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“I’m not the doctor; I’m just the patient”: Patient agency and shared decision-making in naturally occurring primary care consultations

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ABSTRACT

Objectives: To explore interactional processes in which clinical decisions are made *in situ* during medical consultations, particularly the ways in which patients show agency in decision-making processes by proposing and opposing actions, and which normative dimensions and role-expectations their engagement entail.

Methods: Narrative analysis of verbatim transcripts of 22 naturally occurring consultations, sourced from a corpus of 212 consultations between general practitioners and patients in England. After thematically coding the whole dataset, we selected 22 consultations with particularly engaged patients for in-depth analysis.

Results: Patients oppose further actions more often than they propose actions, and they oppose more directly than they propose. When they explain why they propose and oppose something, they reveal their values. Patients’ role-performance changes throughout the consultations.

Conclusion: Assertive patients claim – and probably also achieve – most influence when they oppose actions directly and elaborate why. Patients display ambiguous role-expectations. In final concluding stages of decision-making processes, patients usually defer to GPs’ authority.

Practice implications: Clinicians should be attentive to the ways in which patients want to engage in decision-making throughout the whole consultation, with awareness of normative dimensions of both process and content, and the ways in which patient’s actions are constrained by their institutional position.

1. Introduction

In contemporary Western health systems, shared decision-making (SDM) has become the ideal for making decisions in clinical settings [1–3]. SDM, which is a hallmark of person-centred care, implies moving from a paternalistic model of medical decision-making to one which acknowledges patient autonomy [4–6]. The ideal is that patients and clinicians work together to reach joint decisions about further actions through a collaborative process where decision-making power is shared, and patients’ values respected [1,7–10]. Since the first description of this doctor-patient model [11], competing models of SDM have proliferated [12–16]. The participation of both patient and health professionals in decision-making processes, however, remains a key component. Regardless of precise definitions, SDM can be said to comprise “actions undertaken in collaboration with patients, not just on their behalf” [17] (p. 979). In the UK, this ideal is summarised in catchphrases like “no decision about me without me” [18] (p. 13). Although it has been shown that patients can successfully claim power without compromising the physician’s abilities [19], balancing medical expertise and responsibilities with patient views is a challenging juxtaposition for clinicians [20].

Previous research indicates that SDM is highly advocated but difficult to achieve [21–27]. Despite political, educational and professional attempts to reduce the gap between ideal principles and interpreted practices, “authoritative rather than collaborative” professional positions persist [24]. Barriers and facilitators include a wide range of cultural and structural factors, including quality demands, scarce resources, rigid guidelines and lack of coherence

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between political ideals and educational curricula [6,21,24,26,27]. In undergraduate medical curricula in the UK, for instance, “the language tends towards a paternalistic model of care, appearing to skew the balance of power towards the doctor and suggesting that they are to ‘do to’ rather than ‘share with’ patients” [6] (p. 878). Doctors seem positive towards patients who show agency during consultations but may find certain kinds of actions unhelpful [28].

For clinical encounters to be conducted on the basis of SDM, actions are needed from both parties: clinicians have to be respectful of and responsive to patients’ experiences, needs and values [29,30], and patients have to engage actively. One of the most important attributes of patient-centred care is the active engagement of patients when fateful health care decisions are to be made [31]. However, because the onus of achieving SDM is usually placed on healthcare professionals [13], their role is easily overlooked, and their engagement remains under-investigated [32].

In this paper, we explore the role patients play in interactional processes where clinical decisions are made *in situ* during clinical consultations. Exploring social situations where “action is carried out” [33] (p. 202) is important because the degree of patient agency in these processes is highly situation-specific [34]. Our point of departure is 22 naturally occurring consultations between general practitioners (GPs) and patients in England, sourced from the *One in a million* data archive [35,36]. Our main objectives are to explore the ways in which patients assert influence on decisions about further actions by proposing and opposing medical tests and treatments, and which underlying normative dimensions and role-expectations their engagements entail. During our analysis, we consider pathways towards decisions as equally important as the decision-making itself insofar as it builds up to – and lays the ground for – the final stage of the process. By exploring the ways in which patients engage in decision-making processes, our aim is to shed light on interactional factors that may or may not lead to SDM. Studying how decision-making processes are shared *in situ* prompts us to reflect on what we mean by ‘shared’ and ‘decision’ in clinical consultations; a question we return to in our discussion.

2. Methods

Our study is based on a narrative analysis of 22 naturally occurring GP consultations, sourced from a corpus of 212 consultations from the *One in a Million* data archive (Table 1).

2.1. Data material

Based on a data-grounded thematic coding of all 212 cases in NVivo (version 12.4) [37], we purposively sampled 22 consultations with patients who were particularly active in decision-making processes (Fig. 1). First, we identified all consultations containing at least one score on what we defined as “patient voice” (PV) utterances (further described in note b, Fig. 1). We then selected all consultations containing more than 10 PV-scores (11 consultations). This high-score sample (group H, Table 2) contained more women than men among both patients and GPs. We therefore selected 11 additional consultations (group L, Table 2) with minimum four PV-scores, using a maximum variation strategy based on patient gender, age, education, contact reasons and PV-scores, and GP gender, age, workplace and seniority.

2.2. Data analysis

Based on an in-depth narrative analysis of verbatim transcripts of 22 complete consultations, we explored how patients asserted influence on decision-making processes. We treated each consultation as a whole; placed it in its context, and explored the ways in which it unfolded. While exploring *what* was uttered (content), *how* it was uttered (form) and *by whom*, we distinguish between power over emerging discourse and control over future action [38], in line with the two main stages of the decision-making process: the ‘deliberation’ stage and the ‘determination’ stage [39]. During the first stage, the patient’s problems are defined, and options for further actions are identified, weighed and negotiated, before final decisions are made. Patients may claim or relinquish power in either or both stages. Various types of patient speech have been identified as markers of agency, and we draw on these insights (Table 3).

In dialogues, every utterance is “either a statement establishing the next speaker’s words as a reply, or a reply to what the prior speaker has just established” [43] (p. 78). Meanings emerge through reciprocal exchange, and each utterance must therefore be considered in context. To preserve context and meaning, while also capturing the ongoing dynamics of the interactional flow, we mainly worked with sections of dialogues.

2.3. Ethics

All data were anonymised upon receipt, and there was no contact with study participants. Our study received ethics approvals from the National Health Service (Research Ethics Committee reference 18/WM/0008; Integrated Research Application System project ID 232578), and Bristol Data Repository clearance from the Data Access Committee. The dataset is stored on a password-protected site at the University of York, UK, accessible to first and second author only.

3. Results

During the first stages of the consultations, patients describe symptoms, illness history and medication issues, usually in response to questions from GPs. After these initial sections, they move to discussions about further actions.

3.1. Proposing actions

When patients propose actions, they typically do so late in the consultations and after prior discussions. Usually, they suggest medication they have previously used or discussed. Six patients, five in the high-score PV group, make direct proposals, e.g.:

Table 1
One in a Million: primary care consultations archive [35,36][a].

Type of study	A prospective observational study containing an initial dataset, collected for future research and teaching purposes, and archived at the data repository of the University of Bristol, UK.
Data material	327 film- or audio-recorded and verbatim transcribed naturally occurring GP consultations collected between 2014 and 2015 in 12 publicly funded practices in and around the City of Bristol. Consultations take place between adult patients (aged 18–96) and 23 different GPs. A total of 300 patients gave informed written consent for their data to be accessed and reused by “other researchers, subject to specific ethical approval” (of which we received data for 212 consultations). The dataset also includes patient records; longitudinal patient pre- and post-consultation survey data; sociodemographic data of patients and GPs and GP practice data.
Funding	The National Institute for Health Research (NIHR) School for Primary Care Research (208) and the South West GP Trust.
Ethics	Ethically approved by South West — Central Bristol Research Ethics Committee (ref.:14/SW/0112).

[a] For an extensive list of publications, see http://www.bristol.ac.uk/primaryhealthcare/researchthemes/one-in-a-million/publications/.

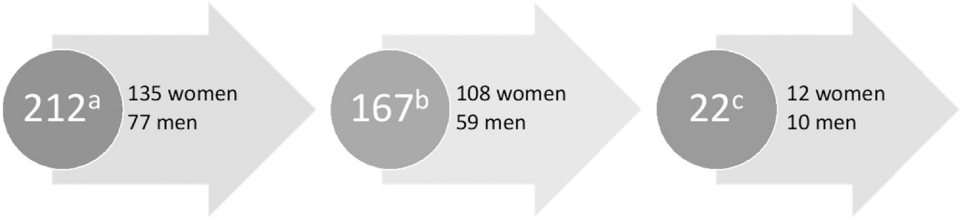

Fig. 1. Selection of 22 consultations and patient gender distribution.

Footnotes (a) The complete dataset. (b) Consultations containing minimum one score in the group of 11 "patient voice" (PV) utterances (various forms of suggestions, opposition, questions and opinions) [37] (c) Consultations used in the present study.

Table 2
Consultations (n = 22)[a].

	PV-group	Average	SD	Range	Sum
Total PV-score	*High*[b]	14	2.9	11–19	–
	Low[c]	6	2.2	4–10	
Duration (minutes)	*High*	20	5.4	15–34	–
	Low	16	5.5	9–21	
Patient Age	*High*	51	21.8	22–84	–
	Low	65	10.9	45–77	
GP Age	*High*	43	9.1	32–54	–
	Low	48	9.4	32–62	
Number of women patients	*High*	–	–	–	7
	Low				5
Number of women GPs[d]	*High*	–	–	–	8
	Low				3
Patients with qualifications stated as professional or university degree[d]	*High*	–	–	–	6
	Low				5
Number of consultations performed with "usual" GP[e]	*High*	–	–	–	7
	Low				6
Number of different main contact reasons represented (of 7 possible)[f]	*High*	–	–	–	6
	Low				6

[a] All patient quotes are identified by unique IDs, systematically numbered by referring to PV-group (H1/L1 = highest PV-score within the group, H11/L11 = lowest) and patient gender (W/M).

[b] PV-group H (n = 11): High total score on "patient voice" (PV) utterances.

[c] PV-group L (n = 11): Low total score on "patient voice" (PV) utterances.

[d] The 22 consultations were performed by 14 different GPs, conducting between one and three consultations each. They belonged to 10 different publicly funded NHS clinics, and they had worked in their current practice between 6 months and 32 years (12 years on average).

[e] Defined by patients.

[f] Psychological; digestive; musculoskeletal; cardiovascular; neurological; endocrine and general.

- I'll tell you what I do need; I need the cream (H6-M)
- Can I have some omeprazole as well? (H7-W)
- I'd rather have the Oramorph (H1-W)

There are approximately three times as many examples, however, of proposals expressed indirectly. Most of these are expressed with 'hedging':

- So maybe I need to take some, what's the stuff called? (H8-W)
- I wonder whether I can experiment with a higher dose (H2-W)
- I just wondered if I could have some more Valium, to try that (L9-W)
- One thing I was thinking is half the antidepressant (H11-M)
- I think you need to prescribe me that medication for the anxiety today (H9-W)
- I think it's probably safer to stay on the Provera, isn't it? (L10-W)

By modifying their proposals with lexical down-toners [44] ("maybe"; "just") and embedding them within other clauses ("I think", and conditional clauses introduced by "wonder"), they mark their proposals as tentative or subjective. By asking for permission ("whether I can"; "if I could"), moreover, patients act within an implicit framework in which the decisive decision-making power is placed with the GP.

When patients indirectly propose treatments they previously have *not* used, they sometimes refer to a third party as a source of authority. Here, a man in his early 40s who meets with a "not usual" GP, hints about changing his anti-depressant medication (which he has already halved due to side-effects) by citing the case of a friend (Box 1):

Box 1
Extracts from consultation H11-M.

P: I was just finding when I went on the prescribed dose of the flu-....
GP: Fluvoxamine.
P: It created more apathy and more of an upset stomach [...] I am fed-up with not feeling well. [...]
GP: Maybe it would be worth persevering on the dose you are on and see how you are for a few weeks [...]
P: I haven't tried Prozac yet [...] A school friend has, and it has just sorted her out after years.
GP: Sertraline does seem to be really good for many people.

In the end, the patient does not object to the GP's suggestion to continue with fluvoxamine for a couple of weeks, and then review and discuss alternatives.

Patients' indirect proposals *function* as proposals in the sense that GPs respond to them as such. Usually, they also take them into

Table 3
Classifications of patient agency.

Active Patient Participation [40,41]	Questions; Concerns; Assertive behaviour (opinions, suggestions, objections)
Patients use linguistic resources to... [19]	Control topic and choose speakers; Offer a candidate diagnosis; Co-construct diagnoses; Challenge diagnoses; Propose treatment; Carry out potentially face-threatening acts; Frame the medical encounter as friendly and invoke favourable cultural schemas in defining the self
Types of 'patient participation' [42]	Information exchange: Patient informs and asks questions; Assertiveness: Patient sets agenda, expresses viewpoint and makes a request

account in further discussions. The most subtle hints, however, are easily dismissed. A man in his mid-60 s who meets with a “not usual” GP, seems to advocate an allergy test because of long-term bowel problems, particularly pain and diarrhoea (Box 2):

Box 2
Extracts from consultation L7-M.

GP: It looks like we’ve done everything I wanted done. [...]
P: It may be on occasions I’ve eaten something that’s causing it, I don’t know.
GP: I think that’s exactly what it is, I think you’ve probably got a condition called Irritable Bowel Syndrome.
P: I was suspecting I might have, because I don’t obviously know, but then I saw a TV programme about it, which is perhaps dangerous as a little knowledge. They said that some people are diagnosed with Irritable Bowel Syndrome, and other doctors prefer to try and take every effort to find if you’re allergic to something first. [...]
GP: So, with the food intolerance aspect of things, Irritable Bowel can be set off by food intolerances, okay. [...] And if you want, there’s a very good diet you can go on to control Irritable Bowel. And I can refer you to the dietician so you can spend some time exploring that.
P: It might be a good idea. [...] Yes, may have been milk or something like that. [...] Where will the dietician be, if I had to see the dietician?

The patient repeatedly hints at a possible cause of his problems: it could be food related. After the GP concludes that “we’ve done everything I wanted done” (our emphasis), the patient tells the GP what he has heard other doctors do in similar cases: they “take every effort to find if you’re allergic to something first”. Ignoring these hints, the GP does not offer him an allergy test (without explaining why), but a referral to a dietician and drugs to relieve symptoms.

3.2. *Opposing actions*

Patients sometimes oppose GPs’ proposals through moderate expressions of reticence:

- I don’t know (H5-M, H10-W, L9-W)
- I don’t think so (H10-W)
- I don’t fancy that (L10-W)
- Well, I’ll see (H8-W)

Compared to the ways in which patients *propose* actions, however, patients *oppose* GPs proposals more directly:

- I’m not taking statins, definitely not (H3-W)
- I don’t want to ever go on them [Lansoprazole] (L1-W)
- Oh, no! [at suggestion of Prozac] (L9-W)

Sometimes, they oppose actions suggested by other doctors (H5-M), or something they previously have used (L10-W):

- I don’t want another operation (H5-M)
- I don’t want to go back on the pregabalin, no, because that definitely [.] did give me a lot of side-effects (L10-W)

One woman in her mid-80s repeatedly opposes suggestions from her “usual” GP very directly (Box 3):

Box 3
Extracts from consultation H3-W.

GP: How are you?
P: Awful. [...] Each day is a struggle [...]
GP: Would you think about seeing the mental health team again?
P: Well, no, because I can’t- I don’t think it would help.
GP: What about trying something to try and make your mood a bit better?
P: I don’t really want any medication either. [...]
GP: I’ve got the letter from the vascular surgeon.
P: Yes, yes, I did; I got one too, yes.
GP: What did you think about what he said? He suggested a couple more pills, didn’t he?
P: I’m not taking statins, definitely not.
GP: Oh. Why was that response not unexpected?
P: Well, in as much as a pharmacist friend of mine took them, not only did she have these muscular weaknesses, and she also had occasional diarrhoea. Well, I certainly don’t want that, you [k]now? [...]
GP: So, what are we going to do about lifting this mood. I mean, our options are: a medication, talking to someone, or is it all this situation and the environment [...] that needs to change? I can’t do anything about that, but I can offer you the medication or the talking to someone.
P: No, you cannot. [...]
GP: But how would you know if you haven’t tried it? [...]
P: Yes, yes. I’m holding my hand out here – it was supposed to be a blood pressure check, wasn’t it? You said, “Make a double appointment”.
GP: Oh, this isn’t a double appointment, I don’t think. This is just a single.
P: Is it? Oh, well check my blood pressure and then I’ll go.
GP: But what are we going to do? This is how it always ends. You always tell me these things and I make suggestions and then you think it’s going to be alright. I think you seem –
P: And you’re wonderful.

This consultation moves back and forth between low mood (counselling and medication offered) and cardiovascular risk (medication offered). The patient opposes all treatment offers, and explains why: she doubts they will help, and she fears negative side-effects. She supports her opposition to statins by citing a credible source with both professional and personal authority (a pharmacist friend). When the GP tries to get her to re-think it all, the patient abruptly cuts her off by asking for a blood-pressure check. The GP does not want to change the subject but when she is about to make a statement about the patient’s emotional state, the patient cuts her off once again, this time with praise: “And you’re wonderful”.

Similarly, a woman in her mid-70s with diabetes, meeting her “usual” GP, rejects an offer of a referral to a dietician outright, before mitigating her opposition (Box 4):

Box 4
Extracts from consultation H10-W.

GP: ... would you like to see a dietician? Would that be helpful for you?
P: No, it won’t be helpful [...] what I’m trying to say is, I’m not being nasty, but I can’t see what benefit I’m going to get from seeing one
GP: Well, I suppose we don’t know unless you’ve tried it, really. They could look at the calories in detail with you and things like that.
P: I don’t think so. As I say, I’m an ex-chef.

Aware that her opposition to the GP’s proposal could be perceived as ingratitude (“I’m not being nasty, but...”), the patient justifies her response by bringing in her own expertise in the area as a source of authority (repeating “I’m an ex-chef”).

3.3. *Declaring values*

While proposing and opposing further actions, patients often explain *why*. Because their “whys” are normatively founded, GPs gain access to their normative stances:

- Well, say, the sertraline, now, doesn’t affect my libido, that venlafaxine killed it (H2-W)
- Oh god, I’ll be like a chemist after all this (H6-M)
- I don’t like to take drugs unless I absolutely have to (L4-M)
- I’m not really keen on taking another drug at all (H8-W)
- I just need something short-term (L9-W)

Through these utterances, patients provide information – directly and indirectly – about what is important to them: they want to avoid taking drugs, especially addictive drugs and drugs that affect their libido. Normative dimensions are particularly pronounced in discussions about medications. Here, a man in his early 60s explains to his "not usual" GP why he wants to continue taking a drug that might be bad for his already high blood-pressure (Box 5):

Box 5
Extracts from consultation L8-M.

> GP: I think it's all about a balancing act really, isn't it?
> P: Well, I think if I was really honest, if you were to say to me, "the prednisolone might shorten your life over getting up, feeling that much better every day", I'd take getting up, feeling that much better every day every time.

By weighing his current quality of life against possible long-term gain, and placing one above the other, he reveals underlying values which are directly relevant for multiple decisions that need to be taken during the consultation. A more extensive debate appears in a consultation with a woman in her late 60s who explains to her "usual GP" why she wants to stop using the hypertension drug amlodipine, although it might have improved her renal function (Box 6):

Box 6
Extracts from consultation H8-W.

> GP: So just talking about your renal function. As I have said, that was the best we have ever had since you have had the nephrectomy. Your creatinine was 129.
> P: Oh, that's absolutely epic.
> GP: Yes, and your urea 10.5 and your EGFR, wait for it, 36.
> P: Oh my God, that is amazing.
> GP: Yes, so absolutely fantastic. I wonder if that is the amlodipine that's done that.
> P: But I hate it. Sorry, I'm here to talk to you about throwing it in the bin.
> GP: Because the thing is that I suspect that what that is doing is just reducing that very borderline hypertension which is obviously having an impact on your renal function.
> P: I know, but it doesn't suit me. [...]
> GP: Well, the reason we had increased it was that your blood pressure was borderline each time you came to see me. I'll just show you my records as well.
> P: No, I know, sorry I know.
> GP: So, it's only just trying to maintain your renal function.
> P: I know. Well, I'm better on 2.5 mg. When I was on 5 mg I couldn't sleep, I got pains and cramps in my legs, I was irritable and terrible, and I just felt weak the whole time.
> GP: Okay. Well look, let's leave it at 2.5 mg and we'll just see what your renal function is like this month, and just see whether it has gone up or down. You want to stop it completely, presumably?
> P: Of course, I do, it's awful stuff.
> GP: It is so difficult, isn't it? Because what we are balancing here is your kidney function versus symptoms.
> P: No, I do appreciate it, I appreciate it, but sometimes you think, "Is it worth living?" I actually had a conversation with [first name] where I said, "Is it worth me taking these tablets and having a longer life presumably because my kidneys are being supported, or packing it in and going back to not being so irritable, being able to sleep and not getting cramp and not being wretched, weak and feeble?" And she said, "Well of course you've got to take the tablets, you must live as long as [you] can forever," you know? And so, I am carrying on, but I cannot say it is really making my life a lot better.
> GP: No. Do you think it is the tablets? I understand they do all carry their side effects, but maybe the irritability, do you think you could be depressed? [...]
> P: No, I'm not depressed. But I cannot sleep very well which doesn't help, and this stuff doesn't make it any better. But I will carry on since you say so.
> GP: Yes. I mean, obviously it is your choice at the end of the day [first name], and we're not going to force you to do it.
> P: I know, you never force me to do anything.
> GP: Yes.
> P: I know it's all for my own good.

In this consultation, the shared joy over the renal panel results is interrupted when the GP points out that they face difficult decisions: balancing the patient's kidney function (improved but still significantly reduced) against medication side-effects. While the GP is focused on the patient's kidney-function, the patient is more concerned about her quality of life ("I cannot say it is really making my life a lot better"). By reporting a conversation with a third party, the patient is able to express her view that longevity should not be prioritised over all else, a view she seems to assume is opposed to the GP's. In the discussion that follows, it emerges that the patient does not think the correct balance has been struck, but she will follow the GPs advice and carry on with the medication. The debate about this patient's values and quality of life, is closed by the GP who notes that it is "obviously" the patient's choice. The choice may be the patient's but, in yielding to the GP's biomedical orientation, she might feel obliged to agree to a decision (continuing with amlodipine) that does not fully accord with her own values: "since you say so".

3.4. Decision-making roles

Patients' actions reveal how they perceive their role as patients vis-à-vis doctors in decision-making processes. Three main forms of role-performances are observed: (1) claiming influence, (2) inviting negotiations, and (3) handing power to the GP. By proposing and opposing actions, they claim influence and invite negotiations. They also invite negotiations by asking for recommendations ("What do you think is best?", H10-W); declaring values ("I just need something short-term", L9-W) and direct invitations ("I'm here to talk to you about throwing it in the bin", H8-W). After options have been discussed, patients usually place the ultimate decision-making responsibility on GPs by brief confirmative answers:

- If you say that's okay, then I'll just go by you (L1-W)
- ... since you say so (H8-W)
- Whatever you think (L5-W)
- Okay (L2-M, L10-W)
- Fine (L2-M)
- Yes (L2-M, L5-W, L6-M, L8-M, L9-W, L10-W, L11-M, H10-W)

When GPs *ask* patients to propose actions (which they rarely do), patients tend to decline (Box 7):

Box 7
Extracts from consultation H6-M.

> GP: In your mind what do you think we should do next? I hear what you're saying, you're reluctant to go to lots of appointments and be faffed around.
> P: Nothing seems to get any better. [...] I'm not even 40 yet and I'm unable to go to work.
> GP: Did you think there was anything in particular that you thought is going to help?
> P: No.

This otherwise active man in his late 30s declines two open invitations from his "usual" GP to propose actions. Given the complexity, severity and longevity of his problems, in addition to uncertainties related to effects and side-effects of treatment options, his answers might be an expression of helplessness and resignation rather than a lack of engagement. Perhaps he wants to be in control but becomes aware that he cannot?

Some patients hand decision-making over to GPs more explicitly (Box 8):

Box 8

Extracts from consultation H11-M.

> GP: Did you have in your mind what you were hoping we might do, or were you just a bit stuck and wanted someone else to help you?
> P: One thing I was thinking is half the antidepressant, I don't really want to go back up because I feel that sets off the bowel. I think that if I look at correlating, the antidepressant and the fatigue seems to have gone together.
> GP: As in the fatigue was worse when you were at the higher dose or better?
> P: I don't know [...] I don't know whether to keep up this half dose and see if it is working or whether I should come off it and go on to something else. I don't know, I feel that is your thing.
> GP: It might be worth sticking on this dose a little bit longer with a view to maybe coming off it later. [...] It will be a chronic thing that you will at times hopefully be able to control really well, but it is something you will have to battle with a bit unfortunately.
> P: I was thinking that this morning actually, it is about control strategies. I don't believe there is a miracle cure, and it will go away through any therapy or anything. I think it is about learning to ignore the voice in your head.

Here, a man in his early 40s concludes a debate about anti-depressant medication by handing decision-making over to his "not usual" GP. His deference ("your thing") is contrary to his previous actions: he has already cut half of his anti-depressant medication due to side-effects, without conferring with the GP. This might be placatory (assuring the GP that she still has a role to play), or perhaps with greater awareness of possible effects and side-effects of the medication he is now less certain and trusts the GP to know best. When their discussion moves to "control strategies", the patient returns to a more active role.

Such shifts in patients' role-performances are common in our data. Patients display ambiguous role-expectations by swapping in and out of different roles during decision-making processes: subordinating themselves (the traditional patient role), inviting negotiations (being a partner), and asserting decision-making power (the role of the empowered patient). The most vivid example is the ex-chef who opposed consulting a dietician. After declining that offer, and a series of complaints about how her "usual" GP previously acted in relation to her bladder problems ("I'm getting fed up with being fobbed off" and "I feel sometimes, you don't listen to me"), she moved the discussion to a suspected hernia (Box 9):

Box 9

Extracts from consultation H10-W.

> P: This hernia is right up here now. To me, that is bigger now. I'm not being funny with you, but I feel –
> GP: What would you like me to do about that?
> P: I don't know, because you're the doctor. I'm not the doctor; I'm just the patient. Not being funny, you should be telling me what you're doing, not me telling you.

After what might be interpreted as a preface to criticism ("I'm not being funny with you, but…"), the GP interrupts the patient and asks what she wants him to do. Throughout the consultation, the patient repeatedly claims expertise and influence, but here she refrains from proposing actions when directly asked to do so by pointing to their different roles: she does not know because she is not the doctor.

4. Discussion and conclusion

Each patient has a distinct voice, but the ways in which they contribute to discussions about further actions are patterned. After discussing these patterns, we reflect on possible implications for clinical practice and further research.

4.1. Discussion

Assertive patients show agency in different ways at different points during decision-making processes (Box 10). When they say what they do not want, and why they do not want it, they express themselves more directly than when they propose actions. Because GPs know the discursive frame of the field in which they are interacting [45], they know how to interpret indirect proposals, and they generally respond to them as such. GPs rarely invite patients to say what action they would like. When they do, patients often decline. This is in line with previous research [46,47]. In clinical settings, information overload may increase uncertainty [48], and that might be the case for two of the patients who declined explicit offers to propose actions (consultation H6-M and H11-M, Boxes 7 and 8).

Box 10

Main patterns of patient agency.

- Patients oppose actions (particularly medicaltreatments) more often than they propose actions, and their opposition might bevery direct
- Patients usually propose actions indirectly;often with mitigated speech and down-toning
- Patients often refrain from proposing actionswhen directly asked to do so
- When patients explain why they propose oroppose something, they often reveal their values
- Patients display ambiguous role-expectationsby swapping in and out of different roles during different stages ofdecision-making processes
- In final concluding moments of decision-makingprocesses, patients tend to hand power to the GPs

Throughout decision-making processes, patients move between subordinating themselves, inviting negotiations and asserting decision-making power. They mainly assert power through option-talk that builds up to – and lays the ground for – the concluding stage itself. By opposing actions and explaining why, patients not only exclude decisions they find unacceptable; they also open negotiations about alternative options [49]. Sometimes, patients rule out suggested options until the GPs come up with solutions they accept.

Although patients say what they want and do not want, they largely defer to GP expertise. Concluding stages of decision-making processes are usually controlled by GPs, which patients seem to accept, or even ask for ("you should be telling me what you're doing, not me telling you", H10-W). This stage could be described as "doctor led with patient acknowledgement" [50] (p. 369), within a proposal-acceptance format [51], but sometimes their acceptance appears more like resignation than agreement. Patients' proposals and objections become influential only if and when GPs take them into account in their final conclusions, which they often do. This is a kind of 'shared' decision making, although perhaps not in the sense of current SDM-models.

Patients might hesitate to take responsibility for final decisions (and thereby also their consequences) because they think it is "the immanent rules of the game" [52] (p. 99); because they know they formally rely on GPs' consent; because they fear GPs may renounce responsibility for options they do not prefer [47], or because they recognise the virtues of medical expertise and the limits of experiential knowledge [53]. Going to the GP is, in itself, an indication of confidence in medical expertise, so it may well be that they trust GPs to know best. The delicate nexus of trust, power and risk/uncertainty [54,55], as well as the fundamental asymmetry between their roles [56], is important here. Patients are in a vulnerable situation: they experience some degree of uncertainty and need help to reduce it, which GPs might provide. When patients hand decision-making power to GPs, they leave their health problems, and sometimes even their lives, "in their custody" [54] (p. 17). Beyond the situational, utterances like "If you say that's okay" (L1-W) and "I know it's all for my own good" (H8-W) are explicit indicators of trust. However, because of the power-imbalance between the two parties, it is not easy to separate trust from power, and "[o]ne person's trust can become another person's power base" [54] (p. 18).

While discussing doctor-patient interaction in relation to 'shared' and 'decision-making', we face some conceptual challenges. SDM presupposes something to be decided on, but the question "what is to be decided?" is not always clear [14]. Clinical consultations contain a longitudinal trajectory of related decisions [25] with multifaceted and value-laden choices that relate to more than biomedical aspects of patients' illnesses. Patients and GPs sometimes talk about different aspects from different perspectives and epistemologies, and it might be difficult to reconcile the scientific 'voice of medicine' and the experiential 'voice of the lifeworld' [57,58]. This complexity makes it difficult to pinpoint exactly what the decision is all about, including whether or not patient and GP agree on what they are supposed to make shared decisions about. Neither do we know whether patients perceive having a 'real choice' or a 'forced choice' [59]. It is also unclear how decisions are enacted, and what constitutes patient influence and choice. Doctors' presentations of treatment options are sometimes biased in favour of the alternative that is most congruent with their own stance [8,47]. Option-listing from doctors might disguise power by generating *perceptions* of choice, and thereby "operate less as a practice for reducing authority and more as one for disguising its exercise" [60] (p. 1265). This prompts questions about what constitutes 'shared' [61–63]; what qualifies as "joint" decisions; how patient influence in clinical consultations can be captured, and how the concordance between doctors and patients perceptions can be assessed. Future debates about the presence and absence of SDM ought to distinguish between patients *having* a choice and *making* one, as well as between the appearance of choice and substantive choice [63]. While doing so, we need to recognise that from their institutional position, patients are enmeshed in a structure of tacitly claimed rules of conduct "that severely constrain their ability to exercise choice" [64] (p. 2742).

Challenges of discussing choice and voluntariness in clinical settings are particularly visible in the case with the woman in her late 60s who initially is more concerned about her quality of life than her reduced kidney-function, which the GP focuses on (consultation H8-W, Box 6). When the patient succumbs to the views of the GP and accepts the biomedical view on her situation, she simultaneously downgrades her own experiences, even though they include the question "Is it worth living?". The epistemic primacy of biomedical over experiential knowledge makes it difficult to say whether this kind of decision ought to be understood as a choice or a surrender.

4.2. Strengths and limitations

Working with observation-data prevents us from asking participants to elaborate their utterances, and we do not know what happens outside the consultation room. Including only 22 cases prevents us from exploring differences between subgroups. Possible biases in the data relate to recruitment of GPs, who self-selected to take part in the study [35,36], and participants might have been influenced by being conscious about being filmed. It may also be that these often indirect and cautious modes of utterances are particular to the English-speaking sub-culture from which our sample is drawn. However, our empirical data gives us a unique opportunity to explore how doctor-patient interaction is conducted in naturally occurring social situations, rather than theorised. By exploring complete consultations, we attain a holistic outlook on whole decision-making processes related to a wide range of conditions.

4.3. Conclusion

Assertive patients mainly claim – and probably also achieve – decision-making influence when they oppose actions directly and explain why. Through normatively founded explanations, GPs gain access to their normative stances. Patients display ambiguous role-expectations in the sense that they swap in and out of different roles throughout the decision-making process: subordinating themselves (the traditional patient role), inviting negotiations (being a partner), and asserting decision-making power (the role of the empowered patient). In the final decisive moment, however, most of them directly or indirectly hand power to the GPs. Due to the tacitly claimed rules of conduct their subordinate position entails, this does not necessarily qualify as an act of individual choice.

4.4. Practice implications

To embed SDM into everyday clinical practice, clinicians need to see the patient as a person [23]; invite patients to tell their stories; encourage them to talk about what is important to them; listen to and respect their views and values; give them the information they need in a personalised way; involve them in discussions and decisions about their care; give authority to their experiential knowledge and share responsibility with them; all with an "other-orientation". Asking patients to elaborate their views could be a useful measure, because their explanations often reveal their normative stances. Clinicians need to be aware of potential for shared decision-making at all stages of the consultation, and consider each patient individually, neither underestimating nor overestimating their willingness to engage [48]. Direct discussions of process could be useful. Clinicians should also be aware of differing ways in which patients offer opinions about their problems and care, and acknowledge and respect patient ambiguity when faced with decisions that have consequences for their lives.

Finally, clinicians need to reflect on how the cultural context of modern biomedical practice influences their interaction with patients and acknowledge that both parties act under constraints from their institutional positions. Raised awareness of how structural forces shape tacitly claimed rules of conduct for both doctors and patients in clinical encounters would increase our understanding of the interaction that takes place there [65,66]. Such awareness is needed to critically assess how to balance biomedical knowledge against patients' experiential and existential perspectives.

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Contribution statement

Olaug S. Lian: Study design, ethics approvals, sampling, conceptualization, data analysis, main author. **Sarah Nettleton:** Study design, ethics approvals, conceptualization, data analysis, co-author. **Huw Grange:** Study design, conceptualization, data analysis, co-author. **Christopher Dowrick:** Study design, ethics approvals, conceptualization, data analysis, co-author. All authors have approved the final version.

Declaration of Competing Interest

None.

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