

'I knew before I was told': breaches, cues and clues in the diagnostic assemblage

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Abstract

Diagnosis can be both a ‘diagnostic moment’, but also a process over time. This paper uses secondary analysis of narrative interviews on ovarian cancer, antenatal screening and motor neurone disease to explore how people relate assembling procedural, spatial and interactional evidence before the formal diagnostic moment. We offer the idea of a *diagnostic assemblage* to capture the ways in which individuals connect to and re-order signs and events that come to be associated with their bodies. Building on the empirical work of Poole and Lyne (2000) in the field of breast cancer diagnosis, we identify how patients describe being alerted to their diagnosis, either through ‘clues’ they report picking up (often inadvertently) or through ‘cues’, perceived as a more intentional prompt given by a health professional, or an organisational process. For patients, these clues frequently represent a breach in the expected order of their encounter with healthcare. Even seemingly mundane episodes or behaviours take on meanings which health professionals may not themselves anticipate. Our findings speak to an emergent body of work demonstrating that experiences of formal healthcare during the lead-up to diagnosis shape patients’ expectations, degree of trust in professionals, and even health outcomes.

Keywords: diagnosis; patient experience; qualitative research; narrative; secondary analysis

Introduction

Diagnosis is recognised to be both a category (a label) and a process (an activity) (Blaxter 1978; Jutel and Nettleton 2011), which once formally applied, can trigger a set of administrative, social and clinical processes (Jutel and Nettleton 2011: 794). A less well-explored area is the *pre*-diagnostic trajectory and how this may overlap with what has been described as the '*diagnostic moment*' (Jutel and Conrad 2014:1). Although there is a sociological literature exploring patient responses to bodily sensations and signs and to experiences of proactively seeking a diagnostic label, to date research into the ways in which patients may inadvertently become aware of their condition before a formal diagnosis is limited. Having conducted narrative interviews with people diagnosed with a range of conditions, the authors of this paper were aware that patients often report 'knowing' their clinical diagnosis before they were formally told. This article therefore reports on secondary analysis of qualitative interviews on experiences of ovarian cancer, antenatal screening and motor neurone disease to explore how people describe beginning to suspect and conjecture a diagnosis. The focus of the paper is on experiences of events that occur outside the body, rather than the bodily sensations and signs that may or may not trigger a consultation.

Background

The experience of being diagnosed with a disease or chronic condition is a memorable event (Jutel and Dew 2014). The '*diagnostic moment*' can be transformative, especially where conditions are life-threatening or life-changing

(Bury 1982; Ahlén et al 2010; Pavey et al 2013). This has long been reflected in the investment in communication skills training for physicians. But the 'diagnostic moment' is only part of the story. The diagnostic *process* is embedded in an altogether more complex timeframe as individuals narratively reconstruct the wider set of life events that are interpreted as leading to the onset of the condition (Williams 1984; Williams 2000). Sociological studies have revealed the ways in which some patient groups proactively work to secure a diagnosis for sensations, signs and symptoms they may feel are dismissed or misunderstood by health professions, including depression (Kokanovic et al 2013), lupus (Price and Walker 2013), autism (McLaughlin and Goodley 2008, Ryan 2013), myalgic encephalomyelitis (Cooper 1997) and Morgellons (Fair 2010). These studies confirm that diagnostic work is both a professional and a lay activity that can involve much investigative effort to pull together experiential, embodied, clinical, codified and cultural knowledge. These diagnostic practices proliferate in the context of e-scaped medicine (Nettleton 2004; Ziebland 2004; Ziebland and Wyke 2012; Lupton 2013).

Thus we know much about how patients work to seek out a diagnosis, and about how patients make sense of and respond to receiving a diagnosis. We know less about the more commonplace and inadvertent social processes that take place *before* formal diagnosis, and in particular those events that lead patients to claim 'I knew before I was told'. Poole and Lyne's (2000) article on women's accounts of experiences of formal healthcare following identification of a 'breast abnormality' stands out as an exception. The authors document how 'seemingly "inert" aspects of the environment can become powerful predictors (or cues) in a

threatening situation' (756). They identify four types of 'threat-related cues' that led women to anticipate formal diagnosis. 'Temporal cues' such as very prompt appointments; 'interpersonal cues', such as practitioners' gestures or expressions of emotion; 'procedural cues' such as unanticipated repetition of diagnostic tests; and 'spatial cues' such as rearranging of chairs at the start of a consultation. Thus relatively customary healthcare practices were interpreted by the women as significant and consequential. Poole and Lyne's study was based on women who had been recalled as a result of an 'abnormal' test result and therefore had reason to be especially alert to such cues. Our analysis draws upon a wider set of circumstances, including people who had no indication that a diagnosis could be imminent

Our exploration of the circumstances that prefigure diagnosis reveals the importance of the mundane. Sociologists have written about the salience of the prosaic in the performance of healthcare. If everyday routines of care are breached patients can read these as moments of significance (Stokes et al 2006). Any slight deviation from what Strong (1979), after Goffman, famously describes as the 'ceremonial order of the clinic' can be of consequence. We examine patients' accounts of the routes to their diagnosis and instances experienced as salient moments of realisation during the 'accomplishment' (Garfinkel 1967) of routine healthcare. Cussins (1998) suggests that the patient is in a 'constant dance' within sometimes multiple healthcare environments, continually evaluating what is said, done and otherwise indicated. Our data cast light on the 'dance' through care; we focus on how breaches and other cues and clues led to participants anticipating their diagnosis. Our analysis is also informed by 'the

new materialism' an approach which has revised our notion of agency (Fox 2011; 2016) Two strands of this turn to new materialism are instructive here. First, agency can be prompted by what are referred to as actants – that is non-human objects as well as humans, and agency can be unintentional as well as intentional. Second is the idea of assemblage. Fox (2011 359) writes about an 'ill health assemblage' – the networks of psychological, biological, cultural, social relations that surround bodies during ill health. These networks both affect and are affected by those who are ill – these relations shift and are fluid as one aspect changes. Inanimate objects such as chairs laid out in a particular way invoke an affect in relation to the context of other affects – experiences, suspicions, letters, anxieties and so on.

Fox explains that 'All relations that a body has may contribute to the assemblage regardless of whether physical, social or abstract in character' (Fox, 2011) By concentrating on interview participants' accounts of the pre-diagnostic events that occurred *outside but nevertheless in relation to the body* (and so in conjunction with any sensations and signs that may have prompted them to consult) we propose a 'diagnostic assemblage' in which breaching features as a key component.

Methods: analysis process

The paper was sparked by a methods workshop on the sociology of diagnosis at the University of Oxford, led by one of the authors (SN) and attended by the others. Participants brought examples from their own qualitative interview data,

coded and extracted from fuller narrative interviews on people's illness experiences (Ziebland and Hunt 2014). As discussion progressed, we were struck how often the idea of *anticipated* diagnosis occurred. Patients with many different health conditions described realising, discovering or working out from signs external to their own bodies what was going on before the formal diagnostic moment. In follow-up exchanges we explored further what clues and signals people were picking up from various sources, and how far these were stumbled across, actively sought or deliberately conveyed by professionals or the organisation.

Using Heaton's five categories of secondary analysis, we suggest this paper falls into the category 'supra-analysis', which 'transcends the focus of the primary study from which the data were derived, examining new empirical, theoretical or methodological questions' (Heaton 2004). We initially selected three exemplar conditions to work with, from the archive of narrative interviews on health and illness held by the Health Experiences Research Group at the University of Oxford (Ziebland and Hunt 2014), sampling across different types of experience. The interviews were all collected by qualitative social scientists working in the same research group and using the same interview method. These interviews combine an initial open narrative ('Could you tell me about everything that has happened since you first suspected a problem?') followed by a semi-structured section where issues raised in the narrative are explored further as well as anticipated themes such as communication with health professionals, reactions to the diagnosis, decisions about treatments etc. The studies have approval from Eastern MREC (03/5/016) and Berkshire Research Ethics Committee

(09/H0505/66). Participants are invited to copyright their interviews to the University of Oxford for use in secondary analysis, among other specific purposes. Interviews lasted for between 45 minutes and three hours. The conditions we analysed were: 36 interviews with people diagnosed with motor neurone disease (MND), a rapidly progressing, life-limiting condition; 45 parents talking about antenatal fetal screening, where diagnosis may not be anticipated at all; and 45 interviews with women with ovarian cancer (which is associated with non-specific symptoms and thus often subject to missed or late diagnosis). The original data collection and analysis had been led by LL (MND and antenatal screening), SZ and colleague JE (ovarian cancer).

Early conversations led us to define 'clues' as something which the patient interpreted as indicating that there was likely to be a diagnosis of significance, and 'cues' as something perceived by the patient as a more intentional prompt given by a health professional, or an organisational process. Some instances could be both – being invited to bring a partner could be a cue (a framing by the professional) and be interpreted as a clue by the patient that a serious diagnosis was imminent. We also used 'breaching' as a 'sensitising concept' to 'suggest directions along which to look' (Blumer 1969: 148), LL, SK and SR read the relevant sections of the interview transcripts and produced an initial categorisation with illustrative data which was circulated to co-authors for reflection. This was followed by a two day workshop attended by all the authors at which the categories were further revised

Our eventual categorisation focuses on spatial, procedural and staff behavioural aspects of the diagnostic process. Categories are not mutually exclusive; moreover it can often be a combination of clues and cues that foretells diagnosis.

Findings

'I already knew ...'

Before looking at the categories in more detail, we start with a lengthier extract¹ from an ovarian cancer interview, illustrating the work patients may undertake in negotiating the diagnostic process, and how professionals may intentionally or unintentionally drop 'snippets' of information along the way. OV23 was diagnosed with ovarian cancer following abdominal swelling.

I knew, I knew as soon as I had had the ultrasound, because I was in with the radiographer and he was doing the ultrasound and I could see this huge mass on the screen. And he gave me the report to take it straight to the doctor, and it said 'papillary projections, pathology required'. And so when I took it into the doctor, realised the speed of everything.

That night at home I had kind of like one of those 'aha' moments, where I kind of woke up bolt upright in bed and said, 'Oh my God, I've got ovarian cancer.' So it happened in such kind of a lightning-bolt thing. So I ran downstairs and grabbed all of my books that might have something relating

¹ Interview extracts have been edited for readability, removing 'um's and repeated words.

to that, and read everything I could and, you know, I knew then. And after that time of course the doctors said, 'Well, we have to do the pathology reports before we know exactly', but even when I was in the hospital after I'd had the radical hysterectomy, you know, I pretty much knew that it was ovarian cancer, and then they kind of just confirmed that.

Interviewer: So how did you feel when you were first told what it was?

Not shocked because, you know, I already knew. I mean, I don't know why that I knew, that was my only shocking moment, so whatever anybody else said, I already knew it. It was okay. I deduced my own diagnosis I guess.

Interviewer: How did they tell you? Did they tell you well, or was it...?

I feel like I was told in little snippets, and maybe they do that so people can deal with it better. But the first day I went in for my ultrasound, you know, there was that feeling then, because I read the report and took it straight to the doctor, and then the doctor's demeanour made me aware that it was serious. And I went to see my husband. So, you know, I was already in the framework of thinking that. And then when I went to see the specialist, she made comments like, 'Well, I want you to meet the Macmillan Cancer Nurse' [specialist cancer care nurse], and so you're already putting more and more of these ingredients into the recipe. And things like, 'Well, it's encapsulated, so that's good.' So I took all those little bits of snippets and kind of put it

together. But it was really that 'aha' principle late at night, where I realised what I had. That was the most jolting. (OV23)

This lengthy extract captures a number of our findings, including demonstrating a rich assemblage in which no single sign or event is predictive, and the network of elements and connections are relational. Awareness of something diagnostically significant was prompted by: perceived urgency; cues from health professionals ('I was told in little snippets'); the manner of practitioners; a flash of insight (the 'aha moment'); investigatory work to piece together clues in the interactions and artefacts that are stumbled across or discerned during the diagnostic process. The 'dance' that incorporates the human and non-human objects in particular the screen, the report, the books, and the realisation (Cussins 1988) is captured here: the patient can see the mass in her abdomen on the radiographer's screen, and then from the written report, the speed of the referral and the nature of the interactions, deduces that she must have ovarian cancer. The extract also highlights how these moments can emerge within a multiplicity of sites spatially separate from, although nevertheless connected to clinic, reinforcing the spatio-temporal diversity and interconnectedness of diagnostic moments that are more complex and fluid than the notion 'diagnostic moment' would allow. For example, for OV23 even though she says that she 'knew' when she had her ultrasound the salient 'aha' diagnostic moment is described as happening several hours later, at night in bed, and then being supplemented by her night-time reading of 'all my books that might have something'.

For this participant, gathering (or being given) clues was interpreted as useful preparation for the actual diagnosis, which she suggests may be a deliberate strategy by professionals ‘so people can deal with it better’. Her observation echoes the finding of a study by Schaepe (2011) that the support and care patients experience before a cancer diagnosis framed their ability to manage illness post-diagnosis, a point we return to in our discussion.

But first we describe in more detail the clues and cues that lead some people to claim that they ‘knew’ their diagnosis before they were ‘told’. We concentrate on events and signs that are *external* to but are nevertheless associated with the body and invoke embodied affects. Participants across a range of conditions described a patchwork set of processes whereby they piece together verbal, non-verbal, spatial, procedural, and ‘special treatment’ clues while drawing on their existing knowledge and the new information that they gather to make sense of what is happening .

Spatial clues and cues

Spatial clues were particularly evident in the antenatal screening data. Women found themselves moving from one space – the ‘normal’ ultrasound clinic where people are expecting to enjoy seeing a picture of their baby – to another setting which they recalled as charged with uncertainty and foreboding. For example, AN20 described what happened at a 20-week scan during her first pregnancy, and how she was told that her ‘stomach was collapsed’ and while that didn’t

mean anything to her, her anxiety was heightened when she was moved to 'the bad news room'.

And that was very traumatic because, you know, I was sort of given no extra information at that point, so you're sitting for 20 minutes thinking, 'What does this mean?'[...]. So then I went back to be rescanned and the stomach was still collapsed. And she said I would have to go and wait, and she'd come out and talk to me. I felt where I had to wait was really quite distressing. It was like a sort of a red room. I mean, she was lovely and dealt with it brilliantly, but waiting in a little sort of red room, which you really felt was like the bad news room, was horrible.

This change of space and isolation breached the expected ceremonial order of the ultrasound scan. While professionals may feel such expectations are misplaced in the context of an anomaly scan, families routinely see scans as an occasion for joy and seeing the baby as a family (Draper 2002). AN20's intense recollection of the colour of the walls is typical of people's accounts of emotionally charged life events.

The idea of a designated 'bad news room' is familiar in cancer narratives (Hendricks-Ferguson 2007). OV10 described how all the other patients in the ward knew the significance of being called to a particular space.

I had a few tears back in the ward, because they were all waiting for me to come back, 'cos one of our patients said 'when you go in that little room, you

know, it must be bad news'. Well, I was called in so they were all very sympathetic, which upset me.

OV10's observation that 'they were all very sympathetic, which upset me' is salient and we return to this below in relation to the cue of 'special treatment'.

Sights and sounds in unanticipated spaces could invoke unease. AN02, expecting her first baby, had an inconclusive nuchal scan (checking for chromosomal abnormalities) and was sent for a repeat scan at a specialist centre. She recalled:

walking down the corridor that doors were opening and closing, and that there were situations of distress happening. I could hear one or two women crying. And yeah, I was aware it wasn't an entirely happy place.

Another quite overt illustration of place was participants being unaware that they were attending specialist clinics. One man subsequently diagnosed with MND recalled attending a clinic where he realised that he was in the company of others who were really quite ill, and this in combination with his wife's query about the doctor's speciality indicated the likely diagnosis rather than a direct disclosure.

It turned out the consultant was holding one of his regular clinics. There were some cases in wheelchairs, some were what I considered then some fairly bad cases. Went in to see the consultant with my wife. He did one or two tests on me, and while I was getting dressed again, my wife asked him

what his speciality was. And at that moment we found out that this was an MND clinic, which MND to be honest didn't mean much to me, but certainly meant something to my wife. (MND26)

Reordering non-human actants (eg furniture) could also cue a disclosure.

Echoing the experiences of the participants in Poole and Lyne's (2000) study, a woman with ovarian cancer recalled the moving of chairs within the consultation room as significant:

I was given the diagnosis by the surgeon who had removed the ovary, and obviously the tumour as well. We had to go in and see him on the Monday and he was an absolute darling. I remember as soon as he said, "Oh no, come and bring your chair closer" to my husband, I knew what it was. (OV21)

The memory of the surgeon as 'an absolute darling' again relates to the 'staff behaviour' category below.

Procedural cues and breaches

Poole and Lyne (2000) identify procedural cues as encompassing instances such as repetition of tests. We have expanded this category to include examples of perceived breaches including apparently hastened procedures, as well as cues, inviting family members to consultations, or practitioners drawing colleagues into the consultations, and administrative procedures. Although the cue might

seem explicit in retrospect, some participants had felt the care providers had probably made a mistake, as in the following narrative:

I received a letter, having been to one clinic, asking me to go back to a different clinic in a different hospital, and it was signed by the MND Coordinator. Which I think was probably a mistake, but actually gave me a bit of breathing space, because that was a real shock. And I'd resisted the temptation to look up neurological illnesses on the internet. I decided I'd be totally neurotic and think I'd got everything. So of course when this came over the weekend we both independently looked and realised that the symptoms fitted. And the next week we went with a very heavy heart to the hospital and received the diagnosis. (MND11)

Whether or not it was a mistake, this non-human object, a letter, was agentic and prompted both the woman and her husband to undertake further investigative work that then confirmed their fears before the formal diagnosis was given. The letter instigated a search for information which they'd resisted when they had previously worked to 'manage' the flow of information , (a common strategy in the face of uncertainty of symptoms) (Chapple et al 2012). In this example it is not clear whether the letter was a mistake, carelessness or a cue – it is perhaps significant that it involved a non-human object.

A woman with ovarian cancer described how she carried the images from her ultrasound scan between appointments and realised her diagnosis from reading the notes.

And I had the ultrasound and I asked the doctor if I could take the ultrasound to the gynaecology clinic because I was going there two days later. And she gave it to me. Again another example of really perfect timing, so I had no waiting around. And there was definitely something wrong with the scan and I opened the report and there I saw that the ovaries were huge. Well, I mean, they were over 13 centimetres and there was also evidence of cancer in the uterus.....So I went to the gynaecologist two days later with the report. I know he was very upset that I'd such a brutal introduction to the disease but actually it was a good one for me. (OV02)

Like OV23 above, OV02 disturbs the routinised system by accessing her ultrasound results directly and reading the report herself. And like OV23 she reports that she is pleased to have 'known' her diagnosis before being informed of it in a formal clinical setting. Cutting out the interactional performance of being given a formal diagnosis appears to have been welcomed by OV02 which raises questions as to what is perceived to be helpful and important to patients. As she points out the gynaecologist was 'upset' that she had experienced a 'brutal introduction to the disease'. We categorise this as a procedural – documentary – clue, however, we cannot be sure whether the ultrasound doctor who gave her report to (at her request) was aware that she would read, and understand, the contents. If a report indicating a diagnosis is intentionally given to the patient to convey to another clinic, this could be a 'cue' as well as a clue.

Existing knowledge of how the UK National Health Service is expected to work is apparent within many accounts, and breaches are read as clues. Perhaps

informed by media interest in waiting times, and friends' and family's experiences, people expect the system to move slowly. Thus speedy referrals or communication and urgently repeated tests were interpreted as indicators of a problem. A woman diagnosed with MND said, 'My neurologist recognised my symptoms immediately, I later discovered, and booked me into hospital for tests that same week. She wouldn't tell me why, but I knew it must be serious from her haste. I burst into tears after leaving her office.' (MND21)

Of course, 'speed' may be perceived differently by different people, but in the following example a woman received a call before she even got home from the appointment with an urgent message to ring the GP. She recalled that 'alarm bells were ringing' because the system would 'not work that quickly unless there was a problem'.

The day after, I received a phone call from the hospital, and ten days later I saw a gynaecologist, in fact I saw two gynaecologists, and they scheduled a hysterectomy for two weeks after. Again, nobody was telling me, you know, if there was anything to worry about, but common sense would tell you that, again, things don't work that quickly unless there was a problem. (OV05)

OV05 explicitly draws on her common sense stock of knowledge (Schutz 1973) of how systems work to know something was 'wrong'. As well as unusual speed, unexpected means of communication, for example phone calls were cited as anomalous when they might have expected a letter.

Another form of procedural clue derives from the number or range of people who are drawn into the diagnostic process. The simultaneous presence of several health professionals in the room was interpreted as non-standard practice in the examples below.

I was sat in bed one day and looked up and saw the doctor coming along with another doctor and the ward sister and I thought 'This is bad news.'
(OV11)

I knew when they all trooped in that there was something wrong because you don't get six people visit you the day after your operation. (OV42)

While six staff visiting postoperatively might be common in teaching hospitals the significance here is that the patient read this as cue. As well as the presence of several health professionals, people frequently understood a request to bring a family member to a consultation as a cue to impending diagnosis. This was evident in the following MND example.

I guess I knew before they told me, in so much as they came round to do their rounds in the morning - and they were lovely, don't get me wrong, they were very nice and I have no complaints about how or what they did. But knowing what they had to tell me, they said they had the results back and wondered what time my wife would be able to come down. I said, 'It's obviously bad, then, because you, you know, you feel I need someone to lean on to be able to give me that.' And I'm pretty good at spotting a fib when I

see one. 'No, no, it's okay, we just, we really don't want to have to explain everything twice.' The bullshit alarms were going off and I just, I knew.

(MND27)

Some people reported that they were less familiar with the usual order and so the presence of additional personnel and relatives had been a missed cue. OV36, for example, only realised 'later on' that there was a clue (or possibly an organisationally intended cue) it was going to be bad news.

I was very, very shocked, yes. My husband was there, and later on somebody said to me, "Oh, if there's two of them and they ask your husband to come in, it's always bad news", and in fact it was just like that. There were two of them and he'd said, "And is your husband coming in this afternoon?" And he came in, the two of them, the gynaecologist and the gastroenterologist. And my husband and I just burst into tears, both of us, when they'd gone. (OV36)

Bringing additional staff and close relatives to the scene can mark out consultations as distinct from routine interactions, and be read as indicators of extra-ordinary events wherein patients may be given special treatment – a cue to which we now turn.

Breaches and clues from staff behaviour

Recall OV10 above who said 'I was called in so they were all very sympathetic, which upset me.' Our common-sense stock of knowledge of social interactions

informs us that where people are sympathetic towards us there is a usually a reason. Indeed our data reveal that a perceived change in the practitioner's manner towards a more sensitive treatment was interpreted as a breach in the expected conduct of the clinic. In the following ovarian cancer example, OV44 is alerted by the way a clinician suddenly appeared to become 'motherly'.

I saw a female gynaecologist. She did a sort of ultrasound thing and obviously, saw something straight away. I realised it was something because her attitude towards me changed and she became quite sort of motherly, you could say, sort of rather nice. And said that she, her equipment wasn't specialised enough to be able to say for sure what my problem was, but that would I go downstairs now and see someone else who had a sort of ultrasound equipment. (OV44)

The relational change was reinforced by the procedural clue of an additional examination with more specialised equipment. But it is the initial change in the clinician's manner which was recalled as a key signal.

In a further example, a woman with MND recalled:

It was horrendous because I knew. I'd been told that I would get the results from the tests via my GP. And when the letter came and I had to go back to the hospital for the results, I knew in my heart of hearts that it was going to be motor neurone disease. And it was something I didn't want to, I didn't want to hear and I didn't want to handle. But I had to. I knew when I walked

into the room by the neurologist's face that it wasn't good news. And he was actually - or whether it was my imagination - but he actually seemed quite tearful. (MND22)

Again, the indication of emotion - real or imagined - by the doctor is not the only clue – a procedural change in the way results were communicated had already rung alarm bells, and in this case the woman's sister had already died of motor neurone disease, so personal clues were also strong. But she recalled the tearful face of the neurologist as confirmation before she was told.

In some instances patients interpreted what health professionals said to them about their signs and/or symptoms as clues to their diagnosis. This was sometimes thought to be intentional on the part of the clinical practitioners (cues) and other times presumed to be unintentional (clues). We have already seen examples where doctors do not speak in explicit terms but instead referred to a 'large mass' or a 'collapsed stomach', or proposed meeting a Macmillan nurse. These are perhaps amongst the most obvious indications to patients, and may represent attempts by professionals to help prepare patients gradually for what is (or may be) coming. Verbal clues could also be elicited through the actions of the patient, as OV04 recalls how she had said to the radiologist 'I know I'm in big trouble and I know you can't tell me anything but please don't treat me as if I'm stupid.' In the following two MND examples, patients interpret the degree of intentionality very differently. MND30 suggests it was a thoughtless and unintentional betrayal of a suspicion, and an under estimation of

his intelligence which could be seen as an exercise of symbolic power in ceremonial order.

I think the way it was handled with me was poor....The doctor saying to me, 'Oh, premature ageing of the motor neurones.' Well, what a stupid thing to say. You know, because it's pretty obvious that an intelligent person like me is going to think, 'Well, I might have motor neurone disease.' (MND30)

By contrast MND41, a family member, implies that the GP has helped to drip-feed a suggestion, and invests what is superficially a fairly innocuous response about an appointment with the GP with meaning and understands it as confirming a serious diagnosis.

By the time the consultant confirmed his diagnosis to us, myself and one or two other family members had already had an idea what the problem might have been. The biggest clue being that when the consultant from the local hospital communicated to the GP her reasons for the referral. The GP actually read us the letter and it was the phraseology and the form of words used, such as 'evidence of degeneration in neural pathways'.....And we were fairly sure that MND is where we were going. So it was a shock to have it confirmed but it wasn't at all a total bolt from the blue. We were ready. (MND41)

Non-verbal clues communicate the prospect of a diagnosis through body language, gesture, facial expression, action, and silence. This was most obvious in

the case of ultrasonographers and radiographers, who may have a clear sense of a diagnosis from what they can see. While they are not supposed to convey their findings to the patient, the (presumably unintentional) non-verbal communication was interpreted as conveying meaning.

I did know by now that there was this lump in my stomach which was not getting smaller anyway. And when I saw the radiographer afterwards I knew that he knew that it was serious, I could see in his eyes, and that's when you know, and when they can't tell you, because usually they'll say, 'Oh that's fine, all clear.' (OV33)

Although sometimes ultrasound technicians warn people they will not say much during the scan, as noted above antenatal scans are generally treated by prospective parents as a happy occasion and ultrasonographers often talk the parents through what they are seeing. Both a completely silent scan and a change from talkative to silent behaviour may be perceived as a breach in normal social interaction in healthcare. AN02 remembered a silent scan, but on reflection recalled a sudden change in behaviour.

The lady who was doing the scan, she wasn't a doctor so she said that she couldn't discuss the scan with us. And so she started the scan and she was very, very quiet. She didn't say anything at all until the end of the scan, and she said, 'I think there may be a problem'. And we of course asked her what the problem was. She said that she wasn't able to discuss that with us,

because she wasn't a doctor, but she would refer us to go and see a doctor who would discuss the results of the scan with us.

Interviewer: Just going back a little bit to this ultrasound technician and when she said she couldn't discuss the results. She did say that before the scan that she wouldn't be able to discuss the results?

She didn't actually. She said it at the point where she went very quiet, where she stopped saying things like, 'And there's the leg, and there's the arm, and there's the head, and there's your baby's tummy'. Then she went very quiet, and it was at that point she said, 'You know I can't discuss the results of the scan with you.' (AN02)

Verbal comments and non-verbal interactions, along with spatial, procedural, and behavioural breaches, are read as clues which predominantly relate to formal healthcare delivery, however our final category considers the ways in which knowledge drawn from an array of sources outwith health care settings contribute to the prefiguring of diagnosis.

Discussion

We are familiar with the idea that people routinely search for their symptoms online, and may try to work towards some provisional diagnosis before consulting a health professional. Outwith the e-scape people also make sense of symptoms, routinely diagnosing conditions such as colds and flu (Prior 2011; Jutel and Banister 2013) and familiar diseases such as chickenpox. However,

what we have focused on here is not how people make sense of, or research, signs and symptoms, but rather turned our attention to the way in which signs and events that are *external* to the body – the organisational, interactional and procedural - may alert patients to a diagnosis. Sometimes even quite prosaic events, when connected with other elements in a highly individual network of environmental, procedural and behavioural cues, prompt diagnostic awareness. Taken-for-granted assumptions as to how administrative processes work and presumptions as to how practitioners interact with patients are socially engrained and reinforced. So when breaches occur (such as displays of sympathy, silences, hastened appointments, an invitation for a partner to attend, an unexpected swelling in the professional ranks during a consultation) patients can be alerted to the fact that all is not 'normal.' A sense of foreboding may be triggered.

There is a tradition of sociological work that has demonstrated the salience of mutual, shared assumptions on which day-to-day social life depends. The ceremonial rules ordering social life (Goffman 1967; Strong 1979) invoke meanings of consequence even when breaches appear relatively minor (Garfinkel 1962; Schutz 1973). The cues and clues described above can be understood as breaches. Some breaches are quite nuanced, for example the practitioner appearing 'motherly' in a consultation, while others are more overt, such as when an appointment is booked promptly, in contrast to expectations of long waits. If expected norms, procedures and modes of communication are violated this is interpreted as flagging up trouble. However, it is not only the breaches per se that are cues and clues but crucially the meanings attributed to

them – most especially in a state of heightened awareness - and the ‘stocks of knowledge’ (Schutz 1973) used to make sense of them. These findings reveal the temporal and spatial diversity of the diagnostic moment or, more accurately diagnostic moments which we refer to as the *diagnostic assemblage*, which is threaded throughout patients’ pathways pulling in a variety of human and non human actants that serves as cues and clues. Diagnoses are prefigured not merely because patients make sense of their bodily symptoms but because of the array of activities played out in a multiplicity of settings which come to be associated with their bodies and so coalesce as a diagnosis.

Our findings speak to an emergent body of work demonstrating that experiences of formal healthcare during the lead-up to diagnosis shape patients’ expectations and health outcomes (Leydon et al 2003). Schaepe’s (2011) longitudinal ethnography of patients’ experiences before diagnosis of cancer, for instance, yields evidence that the ability to manage their condition in the long term was associated less with a single episode in the clinic where the bad news was disclosed, than with the amount of support provided and the nature of multiple interactions with care professionals leading up to diagnosis. Initial impressions, and the organisation of their care, had a long-lasting impact on, for example, levels of trust in health professionals. Schaepe’s work in concert with our findings, chime with Mildred Blaxter’s auto-ethnography of her cancer diagnosis where she concludes that one-to-one communication is less salient than wider organisational processes (Blaxter 2009):

‘Medical sociology has, in studying the practice of doctors, long emphasised the nature of doctor-patient relationships, and communication with the patient and between different professionals. In the case considered [her own clinical case], most of those concerned were trying, often under difficult conditions of clinical uncertainty, to pay due attention to patient communication. It could be argued, however, that in modern medicine it is much more important for sociology to study what Cussins (1998) called the ‘ontological choreography’ of these ever more complex systems’ (P.776).

Conclusion

Drawing on accounts from patients diagnosed with a range of conditions, this article provides insight into the ways in which patients prefigured their diagnosis before they were formally told. This anticipation of their diagnosis was not limited to their experience of symptoms, nor was it due only to the accessing and amassing of information. To be sure symptoms and searching for information could play a part, but in turning the lens to their routes through healthcare settings, we have identified cues and clues that led them to anticipate their diagnosis – to the point that many felt they ‘knew before they were told’. These prompts are predominantly prosaic and bound up with the norms and expectations of the ceremonial order of healthcare.

The data are retrospective accounts from interviews and as such are reconstructions of events. It is likely that some of the cues and clues that are

reported might have been barely noticed, or seemed innocent, at the time and were only visible with hindsight. We recognise that events are inevitably re-cast in the telling, and that narratives meld improvised and remembered events, in accounts which Bury has termed ‘factions’ (Bury 2001). However, in this analysis we have shown how these accounts of breaches (regardless of how authentic they may be as reconstructions of events) illuminate what is perceived as normal and how patients assemble (or might assemble) clues and cues to prefigure a diagnosis. The findings are important for communication skills training and also for health professionals and organisations seeking to improve sensitive and person centred care. Our data suggest that there are numerous opportunities to control the flow of managed cues and avoid inadvertently dropped clues. Given our findings that diagnosis is an assemblage involving the orchestration of interconnected cues and clues in particular contexts, we suggest that healthcare workers would benefit from greater sensitivity to this process. Training in communication skills might include attention to the agency of things and organisational practices in which consultations are embedded, not just verbal communication, for example avoiding inadvertent clues such as sending a letter signed by ‘the MND Coordinator’ before a diagnosis has been given.

Our findings both confirm and extend Poole and Lyne’s work (which was with women who were having *further* investigations in oncology) by also examining the accounts of people who were later diagnosed with a wider range of health conditions. Our analysis includes those who were unlikely to have been on the alert because they had no particular reason to suspect a diagnosis. Our sociological approach also complements Poole and Lyne’s psychological

orientation through our emphasis on the composite network of connected relations between bodies and a myriad of actants in multiple sites. These in combination comprise the *diagnostic assemblage* which will be unique for every individual case, and yet they are also concurrently shaped by common stocks of knowledge and shared expectations associated with formal health care in given settings. When these are breached their embodied affect heightens an awareness that a formal diagnostic moment could be imminent.

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