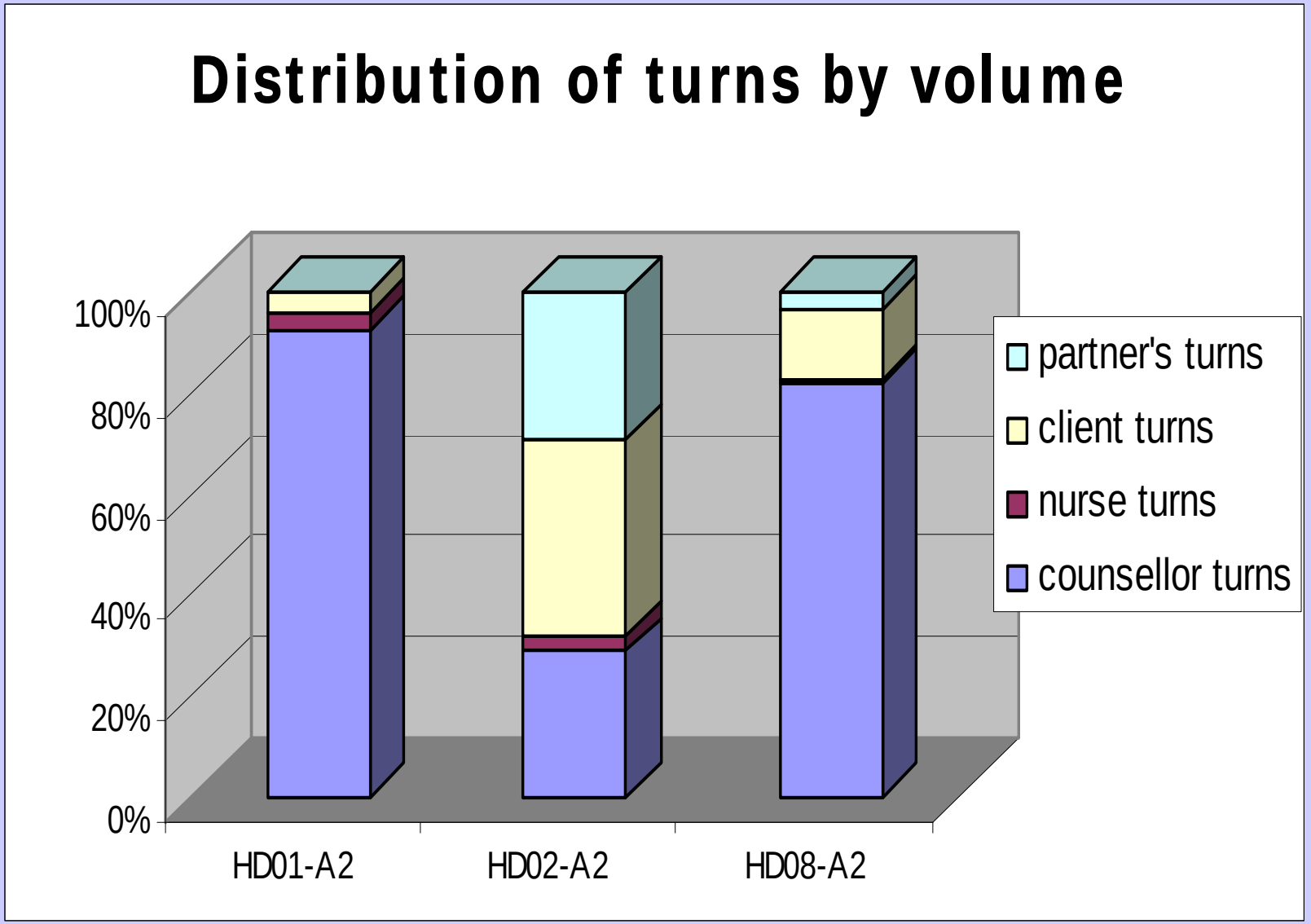
Clinic B
Contd...

59-63	Examination
64-65	Non-medical
66-72	Symptoms
73-83	Causal explanation
83-85	Treatment
86-92	Symptoms
93	Treatment
94-98	Symptoms
99-101	Miscellaneous
101-115	Treatment
116-121	Closing

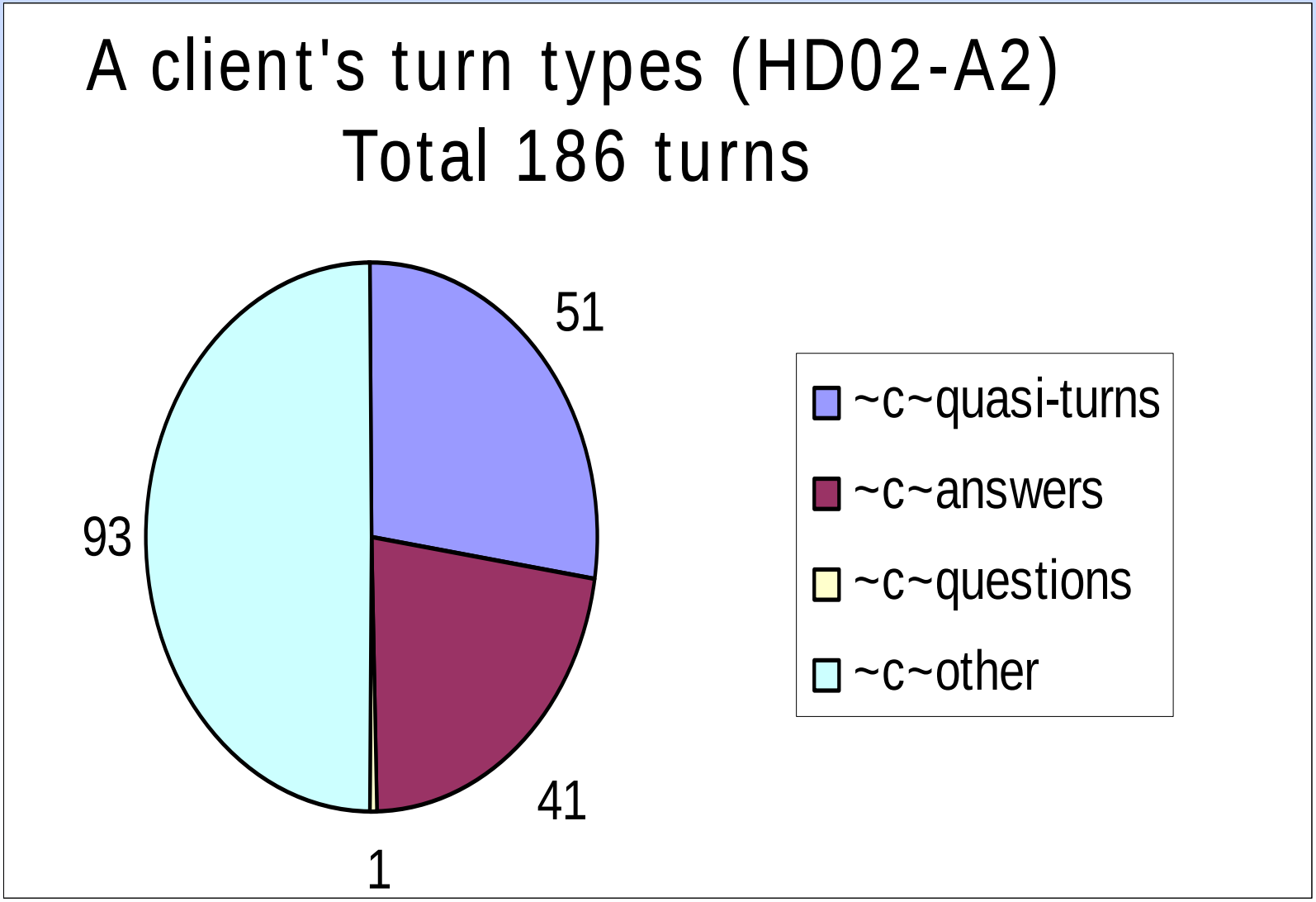
UNEQUAL SHARE OF INTERACTIONAL SPACE IN GENETIC COUNSELLING



UNEQUAL SHARE OF INTERACTIONAL SPACE IN GENETIC COUNSELLING

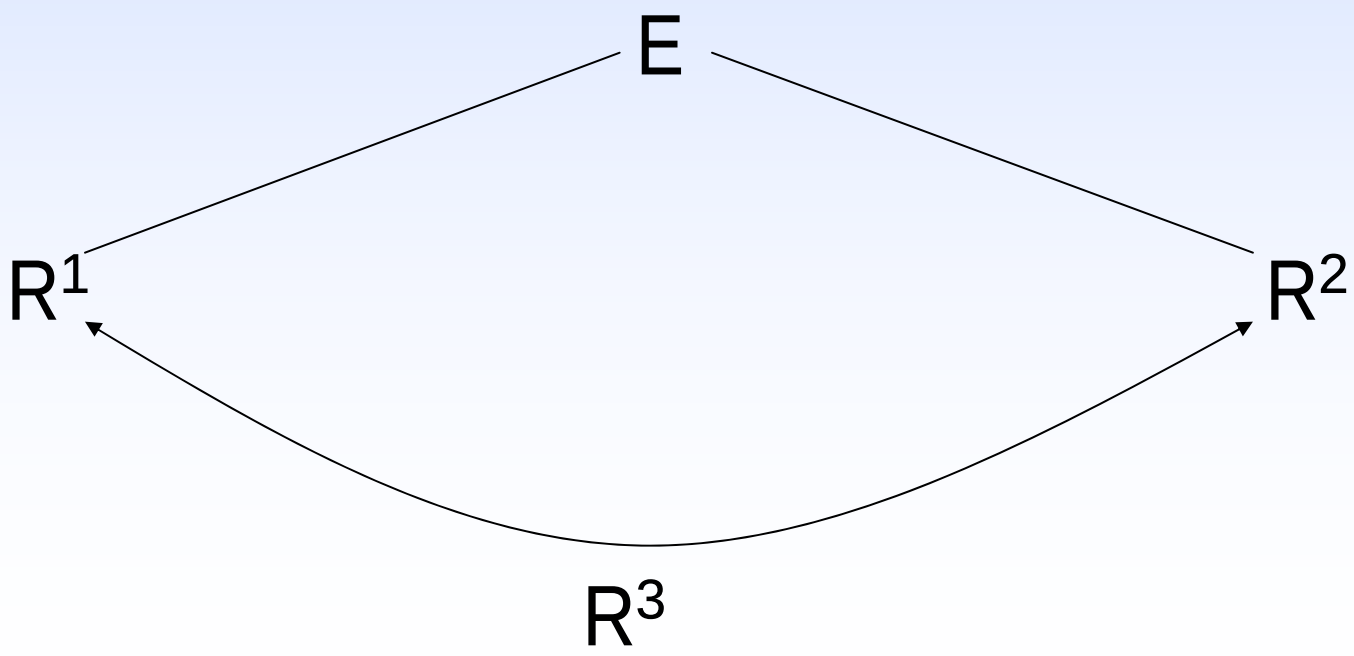


UNEQUAL SHARE OF INTERACTIONAL SPACE IN GENETIC COUNSELLING



STEERING BETWEEN THREE TYPES OF RISK IN GENETIC COUNSELLING

- Unwanted event (E), Risk of knowing (R^1); Risk of occurrence (R^2); Risk of disclosure (R^3)



A TYPICAL MEDICAL RECORD

Doctor's Written Progress Notes

Wt: 146 B/P 112/64 3/21/77: Age 62

Widowed 9 mos. - depressed. Saw internist 4 mos. ago because of vulva irritation - started 1.25 mg. *Premarin* ----> breast soreness, so stopped EST

On estrogen for 7-8 yrs. up to 4 yrs. ago. 1.25 mg. then 0.625 mg. at Phipp'sClinic - Mammogram - fibrosis (1971) - reduced dose of *Premarin*.

General: (1) Large cyst L kidney known for many years.

Has had two kidney stones - age 21 & age 59 - passed spontaneously, Has "kidney infections" of 2-3 years,

(2) Acute glaucoma-surgery 12/75 at UCLA (R eye) - needs for both eyes, 2 children (ages 27-son, 23-daughter)

Surgery: Skull fx age 10, Appendectomy age 17, T&A age 8-9

PH: Diphtheria age 5 Systems Review: D arrhythmia recently - Takes Inderal p & n almost every night.

[Source: Cicourel 1983]

AN EXAMPLE FROM GENETIC COUNSELLING

Having children resigned ((MP)) to not having a family. This issue has not been resolved for ((AF2)), feels badly and gets upset. Realises having children is probably not practical but suffering (abt it)'.

In general much more settled than in ((month of Preliminary Interview)). Especially since they moved house.

Have now decided that they have come to terms with not having more children. Which ever way the test goes. Want to know to remove uncertainty and for their children.

Will tell ((name of daughter 1)) + ((name of daughter 2)). ((Daughter 1)) has been trying to get pregnant. Both are keen to know.

Will not tell father as he does not want to know and they do not have contact with him.

Also will not tell brother. Does not think they will find out from any other source.

CONCLUSION

- Patient-centredness defies any simple characterisation, ideologically and interactionally, and in consequence, it raises questions about training and assessment provisions: balancing of signs, symptoms and self presentations.

- Patient-centredness inevitably means context sensitivity and tolerance of variability, bordering on compromise of professional neutrality and active involvement with patient's lifeworld.

- Inevitable tensions: within the healthcare profession, can evidence-based practice (scientific mentality) and patient-centredness be married? Does professional neutrality compromise patient-centredness? Where do we draw the line between patient-centredness and paternalism?

CONCLUSION

Future challenges in research and practice:

- Moving away from talk/interaction bias: explore the role of text in the context of patient-centred ideology/ecology (Writing up follow-up letters, Patient records etc.)
- Patient-centredness in the context of intercultural healthcare delivery
- Patient-centredness involving ‘difficult’ (heart-sink) patients
- Patient-centredness in multi-party clinical settings (paediatrics, geriatrics, genetics etc.): towards family-centred medicine (nagging vs. responsible parenting/caring – Silverman 1987)
- Balancing patient education (epistemic) and patient involvement/participation (affective)

PATIENT EDUCATION VS PATIENT INVOLVEMENT