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Advice, authority and autonomy in shared decision-making in antenatal screening: the importance of context

Alison Pilnick[1] **and Olga Zayts**[2]

[1]*School of Sociology and Social Policy, University of Nottingham, UK*
[2]*School of English, University of Hong Kong, Hong Kong*

Abstract Shared decision-making (SDM) has been widely advocated across many branches of healthcare, yet there is considerable debate over both its practical application and how it should be examined or assessed. More recent discussions of SDM have highlighted the important of context, both internal and external to the consultation, with a recognition that decisions cannot be understood in isolation. This paper uses conversation analysis (CA) to examine how decision-making is enacted in the context of antenatal screening consultations in Hong Kong. Building on previous CA work (Collins *et al.* 2005, Toerien *et al.* 2013), we show that, whilst previously identified formats are used here to present the need for a decision, the overriding basis professionals suggest for actually making a decision in this context is the level of worry or concern a pregnant woman holds about potential foetal abnormality. Professionals take an unknowing 'epistemic stance' (Heritage 2012) towards this worry, and hence step back from involvement in decision-making. We argue that this is linked to the non-directive ethos that prevails in antenatal screening services, and suggest that more research is needed to understand how the enactment of SDM is affected by wider professional contexts and parameters.

Keywords: shared decision-making, doctor-patient communication/interaction, screening

Background

Shared decision-making (SDM) has been widely advocated across many branches of healthcare. The rationales used to support SDM are equally wide- ranging, extending from the ethical (based on the notion of bodily integrity), through the philosophical (the principle of individual autonomy) to the practical (an assumption that compliance is more likely with a shared treatment decision) (Matthias *et al.* 2013). However, there is also considerable debate over the practical application of SDM, whether all settings are amenable to it, and whether decisions can be studied in isolation from the rest of the clinical encounter.

A sizeable body of research has focused on identifying key concepts of SDM (e.g. Dy and Purnell 2012, Makoul and Clayman 2006). Dy and Purnell (2012: 582) cite the following definition of SDM: 'A process by which a healthcare provider communicates to the patient personalised information about options, outcomes, probabilities and uncertainties of

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available options, and a patient communicates values and the importance of benefits and harms' (Foundation for Informed Medical Decision-making 2006), and suggest that trustworthiness, information quality and communication are key components in achieving this end. They conclude their study by suggesting that more work is needed on decision-making style and the impact this has on SDM. Makoul and Clayman (2006) carried out a systematic review of 418 articles on shared decision-making, selected through a PubMed search, to identify concepts commonly used in definitions of SDM. They found that no single concept was listed in all these articles, and that 20 concepts appeared in more than 10 per cent of the papers reviewed. The most commonly occurring concepts were patient values/preferences, options, and partnership. However, the need to make (or to explicitly defer) a decision based on these values/preferences, and the available options, was also a recurring theme in this literature.

The importance that has been placed on the making of a decision based on patient values and preferences has been reflected in the development of instruments explicitly designed to address the quality of shared decisions. Perhaps the two most prominent amongst these are provided by Braddock *et al.* (1997) and Elwyn *et al.* (2005). Braddock and colleagues developed their instrument through an initial synthesis by the authors of ethical models of informed consent in the bioethics literature. This led them to identify six key elements; the extent of discussion leading to each decision can then be graded according to the presence or absence of these six elements. Using this approach, an element is counted as present if discussed at all, however briefly. However, as other authors have subsequently suggested, actions such as providing an alternative are not necessarily independent factors indicating whether a decision has been shared; for example a patient given clear alternatives can still be steered towards a practitioner's preferred option (Brown *et al.* 2004). Elwyn *et al.*'s (2005) OPTION scale embodies a slightly different approach to this issue, offering a 'skills framework' that is designed to represent a set of competences rather than a more discrete list of elements. In order to operationalise this skills framework, a 12 item scale is used, to which an overall numerical score can ultimately be assigned. As might be expected, this scale focuses both on how different options are presented to and explored with the patient, as well as establishing the level of involvement with decision-making that the patient requires.

It is clear then, that a focus on assessing the actual mechanics of decision-making pervades the SDM literature. It is also the case that the issue of decision-making is often conceptualised as having a straightforward relationship to treatment. However, the data set presented in this paper cannot be straightforwardly interrogated from this perspective. In an antenatal screening setting, what is at issue is not treatment, since no treatment can be offered during pregnancy for foetal abnormalities. Instead, when a pregnant woman receives the results of her screening tests, her available options are to do nothing, or to undergo further testing. This further testing, carried out by means of amniocentesis or chorionic villus sampling, will be diagnostic for some foetal abnormalities, but also carries with it a risk of miscarriage. In this setting, then, the relative importance of benefits and harms to a particular woman are key; whilst for some women any risk of miscarriage may to be too great to consider, for others, any risk of a child with Down's syndrome is seen as unacceptable. What the difference between this setting and others more commonly studied from the perspective of SDM highlights, then, is the way in which context and decision-making are intertwined.

Matthias *et al.* (2013) make the case for a consideration of context strongly in their discussion of SDM, though they also make a distinction between internal context, and external context or setting. In terms of the former, they highlight how previous studies of SDM have frequently focused only on the point where a decision is made in a consultation. They also note that scales designed to evaluate the nature and quality of shared decisions (e.g. Braddock *et al.* 1997, Elwyn *et al.* 2005 as described above) tend to focus only on portions of the consultation where decisions are discussed. However, they argue that no part of an interaction can be fully understood in isolation, and that what happens in the decision-making process itself is inextricably linked to both what has happened before and what happens after. For example, if a clinician who has been very directive at the outset of a consultation later tries to involve a patient in a decision, the patient may be confused or reticent. They conclude by proposing an alternative model for examining SDM – the 'Four Habits Approach' – which focuses on investment in the beginning and end of the encounter as well as eliciting the patient's perspective and demonstrating empathy. The aim is to provide a consistent internal context to support participation.

This recognition of the importance of context, both internal and external, is also shared by other authors. Karnieli-Miller and Eisikovits' (2009a) study, conducted in a clinic for adolescents with Inflammatory Bowel Disease, took a phenomenological approach to their data, aiming to explore how decisions were made in a real time context. They draw on observational, audio/video recorded, and interview data, to analyse consultations in which diagnoses are given and treatment decided. Their analysis identifies a number of persuasive strategies used by doctors to gain agreement to treatment decisions; such strategies are at odds with usual definitions of a SDM approach, but the authors caution that the specific external context here, and in particular the nature of the patient group, limits generalisability. In a subsequent response to a critique of their paper (Karnieli-Miller and Eisikovits 2009b: 13), they conclude that 'only by looking at the context, which includes the dynamics during the entire encounter, the way treatment is presented and the opportunity to negotiate, deliberate and share the decision, can one assess whether the decision was shared or not'.

Other researchers investigating SDM have come to similar conclusions about the importance of context, but addressed these in a different way. Collins *et al.* (2005) argue that conversation analysis (CA) is an ideal method for research in this field, because of its rejection of *a priori* models, whether these seek to take account of internal context or not. As they highlight, CA studies are not based on preconceptions of what patient participation ought to look like, and so rather than seeking to identify the presence or absence of existing key concepts or elements, they focus instead on how decision-making is enacted, and how the interactional configuration shapes opportunities for patient involvement. Toerien *et al.* (2013: 873), in their paper using conversation analysis to investigate decision-making in neurology consultations, conclude that 'Future CA studies should map out the range of ways ... in which ... decision-making is initiated by clinicians', arguing that this is necessary to produce evidence-based contributions to the debate on shared decision-making. This paper aims to contribute to such an endeavour.

Methods

This paper arises from a study of antenatal screening provision in Hong Kong (see also Pilnick and Zayts 2012, 2014). The overall data set currently comprises over 120 video recorded consultations. This paper draws on a subset of these data: 28 women who receive 'high risk' results from initial screening (in this setting a result of greater than 1 in 250 for women undergoing a combined test, and greater than 1 in 320 for an integrated test which assesses additional screening markers[1]). As described in Pilnick and Zayts (2012), these women receive a telephone call asking them to return to the clinic and discuss their results; though the actual results are not given over the telephone, they can therefore infer that they fall into the 'high risk' category before they arrive at the clinic. During their consultation at the clinic, the actual results are given, and the available options for further invasive, diagnostic testing (amniocentesis or chorionic villus sampling) are discussed. On average, these consultations are approximately 15 minutes in length. Consultations in this setting are routinely scheduled 15 minutes apart, since providing antenatal screening services is only one aspect of obstetric provision the staff conducting the consultations are involved in. Ethics Committee approval was obtained from both the University of Hong Kong and a hospital authority cluster overseeing the hospital where the data were collected. The recruitment procedure involved a study nurse approaching potential participants and introducing the research project to them before seeking consent to participate. The background of the recruited participants reflects the diversity of the client population at this particular hospital, which although it is a public hospital, is also used by those who would generally choose private healthcare because of its status and facilities as part of a Hong Kong University. Women in our sample originate from various parts of Asia (Hong Kong, Mainland China, Philippines, Thailand and Indonesia), North and South America, Europe, New Zealand and Australia. Their socioeconomic background also ranges widely, from women employed as domestic workers to those in professional occupations. The age of the participants is from 35 to 41 years old.

Consultations were conducted by four medical professionals (three doctors and one specialist nurse), all of whom are Hong Kong Chinese. The consultations chosen for presentation here are all conducted by doctors, marked as ‘D’ in the transcripts. Some women attended clinic alone, whilst others attended with a partner or significant other; in the transcripts that follow pregnant women and their partners/significant others are referred to as P and S respectively). In the consultations either English or Cantonese are used as the first or the second language of the participants. The consultations conducted in Cantonese were initially transcribed and then translated into English. As we have described previously (Pilnick and Zayts 2012), we are aware of the social, cultural and political challenges involved in any act of transcribing, and particularly so in transcribing translated data (Bucholtz 2007). We have therefore paid particular attention to ‘validating’ (Peräkylä 2004) the translations of the transcripts. More specifically, the initial transcriptions and translations were carried out by two bilingual research assistants. Both the transcripts and their translation were verified by a bilingual member of the research team. We have also followed the procedures for validation as suggested by Peräkylä (2004:216) in that we have paid particular attention to ‘the next speaker’s interpretation of the preceding action’ in our analysis. In conducting our analysis, we used four line transcripts where consultations were conducted in Cantonese. These present first the Cantonese characters, followed by a pinyin representation which represents the phonetic sounds of the Cantonese speech in the Roman alphabet. The third line is a literal translation from the Cantonese, and the fourth and final line is a representation which makes sense in spoken English. As far as was possible, given the grammatical differences between the two languages, features of speech such as ‘stretching’ of sounds, emphasis, and pauses have been retained in this final translation. However, in some cases, where particles of speech are not directly translatable, such features have been lost. For reasons of space in this paper, where data have been translated into English, we have presented only the final translation here. However, the original transcripts and translations are available by request from the authors.

The analysis was conducted using conversation analysis, and extracts reproduced here employ standard CA transcription notation (ten Have 2007, Jefferson 1984). Using conversation analysis, we examine these consultations to show how decisions are made in this context.

Analysis

The analysis presented here begins with a consideration of the ways in which professionals in this setting present the need for a decision to be made regarding future action and the options that are available. There are a variety of decision-making formats which have been previously described in the literature, and which can also be found in this setting; however, as we will demonstrate, the context of the antenatal screening clinic appears to impact on the relative frequency with which these occur, and also give rise to some context-specific features. In later sections of this paper, we will turn to consider the basis on which professionals suggest a decision about future action should be made. For the present, we begin with the distinction that has previously been made between 'unilateral' and bilateral' presentations of decision-making.

Unilateral approaches to decision-making

In their analysis of decision-making in ENT and oncology clinics, Collins *et al.* (2005) break the process down into a number of analytic phases. They characterise these as follows: first the 'opening of the decision-making sequence' sets the scene for presenting and characterising a problem; subsequently the 'presentation and evaluation of the test result or diagnosis' provides various opportunities and avenues for talking about and reflecting on the problem. The 'introduction of the decision point' is where a decision is initially referenced. This is followed by 'consideration and discussion of options' in which one or more options are identified and debated. Finally, the 'conclusion of the decision-making phase' presents the chosen course of action (which in their data may be a treatment selection, or may be an agreement to continue discussion on another occasion). Following this, transition to another consultation phase begins. Collins *et al.* draw a distinction between 'unilateral' approaches, where the doctor more or less autonomously conducts the decision-making process through these phases, and 'bilateral' approaches, where patient views are solicited and there is what they describe as 'a sharpening of focus' through the answers provided by the patient.

Such unilateral, doctor led approaches are occasionally found in our data. In two out of 28 cases collected and analysed so far in our subset, doctors present a decision (in both instances using the imperative form 'we need') to suggest that further testing ought to take place. In one instance this relates to amniocentesis, and the 'need' for the test is presented in unmitigated fashion and without discussion (see Pilnick and Zayts 2012 for a more detailed consideration of this consultation). In the instance reproduced below it relates to a further ultrasound scan. In the consultation from which the extract below is taken, the pregnant woman has just received the results of her screening test, which have shown a low risk for Down's syndrome but a raised risk for a different chromosomal abnormality, Edwards' syndrome.[2] The three participants are the doctor (D), pregnant woman (P) and her husband (S).

Extract 1 [FYMC]

Context: The woman is 37 years old; after the initial screening her risk of having a child with Edward's syndrome has been estimated as 1:40 (the risk of Down's syndrome is 1:460). This is the woman's third pregnancy, she has two healthy children. The woman attends the consultation with her husband. All participants are Hong Kong Chinese, and the consultation is conducted in Cantonese (participants' native language).

D: But, we say the chance is one in forty. (0.3) For: this, I think:, we for the time
being <say: then:: (.) also::> (0.6) .hh em::: (0.4) >I think< we need to have an
ultrasound.
(0.4)
P: Mm[mm]
D: [>some]times:< (.) after we: (0.2) have seen it, .hh (0.4) >because the

(continued)

27. ultrasound:<, (.) >because< (0.3) this condition, compared (.) with Down
28. syndrome, is very different. .h
29. S: Mm hmm.
30. D: Because, the ultrasound can clearly show problems on the structure.
31. (0.2)
32. S: Okay
33. D: So (.) if we have seen it and then discuss it further, it will °be° better.
34. P: [Mm hmm.] ((while nodding))
35. S: [Mm hmm.] ((while nodding))

Here, then, the result of the test is presented with use of the institutional 'we' ('we say the chance is one in forty', line 21), which locates the finding within a wider framework of medical expertise. This use of 'we' is continued into the doctor's next utterance (lines 21–23), but this time the 'we' presumably also incorporates the pregnant woman, since she is the person who will actually 'have' the ultrasound. The imperative character of the proposal ('we need to have') is softened here by the use of the mitigator 'I think', and also by invoking temporal factors (that this is a proposal 'for the time being', thereby implying that subsequent decisions remain open to discussion). Although the word 'also' is used in this formulation (line 22), the proposal for ultrasound does not appear to be ancillary to any other proposed new action here, and no additional proposal for a new action is made during this consultation; it may refer instead to the ultrasound as an addition to the test that has already taken place. After a short pause, there is a very minimal and soft acknowledgment made by the pregnant woman, before the doctor continues with a rationale for this decision (lines 26–28), which may be aimed at eliciting a more overt measure of agreement by the woman. As conversation analytic work on advice giving in a variety of health care settings (e.g. Heritage and Sefi 1992; Pilnick 1999; Koenig 2011) has repeatedly demonstrated, an utterance which promotes or forwards a future course of action for a patient is treated as requiring a response. In addition, and more specifically, Stivers (2006) shows how doctors routinely pursue responses to treatment recommendations when these are not initially forthcoming from patients. Minimal receipts or silence may be treated as passive resistance to a course of action, therefore doctors may do more work to justify this and to elicit a more extended response. As Stevanovic and Peräkylä (2012) highlight, because treatment decisions concern patients' future actions, a patient is required to demonstrate that s/he assumes some responsibility in this regard. This time it is the husband who provides a minimal acknowledgment to the doctor's proposal, in line 29; this minimal acknowledgement produces a further account for the proposed procedure from the doctor (line 30), before the husband produces an 'okay' in line 32. In response to this the doctor provides a third account for the proposal, which is presented in a depersonalised format ('it will be better'). This version of the account suggests that an ultrasound scan is a desirable precursor for any further discussion about future action, and in response both the woman and her partner signal agreement both verbally and non-verbally.

This decision then, is produced as a (strongly advocated) proposal by the doctor, for which assent is sought, in the absence of any solicitation of the pregnant woman's views. Despite this, the active pursual of an agreement suggests that the doctor does not treat her own utterance as merely informational. However, as Toerien *et al.* (2013: 886) note, presentation of only one treatment option can create a scenario which does not give patients much 'room for manoeuvre', and only a single option is on the table here, though various different rationales are used to justify it. Whilst further work by Reuber *et al.* (forthcoming) shows that single options can be delivered in ways that give the patient a choice, any choice in Extract 1 above is backgrounded by the doctor's delivery.

Collins *et al.* (2005) suggest that unilateral decision-making is characterised by the emphatic presentation of test results or diagnosis, pointing to the necessity of doing something and perhaps of acting quickly, and omitting consideration of the option of doing nothing. The option of 'doing nothing' is a particularly salient one in this setting; given that there is no treatment for any of the conditions that can be identified here, it is an ever-present option for women to set against the possibility of further invasive testing and/or termination of pregnancy. However, this option may be made more or less visible in these consultations, and its visibility is minimised in the extract above; it is the doctor who knows what ought to be done and assent is then sought for her proposal.

Recent work in conversation analysis has focused on the area of epistemics in interaction: examining how claims to knowledge are produced, understood and contested through talk (Heritage and Raymond 2005, Heritage 2012). This literature makes distinctions between epistemic status (who has access or primary access to an element of knowledge) and epistemic stance, which encompasses the position that a participant takes *vis-à-vis* another participant's knowledge. For example, a question may convey an unknowing epistemic stance, regardless of whether some part of the answer is known or suspected by the asker (Heritage 2012). A third element to such analyses is epistemic authority: whether participants have the right (or primary right) to particular elements of knowledge. For example, as Heritage (2012) describes, and except in the special case of psychotherapy, participants are generally seen as having both primary knowledge of and primary rights over their own internal feeling states.

Relating this work to the topic under investigation here, one way to conceptualise the exchange in Extract 1 is that the doctor in this instance claims not only epistemic authority, but also 'deontic authority' (Stevanovic and Peräkylä 2012): the right to determine another's future actions. Stevanovic and Peräkylä (2012: 298) make a distinction between epistemic authority and deontic authority as follows: 'epistemic authority is about *knowing* how the world "is"; deontic authority is about *determining* how the world "ought to be"'. It follows from this that to a first speaker's suggestion, a second speaker can acquiesce to or resist plans, but also acquiesce to or resist the speaker's right to make them. In this instance the pregnant woman and her partner produce neither kind of resistance, the 'needed' ultrasound proposed by the doctor is arranged, and her deontic authority remains unchallenged.

Non-unilateral approaches to decision-making

Recommendations

As we have noted, these unilateral presentations, where alternatives are not presented and women's viewpoints are not explicitly solicited, are rare in our data. The remainder of our consultations contain presentations that, on this basis, might appear to fall into Collins et al.'s (2005) bilateral categorisation. However, we will return to the issue of whether some of the approaches seen in our data can truly be categorised as bilateral, in the sense that this term has been previously used, below. Once again, existing literature has shed light on some of the interactional mechanisms through which such non-unilateral decisions can be presented. In their paper examining decision-making in neurology from a CA perspective, Toerien *et al.* (2013) identify two types of practice that are commonly used in that setting: recommending a particular course of action; and 'option listing', entailing the construction of a list of possible options from which patients must actively choose. In recommending, they suggest that a professional claims to know both what can be done and what the patient should do, so that they claim not only medical knowledge but also the right to advise the patient. Knowledge, and the issue of who has access to this knowledge, is thus key in this setting; the professional and patient have unequal epistemic access to the domain of treatment information. In three of our

28 cases, practitioners do provide alternatives, but accompany these with a recommendation as to which should be chosen. Extract 2 shows an example of a recommendation from our data.

Extract 2 [JTJ]

Context: The woman is 36 years old, this is her fifth pregnancy. After the initial screening her risk factor for Down' syndrome has been estimated at 1:170; and for Edwards syndrome at 1:30. The woman is attending the consultation together with her husband. The consultation is conducted in English.

14. D: Our cut off is (.) uh one out of (.) uh two hundred fifty.
15. S: [Right.]
16. P: [Yeh.]
17. D: Um (.) above that cut off, we will suggest that, em you have an
18. amniocentesis, to find out if the baby really have Downs. Okay?
19. .h It- it is our recommendation, but it's really up to [you]
20. P: [Um huh]
21. D: whether (0.5) .h you <would (.) [want] to>=
22. S: [Sure.]
23. P: =Um huh.
24. D: Go further on for a test. Okay? (.) .hh um: (0.5) the (0.3) mainly, I think it is the
25. uh, (0.3) the pregnancy uh associated uh protein (0.2) um .hh which is:
26. lower than average.
27. S: Yeh

In this extract, at line 17 there is a suggestion (again made using the institutional 'we') that those people who find themselves in the class 'above the cut off' should have amniocentesis (c.f. Silverman 2007). However, there is no immediate uptake of this suggestion following the pursuing 'Okay?' in line 18, and in line 19 this is reformulated as a recommendation. However, the fact that this is something to be actively accepted or rejected by the couple is explicitly signalled, and the agency of the couple is explicitly invoked in deciding what should happen next. This agency is accepted by the husband in his overlap of 'sure' in line 22, which acts as an agreement that this is 'up to them'. Here, then, whilst the doctor asserts epistemic authority in relation to the status of the test results and what they should be taken to mean, deontic authority – the right to determine another's actions – is not claimed. Recommendations may, of course, be produced more or less directively by professionals (and at the extreme end of this spectrum it may be argued that they are not really 'bilateral' approaches at all), but in the context of our data they are always accompanied by an active solicitation of views from pregnant women. This kind of presentation foregrounds the issue of choice. It is also notable that the doctor in this case makes considerable efforts to demonstrate the basis for the epistemic authority on which her recommendations are based. In this case she does so through a focus on a particular component of this specific result ('pregnancy associated protein' in lines 24–26); in other examples doctors draw on their knowledge of population level statistics.[3]

Option listing

As we noted earlier, Toerien *et al.* (2013) identified a second practice in their neurology data: option listing. They argue that when clinicians use option listing, they work to relinquish a little of their authority. This is because option listing claims only knowledge of which options are available, and not which ones patient should take. They also suggest that option listing not only encourages active patient participation but makes it relevant in order for the interaction to proceed, since it 'creates a slot where the patient's announcement of their selection from the list is relevantly due' (Toerien *et al.* 2013: 881). Such option listing occurred frequently in our data (12 out of 28 cases) and Extract 3 below shows an example.

Extract 3 [LTMA]

Context: The woman is 37 years old, after the initial screening her risk has been estimated as 1:244. This is the woman's first pregnancy. She is attending the consultation together with her husband. All participants in this interaction are Hong Kong Chinese, and the consultation is conducted in Cantonese.

52. D: .h so but based on this, (0.4) the cut off, (0.2) is set like that, .h this
53. (0.2) .h is the cut off, which (0.3) means (0.5) <the report is positive.>
54. P: Um.
55. (0.4)
56. D: It depends on whether you and your husband::: (.) are (0.3) worried, (0.4)
57. and want to go for amniocentesis. Or (.) we can have an ultrasound, to see
58. if roughly (0.9) eh::: we don't see anything special,
59. P: Um.

In this extract, again the results from the screening tests are presented as the driver for a decision (lines 52–53). Interestingly, only two of the three possible options in this scenario are explicitly presented – amniocentesis and further ultrasound (lines 57–8) – while the third, to take no action, is left unsaid (though perhaps could be heard implicitly). However, what is more significant for the analysis presented here is the basis on which the practitioner in this instance suggests the decision should be made between these options – whether the woman and her partner are 'worried' (line 56). We will return to analysis of this consultation, as it continues to unfold, later in this paper, but for now we will focus on the work that is done here by invoking worry as a factor in decision-making.

As we have previously noted, Heritage (2012) makes the distinction between epistemic authority and epistemic status, where the latter is not just about the possession of information but also incorporates rights to articulate this. In these terms, thoughts, feelings and hopes are generally treated as a person's to know and describe. 'Worry' is a subjective feeling, and accordingly it is treated by the doctor in this extract as known by the pregnant woman, but not by her; she takes an 'unknowing' epistemic stance towards this worry. Toerien and colleagues (2013) have described how option listing in their study setting worked to relinquish medical authority and invoke patient participation. However, we would argue that what happens in this extract, and this context, goes considerably further than that. The implication of the doctor's epistemic stance in this consultation is that a decision on which option is preferable here is not one to be taken on the basis of medical meaning making or medical recommendation, but on how the woman feels. Whilst this may seem a pragmatic approach to dealing with the issues at hand, it also has huge implications for shared decision-making. If it is suggested that a medical decision should be made on the basis of an internal feeling state to which a practitioner has no direct access, it follows that the decision is treated neither as one that the doctor has rights over, nor as one that can be 'shared', but instead one that the woman alone can make. To return to Collins et al.'s (2005) characterisation, whilst the presentation of the decision may show features of a bilateral approach, we would argue that it cannot be truly described as bilateral because the doctor places the end decision firmly in the woman's domain and steps away from any involvement. However, neither is it unilateral in the sense previously described in the literature, where it has been assumed that doctors or other professionals are the agents of unilateral decisions. In the final analytic section of this paper, we will turn to consider this finding in more detail, alongside its implications.

'Worry' as a determinant of choice

In our data from this project, whenever an 'option listing' approach to decision-making is used, it is always combined with a reference to worry (or less commonly, 'concern') as the factor on which choice between the options should depend. Extract 4 is a further example of this:

Extract 4 [TYY]

Context: The patient is 36 years old and Hong Kong Chinese. She has taken an integrated test[1], and her risk factor has been estimated at 1:295 (the cut-off value for the integrated test is 1:320). This is the woman's third pregnancy; she is attending the consultation on her own and it is conducted in Cantonese.

35. D: ok, actually, (.) we can say the- the chance of the baby having Down
36. syndrome is high, or low, (0.4) .h here we say, the chance is one out of three
37. hundred and twenty, (0.3) so this is (0.4) .h that is a bit higher, so we also:
38. (.) assume it's high, so we call you to come back to explain it further.
39. P: °Alright.°
40. D: It doesn't mean that the baby (0.6) must have Down. (.) It (0.4) depends: on
41. how much you worry about it. (0.6) and (0.9) whether you want to have
42. further investigation to confirm this result. (0.6) If you don't worry about it,
43. then you can:, (0.5) that is to have further check after the baby is born. (1.0)
44. But if you really want to know, (.) that is before the baby is born you want
45. to know the result, (0.3) .h then you need to (0.8) that is to do the
46. amniocentesis.
47. P: Um:.

In this extract, the test results are first presented as a rationale for having asked the woman to re-attend the clinic, and following an acknowledgment of these in line 39, the doctor states what they do not mean, that is, that they are not definitive (see Pilnick and Zayts 2014 for a detailed discussion of how uncertainty of results is managed in this setting). Once again in this consultation, as in the consultation from which Extract 3 is taken, what should happen next is presented as contingent upon the level of worry that the woman holds ('It (0.4) depends on how much you worry about it' in lines 40–41), before the two options – of doing nothing at present, or of having amniocentesis, are presented. This time, each of these options is tied to a particular hypothetical epistemic (and emotional) position for the woman; if she is not worried about not knowing, then she can wait to obtain further knowledge, but if she needs to know a certain outcome now, she should take the amniocentesis. Once again here, the doctor does not claim the right to advise or know what to do in this particular situation- which might be seen as adhering to key principles of SDM – but what is significant in this setting is that the means for making a decision is placed firmly outside the domain of medical knowledge or expertise.

We have previously highlighted Heritage's (2012) assertion that it is generally the case that persons are treated as having primary access to, and authority over, their own feeling states. In line with his research, we do not find it surprising that doctors should take an 'unknowing' epistemic stance towards the levels of worry that women hold in this context. However, as we have also noted, the consequence of this is that decisions which invoke worry as the means of choosing between options are not presented or treated as something to be shared, or as a situation in which medical expertise can assist with choice. We began this paper by making a case for the importance of context in studies of shared decision-making, and it is worth considering here for a moment the specific context in which these interactions occur. Antenatal screening is a particularly sensitive setting for decision-making, since most anomalies that are detected cannot be treated or cured. Termination of pregnancy is therefore a potential end consequence of screening and testing decisions. As a result, antenatal screening settings have received a considerable amount of sociological attention, with some commentators arguing that the way in which the service is provided amounts to a form of 'weak eugenics' (Shakespeare 1998). In response to these charges, the concept of non-directive practice has been widely adopted, though a number of critics have suggested that while it may be a philosophical ideal, it is ultimately interactionally unworkable (e.g. Anderson 1999, Brunger and Lippman 1995, Gervais 1993, Rentmeester 2001). However, as previous studies have demonstrated, a common interactional manifestation of practice that is designed to be non-directive is an unwillingness by practitioners to give specific advice (e.g. Zayts and Schnurr, 2012). It is possible, then, that the recourse to 'worry' as the arbiter of choice which recurs in our data is so common precisely because it works as a way of managing this ideal of non-directiveness. In a situation where a decision is framed as dependent on the level of worry a pregnant woman has, a professional cannot advise on the best course of action because they cannot know what it is.

Thus far, we have suggested that the common practice in these consultations of invoking worry as a feeling state over which pregnant women have epistemic primacy is in line with what would be expected from previous literature. We have also suggested that such invocations may work as a way of managing non-directiveness, since if a doctor does not know the level of worry a pregnant woman holds, he or she cannot make further suggestions on how a decision should be made between the available options, or give advice on which should be chosen. However, what is also notable on analysis of these consultations is that the worry that is invoked is not treated as a topic for articulation by the pregnant woman, or for further discussion. This is particularly significant in light of the fact that commonly used definitions of shared decision-making stress the importance of exploring the relative importance of the benefits and harms of particular courses of action for patients (e.g. Dy and Purnell 2012). In none of the consultations in our corpus do professionals actively seek any further information about whether women are worried, the level of worry they hold, or what their worries may specifically be about. Despite this lack of direct solicitation, we do have cases in our corpus where women themselves attempt to share their worry. Extract 5 below is a continuation of the consultation from which Extract 3 above is taken (in the intervening 10 lines the doctor has placed an accuracy figure on the results of a further ultrasound scan as 40–50 per cent, emphasising that this will not give a definitive answer). In this continuation, following the doctor's previous making relevant the issue of worry, the pregnant woman explicates her specific worry as being tied to the consequences of further invasive testing.

Extract 5 [LTMA]

70. P: But if actually I- I am worried, (.) if I have amniocentesis, (0.4) .h what the
71. consequence will be, because I heard that, out of two hundred, there is (0.4)
72. one miscarriage.
73. (0.2)
74. D: Yes. (0.4) ((while nodding)) Because having amniocentesis (0.3) <is::: (0.6)
75. that <people are (.) worried: about the chance of miscarriage.>
76. (0.2)
77. P: Um hmm.
78. D: That is the chance of miscarriage (0.5) .hh is one in two hundred to one
79. hundred.
80. (1.6)
81. P: Two hundred to one hundred?
82. D: Yes.
83. P: huh huh ((nasal laugh)) ((looks at S))
84. D: hh ((nasal laugh))

Over lines 70–72, the woman here articulates a very specific worry: the risk of miscarriage following amniocentesis. She formulates her knowledge about this risk as a proposal to be confirmed, and the doctor subsequently provides this confirmation in line 74. The doctor then continues to expand on the actual risk figure over her following turn, finally arriving in lines 78–79 at a range formulation which has the woman's original proposal as its lower limit but indicates the possibility may also be higher. Her response, then, attends to the medical verification of the woman's statistical understanding, but does not extend to any further unpacking of the worry around this. Following wry laughter from the woman, with which the doctor joins in, the topic is temporarily concluded and a discussion of timescales and the procedure for arranging subsequent testing should it be required (not shown here) ensues. The consultation then continues as in Extract 6 below.

Ex 6 [LTMA contd]

110. P: °Do you have anything to ask?° ((talking to S and clearing her throat))
111. (2.6)
112. P: Actually I am worried, that is after having amniocentesis, (0.8) what it may
113. lead: to (0.4) what it will become, because=
114. D: =Um.
115. P: Because overall it's our first baby, and my age is high.
116. D: Right. ((while turning over and reading the report))
117. (1.2)
118. D: You didn't have bleeding recently?
119. ((P shakes her head))
120. (2.2)
121. D: Ok, so:

In line 110, the pregnant woman turns to her husband and softly asks if he has any questions. After a pause, it is actually the pregnant woman herself who speaks again, returning to the issue of her specific worry. Again, the issue of miscarriage following amniocentesis is referred to (lines 112–13), though this time in a much less direct format that leaves the consequence of miscarriage implicit rather than explicitly named. Following a minimal response from the doctor in line 114, the woman goes on to contextualise her worry even further: this is a first baby, and her age means it may not be easy to become pregnant again. Her own knowledge of her feeling state, then, is both shared with and explicated for the doctor. However, once given access to this feeling state, the doctor does not directly respond to it, or use it to help contextualise a decision. Instead, her subsequent question in line 118 ('you didn't have any bleeding recently') seems designed to establish whether there are any additional risk factors for miscarriage; notably this question is designed to project a negative, 'no problem' response (Boyd and Heritage 2006, Raymond 2003). Ultimately, even though the pregnant woman shares both the nature of her worry and the reasons for her feelings, the doctor does not pursue this in the context of decision-making.

Rapley (2008a) has persuasively argued in this journal that research on decision-making in healthcare has neglected the ways that individuals' decisions are shaped over time by knowledge and encounters beyond the immediate space of a single consultation. We share his call for an understanding which is better contextualised. However, in our setting, it appears that decisions are not simply shaped beyond the consultation, they are actively pushed beyond it by the emphasis that is placed here on subjective feeling states.

In a context where non-directive practice is held as an ideal, it is easy to see why professionals do not generally assume deontic rights over decision-making. However, the issue of epistemic rights is more complex. Whilst nurses and doctors may not have epistemic rights regarding feeling states, and hence the ultimate decision to take a test or not, they still have greater epistemic resources regarding outcomes of antenatal screening in general, based on their experience and training. Such epistemic resources are commonly shared in the delivery of results, in order to help women understand what different risk figures should be taken to mean, and where contextualisations such as ‘not so high’ are commonplace. However, in relation to the issue of worry, any contextualisation appears to be much more limited (as in the repeat of official statistics for the risk associated with amniocentesis cited in Extract 5 above). The end consequence is that where, following the process of option listing, women seek help in working out which is the best option for them, such help is not forthcoming.[4]

Conclusions

Our analysis has shown how data from this setting exhibit features that have previously been identified by those who have studied decision-making in healthcare contexts. However, previously identified formats also map imperfectly on to these data. Though it is a rare occurrence, doctors do on occasion assume the deontic authority to tell people what to do. This is seen in the unilateral delivery of Extract 1. Since we have only two cases of this kind in the current corpus, it is difficult to draw any firm conclusions as to why this might occur. As we have previously noted (Pilnick and Zayts 2014), there is no straightforward correlation in our data between the level of risk a test result shows and the extent to which future courses of action are more or less assertively promoted by professionals. However, we note the minimal responses of the pregnant women and their spouses in these scenarios, and we also note that we have no examples of this unilateral delivery of a decision, or the associated assumption about the right to assume deontic authority, being resisted. This is not to say that the women in these cases are victims: as Costello and Roberts (2001: 242) argue ‘[p]atients both accept and resist recommendations; they do not simply fall victim to physicians’ preferences’. These examples demonstrate that when doctors do make unilateral decisions in an antenatal screening context, they are treated as having rights to do so. Our analysis here, then, responds to Stevanovic and Peräkylä’s (2012: 318) call for ‘comparative research on participants’ orientations to deontic authority in different institutional and everyday environments’.

Our analysis has also shown that in this context, professionals sometimes make recommendations. The three examples of this in our data set vary in the way in which these are presented, but they have in common a solicitation of views from pregnant women and their partners; so whilst professionals in these consultations assume the right to advise, they do not assume the right to decide. More commonly in our data set, professionals option list, but we have identified an important difference between the work of Toerien *et al.* (2013) and the data we present here. In contrast to studies of treatment decision-making in other contexts, in the antenatal screening context the basis for the decision is commonly suggested to be not the specific level of risk the test result suggests, but rather ‘feelings’ about this result. Despite their medical knowledge and status, professionals frame the decision to be made in terms of worry and concern, with the result that the decision is cast as a matter in which only pregnant women and their partners have expertise. Such a presentation undermines the ‘bilateral’ nature of the consultation (Collins *et al.* 2005) which has initially been constructed, and suggests that the distinction between unilateral and bilateral decision-making is less straightforward than has previously been assumed. In particular, the assumption that the professional is always the agent of unilateral decision-making does not hold in this setting. Whilst the presence or absence of the worry felt by pregnant women is topicalised, since it is not further explored by professionals, the decision cannot be shared. Even where women themselves express clear worry or actively seek to share this worry and so level the 'epistemic gradient' (Heritage 2010), no input into their decision is forthcoming. Hence, one of the tentative conclusions to be drawn here is paradoxical: that women who do not ask for input may have their choices determined, but women who actively seek guidance do not receive it. We argue that this particular operationalisation of SDM in practice is tied to a context in which non-directiveness has long been upheld as a principle, and that this highlights the importance of considering context in research into SDM. Indeed, as Rapley (2008b) has argued, ideas about 'good participation' are deeply situated in the task at hand, the activity and the ceremonial order of that discipline. It follows from this argument that in order to examine SDM in a meaningful way, any method used has to be able to take account of these factors in analysis.

Collins et al.'s (2005) analysis of shared decision-making from a CA perspective also highlights the importance of external contextual factors; noting that the 'unilateral' approach they identify tends to be more common in an oncology setting, they suggest this may be underpinned by a sense of urgency and a limited time span in which to make a decision. We observe here that antenatal screening also offers a very limited time span for decisions, and for subsequent termination of pregnancy, so it is interesting to reflect on the comparative scarcity of the traditionally described unilateral approach in our data.[5] Instead, it seems that the ethos of non-directiveness prevails over clinical urgency, with the result that women are left to make their own decisions. Whilst the routine and widespread adopting of deontic authority by professionals would likely be seen as ethically problematic in this setting, what also happens here is that the epistemic resources that professionals have (in relation to testing processes, outcomes, etc.) get sidelined. This results in a kind of vicious circle; that professionals have this knowledge by virtue of being professionals, but also by virtue of being professionals they decline to use it to impact on decision-making. Shared decision-making generally assumes a bidirectional dialogue about action/treatment (Peek *et al.* 2010), and it is generally assumed that it is the patient's perspective that is missing from this dialogue, but in this setting professionals do elicit this perspective but then decline to engage with it. Here, then, decisions are not so much shared by doctors as devolved to pregnant women to take unilaterally, and on the evidence presented in this paper this autonomy of choice, and the associated authority to determine future action, may be experienced as a burden rather than a means of empowerment.

These findings also have resonance for debates around the notion of consumerist medicine, generally taken to mean a scenario in which medical care or treatment is seen as a commodity to be freely chosen by individuals. It could be argued that the majority of the consultations here would fall into this categorisation, by virtue of the fact that decisions are devolved by doctors for patient choice. As Fotaki (2014) has argued in this journal, consumerist models of medicine are based on the economic premise of rational individuals who, given the necessary information, will make a rational decision to maximise their welfare. However, as she goes on to note, and as we have described here, an inherent imbalance of knowledge between professionals and clients means that trust in a doctor's judgement may not easily or straightforwardly be replaced by choice.

Such conclusions leave a larger question unanswered: what are the resulting implications for practice, and for the debate over what constitutes successful application of SDM? Again, we emphasise the importance of context. As Seale *et al.* (2006) have asserted, it is erroneous to assume that the only rival to SDM is outmoded paternalism; instead there needs to be a recognition that no one model of practice can fit all settings. This is echoed in the work of Frank *et al.* (2010), who suggest we will make little progress in researching how treatment decisions might best be shared between practitioners and patients until we recognise that this is a distributed process which can be affected by multiple other mediators beyond client participation, including policies, protocols and the use of technologies. We argue, then, that rather than assuming that shared decision-making can be assessed as something that does or does not take place, it might be better conceptualised as a continuum, with an acceptance that different healthcare contexts may require practitioners to adopt a different position on this continuum. To inform this debate, further investigation into the way in which SDM intersects with wider contextual parameters – including non-directiveness – is needed.

Address for correspondence: Alison Pilnick, Room B33 School of Sociology and Social Policy University of Nottingham University Park Nottingham, NG7 2RD. E-mail: alison.pilnick@nottingham.ac.uk

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Notes

1 The combined test uses a combination of ultrasound scan and maternal blood test, and is carried out at the end of the first trimester of pregnancy (around 10–13 weeks). The integrated test is carried out slightly later (usually around week 16) and assesses screening markers from both the first and second trimester of pregnancy. It is more effective in avoiding 'false negative' results (where cases of Down's syndrome are not identified) as well as 'false positive' results.

2 Edwards' syndrome, otherwise known as Trisomy 18, is a serious genetic condition caused by an additional copy of chromosome 18. Most babies with this form will die before infancy. The vast majority of cases are initially picked up through ultrasound examination, though serum screening tests can also give an indication of risk. However, amniocentesis or chorionic villus sampling is necessary to definitively confirm a diagnosis.

3 For a more detailed consideration of the ways in which risk is presented in this setting, and how professionals 'make meaning' from these numerical figures for pregnant women, see Pilnick and Zayts (2014).

4 See Zayts and Pilnick (2014) for a discussion of an example in which a woman very explicitly asks for guidance in making a decision, but where this guidance is not forthcoming.

5 In the clinic which the data presented here are taken, approximately 59 per cent of women immediately opt to undergo amniocentesis or CVS, approximately 34 per cent make an immediate decision not to pursue any invasive testing, and the remaining 7 per cent defer decision-making to a later date.

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