



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



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## ARTICLE INFO

### Article history:

Received 8 October 2015  
Received in revised form  
22 February 2016  
Accepted 22 February 2016  
Available online 26 February 2016

### Keywords:

Diagnosis  
Patient experience  
Qualitative research  
Narrative  
Secondary analysis

## 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.

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## 1. 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, 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.

## 2. 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; Ahlžén 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

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interpreted as leading to the onset of the condition (Williams, 1984, 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 (Dumit, 2006), 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.

### 3. 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 min 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

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