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Becoming a diagnostic agent: A collated ethnography of digital-sensory work in caregiving intra-actions

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ABSTRACT

Sociological contributions on digital health have acknowledged the enduring significance of sensory work in diagnosis and practices of care. Previous explorations of these digital and sensory entanglements have focused separately on healthcare providers or patients/caregivers, rarely bringing these worlds together. Our analysis, based on the collation of ethnographic fieldwork in clinics, medical schools, and homes in Australia, offers rare insights into caregiver and practitioner perspectives. We interrogate the work involved in digital-sensory becoming, as caregivers (in our case parents) learn to assign diagnostic meaning to potential childhood disease. Working with Karen Barad's concept of 'intra-action', we demonstrate how diagnostic knowing is enacted between practitioners, parents, senses, and devices. We identify seven aspects of digital-sensory learning: attention to the change from normal; testing/searching for signs and symptoms; confirmation and direction from more experienced others; mimicry; analogy/metaphor; digital archiving; and reference to validated digitised signs. We found that this learning does not take place discretely in the clinic or at home. Doctors and parents both do digital-sensory work to register, co-witness, and mutually enact disease by interpreting signs and symptoms together in their caregiving intra-actions. Our article also champions collated ethnography as a methodological approach for making sense of complex assemblages in healthcare.

1. Introduction

This article considers an enduring question in medical sociology, regarding how patients and their caregivers correspond with and relate to healthcare practitioners when it comes to making sense of symptoms and signs of possible disease. As sociologies of diagnosis point out, diagnosis is a process (Blaxter, 1978), the result of multiple investigations and the negotiations of multiple actors (Jutel and Nettleton, 2011). For doctors, diagnostic decision making is both embodied and technological (Gardner and Williams, 2015; Schubert, 2011). The patient, too, is part of this diagnostic ensemble, judging when to seek care, animating clinical signs in consultations (Heath, 2006), and collecting diagnostic data (Oudshoorn, 2008). The possibilities for 'lay' expertise and diagnostic work among patients and caregivers have been greatly expanded by digital media (Schaffer et al., 2008; Whelan, 2007). This extension of diagnostic work beyond the clinic raises questions about information quality and the doctor-patient relationship, particularly among medical scholars (Buijink et al., 2013; Eysenbach et al., 2002). Recent sociological contributions have suggested that, rather than

viewing medicine as 'e-scaped' (Nettleton, 2004), it can be 'recaptured' by practitioners as they integrate digital media into their practices and the doctor-patient interaction (Stevenson et al., 2019).

One way in which we contribute to these conversations is by bringing together two actor groups mostly addressed separately: caregivers and doctors. Our focus is how caregivers (in our case, parents) learn to sensorially register health and disease in their young children ahead of care seeking, in relation to their own embodied judgments, digital media, and in relation to their doctor. Many studies of digital-sensory work take the case of health and medical self-tracking. Previous contributions have highlighted how digital data can iteratively configure and extend on users' sensory perceptions, as in the case of cyclists who described knowing their ride through 'the numbers' (Pink et al., 2017), and women who distinguished between 'real' and 'false' bodily sensations through their data (Lupton and Maslen, 2018). Users can become reliant on devices for spatial and bodily sensing, to the extent of experiencing anxiety without them (Mopas and Huybregts, 2020). Rather than the data presenting ready, disembodied answers, others have suggested users learn with the technology, with their understanding

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filtered through their embodied knowledge (Fors and Pink, 2017). While these contributions speak to particular forms of digital-sensing, the specifics of knowing practices, especially in regards to how sensory knowing is learned and cultivated technologically, has not been the focus of these studies to date.

We thus extend these insights into a more expanded, ethnographically informed consideration of how the digital and sensory work together in healthcare. To further this analysis we could draw from a number of theorists across multiple disciplines addressing technological-embodied relations. For decades, scholars have grappled with how tools and instruments become extensions of bodies (Merleau-Ponty, 1962), how they might become part of the materiality of perceiving (Latour, 2004), or what bodies can be (Ihde, 2002), and the ways in which disease becomes enacted (Mol, 2002), or become part of cyborgic formations (Haraway, 1991). In the expanding domain of sensory studies, the field of haptic studies is opening up new domains for technologies of touch (Jewitt et al., 2017; Parisi, 2008), while scholars such as Jennifer Gabrys (2019) highlight the importance of thinking about non-human sensing, in her research group's ground breaking work on sensors.

With so many theoretical threads to pull on, thinking through our material is enhanced most by reading it with the work of feminist science studies scholars, and in particular the work of Karen Barad. The central idea behind Barad's work is that the ability to act is always already co-constitutive through 'entangled intra-relating' (Barad, 2007, ix). In contrast to the notion of 'interaction' which assumes pre-existing and independent entities, she adopts the term 'intra-action' to focus on relationality and the ontological inseparability of phenomena:

The 'knower' cannot be assumed to be a self-contained rational human subject, nor even its prosthetically enhanced variant ... Rather, subjects are differentially constituted through specific intra-actions. The subjects so constituted may range across some of the presumed boundaries (such as those between human and nonhuman and self and other) that get taken for granted. Knowing is a distributed practice that includes the larger material arrangement. To the extent that humans participate in scientific or other practices of knowing, they do so as part of the larger material configuration of the world and its ongoing open-ended articulation (Barad, 2007, 379).

This framing of technological relations gives us a means to conceptualise a decentering of the human in healthcare, highlighting the relationality of agency (see also Haraway, 2003). In contrast to Cartesian philosophy which presupposes an agential cut between subject and object, for Barad, it is material-discursive practices that enact such a cut. Such agential cuts do not disentangle phenomena; they are 'boundary-drawing practices' for a given apparatus (Barad, 2007, 140).

Thinking with this lens helps to highlight how bodies, devices, recordings, and images differentially merge to enact medicalised apparatuses of knowing bodies in caregiving. As sensory modalities are enacted differently according to their material-discursive arrangements, we look to detailed vignettes to demonstrate how sensing is configured and reconfigured in the clinic and in the home. We ask: How do caregivers become sensitive to others' bodies and cultivate their sensing practices? How does this diagnostic work move between the home and the clinic and get reshaped in these spaces (and the travel between)? How are the sensitivities of doctors enacted in intra-actions with caregivers?

Our chosen theoretical framework has political significance for how we think of agency and responsibility. It means that diagnosis is distributed among sensing entities, whether clinician, parent, child, smartphone or other elements of the apparatus, to use Barad's terminology. Diagnosis then does not precede the clinical situation, in the form of say textbook knowledge, but rather is enacted between those involved. Finally, it means that there are dissolved boundaries between what work happens in the clinic and what happens at home, as well as more fluid ways of thinking of whose bodies/machines know what and how these bodies/machines inter-relate.

In developing our analysis, we bring together the literature and thinking regarding digital technologies and sensing in clinical decision-making and medical education, with the corresponding literature on sensing and digital-sensing among caregivers. We collate fieldwork and interview material from two separate qualitative studies of sensory knowing in medicine that both address the role of digital media in clinical encounters between parents and doctors, a methodology we explore in more detail below. We argue that parents' sensory understandings of disease symptoms and signs emerge in intra-action with digital media and within the caregiver-doctor relationship in what we have identified as a particular form of *digital-sensory work* in contemporary healthcare.

1.1. Sensing health and disease

There has been a growing interest in the social sciences on the sensory training of medical professionals, with studies particularly addressing how doctors and nurses learn to listen (Maslen, 2015; Harris and van Drie, 2015; Bijsterveld, 2019; Hammer, 2017; Krebs and Van Drie, 2014), touch (Kelly et al., 2019; Kuriyama, 1999; Prentice, 2013; Harris, 2016), and see (Atkinson, 1995; Saunders, 2008) in conversation with a vast body of literature on medical training in sociology and anthropology (e.g. Holmes et al., 2011; van der Geest and Finkler, 2004), and histories of medicine that deal with sensing (see Howes and Classen, 2013). To offer some relevant insights from this body of work, Rachel Prentice showed that in surgical training, after first demonstrating a given procedure, surgeons use embodied cues to guide residents' practice, such as placing their skilled hand on top so as to move the learner's hand in the right direction. In effect, the surgeon 'wields' the student's body until they are 'handy' enough to wield the drill on their own (Prentice 2013).

Many other ethnographies of medicine and surgery also point to entanglements of bodies and technologies in practice (Hirschauer, 1991; Mol, 2002; Moreira, 2004; Maslen, 2017; Harris, 2011). In the operating theatre, anaesthetists pay dual attention to monitoring systems and their embodied judgments of the patient's body (Schubert, 2011). Such tools can 'withdraw in use by becoming part of embodied perceptual habits' (Schubert, 2011). Some have found that staff can become desensitised to alarms, hearing them as untrustworthy (Schlesinger and Shirley, 2019), while our own ethnographic work shows that nurses develop skills for listening to the machines, and shaping the settings in a way that corresponds with their expertise (Bijsterveld, 2019).

Contributions that have addressed how caregivers relate to children focus on pregnancy and mothers' early parenting. In pregnancy, mothers feel the development of the foetus, with the embodiment of each intertwined (I. M. Young, 1990). Practitioners' judgments can subjugate women's bodily experiences in pregnancy (Duden, 1993), discouraging women to know about their pregnancy through sensory means (Casper, 1998). This intercorporeality extends into early parenthood, as mothers develop a 'new sensitivity' in response to the sounds of a baby's voice, the feel of the baby's body, and the tactile experience of breastfeeding (Wynn, 1997, 260). Caregivers' sensory awareness is cultivated through attention to nuances in cries and movements.

To assess health and disease, mothers 'read' their babies through close, day-to-day observations—including listening, feeling, and smelling—with illness registered based on changes to a child's behaviour (Lauritzen, 1997, 451, 454). While studies of caregivers of children with medical conditions are numerous, mostly the sensory work of evaluating symptoms is out of focus in comparison to issues such as parents' demonstration of responsibility (Gunnarsson and Hydén, 2009), and the strain of 'keeping watch' (B. Young et al., 2002).

Early contributions on the digital-sensory work of caregivers contest some claims of mothers' disembodiment in response to medical dominance. In pregnancy, mothers' dual attention to foetal movement and ultrasound images can be synergistic (Ross, 2019; Schmied and Lupton, 2001). In relation to tracking, one mother described using an app to

understand her child's sleep needs, following an observation of crankiness (Lupton and Maslen, 2018). In a study of parents of older children, caregivers mostly rejected tracking technologies, experiencing digital sensors as misleading and an interruption to the desired parent-child relationship (Maslen, 2021).

Doctors' judgments are the result of communicative body work between practitioner and patient, in which the clinician- and patient-body 'mutually configure one another' (Gardner and Williams, 2015). In clinical exams, doctors' hearing of breath sounds relies on patients undertaking specific actions to animate signs based on clinicians' gestures and verbal instructions—for example, 'can you breathe in and out deeply?' (Heath, 2006; Måseide, 2011). Telemedical assemblages demand invisible work on the part of practitioners to support the doctor-patient interaction, a sense of 'intimacy at a distance', and to turn patients into effective users (Oudshoorn, 2008). Vitrally, such systems delegate some interpretative work to patients, requiring them to act as a 'diagnostic agent' (Oudshoorn, 2008). This interpretative work is sensory, as patients 'inspect' their own bodies.

Digital-sensory entanglements have rarely been examined between doctors and caregivers outside of telemedical ensembles. Our interest is in the ordinary work of making sense of health and disease in a contemporary digital context. We investigate how caregivers become diagnostic agents (Oudshoorn, 2008), even sensory agents (Lupton and Maslen, 2017), between the home and the clinic in the following.

2. Methods

We collate fieldwork and interview material from two qualitative studies of sensory knowing in medicine that both addressed the role of digital media in clinical encounters between parents and doctors. Collated fieldwork is a common practice in research teams, but is less discussed in the social studies of medicine between different research studies. We outline our various studies here, and return to the practice of collated ethnography in the conclusion.

2.1. Study 1

Study 1 employed digital ethnography methods to examine how parents consume and co-produce parenting and child health information. In 2018, Sarah conducted interviews with parents to examine how they worked through challenges on topics including children's health. In cases where parents used a form of digital media as part of their sensemaking process, parents were invited to demonstrate their digital media use, with demonstrations or re-enactments video recorded for analysis. This method offers 'ways to release muscle memories of habitual activities never usually spoken about' (Pink et al., 2016). Participants were also asked to show the data that they generate and how they engage with these data. Sarah was sensitive to sensory knowledge practices, taking fieldnotes on gestures that reflected bodily knowledge, and mimicry of aural knowledge. Where sensory knowledge practices were expressed by participants, Sarah asked questions on these judgments and how they related to a caregiver's digital knowledge practices. Interviews and demonstrations were mostly conducted in participants' homes. Interviews lasted on average one hour. Audio tapes of interviews were transcribed by a professional transcription company. All names in the paper are pseudonyms.

The study involved both mothers and fathers of children aged between two and eight, and was also open to both users and non-users of various digital media in parenting. It was conducted at two Australian field sites: Canberra and Tamworth. These locations were chosen because they represent publics who reside in a city with high average socioeconomic status and education levels (Canberra) and the often-neglected environment of the country town with lower average socioeconomic status and education levels (Tamworth). At both locations, the study was advertised through early learning centres for children birth to six years, community services, playgroups, and selected workplaces. In

Canberra, the study was advertised on the Canberra Mums Facebook page. Participants were also recruited through the snowballing method. The 37 participants were almost evenly recruited at each field site. Two-thirds of the participants were mothers. Thirty-four identified their ancestry as Anglo-Celtic, two as Asian, and one as African. Twenty-seven participants reported university-level education, while ten had high school or technical qualifications.

2.2. Study 2

Study 2 employed ethnographic methods to examine how clinicians, educators, and students communicate about and share sonic information in clinical education and practice. The study was conducted at multiple field sites in Australia and the Netherlands, however this paper refers only to the research conducted in Melbourne, Australia. In 2013, Anna conducted participant observation fieldwork at a university, a hospital, and several general practitioner (family doctor) clinics. The study involved hundreds of hours of observation, focusing on students and teachers who were learning or teaching the skills of auscultation in particular. Anna also conducted 15 semi-structured interviews with 8 students and 8 teachers who had been part of the ethnographic study. When possible, the interviews were conducted in classrooms so the materials used in teaching and practice could be brought easily into the conversation, including smartphones and other technologies. A sensory interviewing technique was utilised which involved the use of prompts to understand more about listening practices (Harris, 2015). Anna was also sensitive to forms of mimicry that her participants used in recreating bodily sounds. Interviews were audio-recorded and lasted on average one hour. Anna also made handwritten notes for each interview, including gesture illustrations. The interviews were transcribed and anonymised by a student assistant. All names in the paper are also pseudonyms.

2.3. Data analysis

Our analysis involved a combination of thematic analysis and the generation of vignettes for a selection of participants to be shared with the other author. Vignettes, as we used them in our analysis, are short narratives that pull the threads of an individual's account together to contextually locate people's accounts of their experiences. In selecting the vignettes, we reviewed our data sets, looking for cases that richly demonstrated digital-sensory practices between the home and the clinic.

We detail some of the themes across the two studies as context. Study 1 identified universal device ownership and internet connectivity among parents. Most routinely used search engines to find information on parenting and children's health. They also valued their embodied judgments and the experiential know-how of family and peers (Maslen, 2021). On children's health, parents tended to defer to the expertise of their doctors. The vignettes selected are thus in step with many of the dominant themes of the research, rather than outliers.

Study 2 found that doctors engaged with students and their patients using materials in creative ways to create 'sensory alignment', meaning a shared vocabulary and understanding of what sensory signs might mean. The vignette described in this study is representative of the kinds of improvisatory and creative methods the teachers use. However, it captures how doctors incorporated digital and other technologies into their sensory alignment work with parents, rather than students.

3. Vignettes

Here, we present the stories of four of our participants/interlocutors, chosen for the different aspects of digital-sensory work that they help to portray. The first three vignettes are taken from Study 1 and give account of a scenario faced by parents and their digital-sensory work in arriving at a decision over whether to seek medical care for their child. The final vignette, taken from Study 2, shows how a family doctor works

with parents to refine their digital-sensory diagnostic work.

3.1. Melissa

During a family holiday, Melissa (43, Anglo-Celtic, vocational training, rural) was sleeping in closer proximity to her son than normal and she observed his breath in sleep in a way that she would not normally. It was three o'clock in the morning. She had reached the point of panic due to what she was hearing: periods of absent or reduced breath sounds followed by rapid breathing. She registered the potential diagnostic significance of these sounds based on the change from her embodied, experiential sense of 'normal' breathing for her son. In working through this moment in the interview, she adopted a mimicry strategy, articulating the sounds as 'chchchchchchch' and then 'ahahahahahaha'.

In her re-enactment, the 'ch' sound is an archetypal choking sound. Reflecting on her embodied sense of the three sounds (ch, silence, aha) she began to form a sense that this might mean that her son was having periods of 'not breathing'. There was doubt in her mind over the severity: 'He obviously gets through the night in his bedroom ... but lying next to him it's a really hard thing to hear'. Every five minutes, she was hitting her sleeping son in the hope of 'restarting' his breathing. Mimicry makes it possible for her to express a version of her heard sound that she does not have the language to describe in words. It is also a way for her to interrogate the sound, acting as an intercorporeal bridge between her own crudely defined senses, and between her body and her child's. As Merleau-Ponty argued, our senses encroach on one another, 'strange movements of the throat and mouth ... end in sounds and I hear them' (Merleau-Ponty, 1968, 144).

In a state of panic, and anticipating what might best feed into diagnosis in the clinic, Melissa got out her smartphone, first using its recording app to try and capture a form of her embodied sense of her son's breathing. She still had these recordings on her phone and played them in the interview. When played back, the breath sounds are visually and aurally represented by the app: flat line for no breath sounds, quick flicks when the 'ch' sound occurs, a wide sound wave as her son resumes breathing. When replaying this recording, Melissa held tension in her hand for the duration of absent breath sounds (Fig. 1). A second after her son resumed breathing, she relaxed her hand albeit into a loose fist (Fig. 2). The recording is not a digitised object separate from Melissa's body, or from her son's, as we see in her embodied-affective response to the recording. Her senses are not separate, either. She rehearses the breath sounds as visualised by the app as much as through the recorded sounds. Each is configured and reconfigured in intra-action, and in anticipation of intra-actions in the clinic, generating diagnostic agency.

After making the recording, she used her device to search for the symptoms that she was observing in the hope of possible interventions

Fig. 1. Melissa holds tension in her hand as she hears and sees no breath sounds on the recording.

Fig. 2. Melissa relaxes her hand as she hears and sees 'normal' breath sounds on the recording.

that she could implement immediately. Melissa re-enacted this process of searching in the interview. She entered the search term 'apnoea in kids' and selected the result from the Royal Children's Hospital, which she trusted. She skipped through the entry looking for information such as a sleeping position that might aid breathing. As she skimmed through a list of signs and symptoms of apnoea on the website (Fig. 3), she said:

He's a very loud snorer and everything that [the website] says, he's a really sweaty sleeper, he's always breathed with his mouth not his nose, even from the day he was born. He doesn't have headaches and he doesn't wake up tired but he tires really easily.

Her re-enacted reasoning around her son's condition reflected what she was seeing on her device, and the clinical observation of her family doctor that occurred later:

It said to put them on their side but he's got quite enlarged tonsils, so that's the obstruction but as you lie down your throat relaxes and collapses down on itself. So if you're sleeping on your back, which he does, and if you've already got enlarged tonsils then that just creates that airway obstruction.

Returning to the list, she noted all the symptoms that applied to her situation. The symptoms included some sensory cues. She noted the 'loud' snoring, but did not engage with other aural indicators such as chokes, gasps, or snorts in her account. Visual and tactile cues, such as sweatiness in sleep and breath through the mouth not the nose, were

Fig. 3. Melissa tests and extends her diagnostic assessment against the signs and symptoms of childhood obstructive sleep apnoea in kids as listed on the Royal Children's Hospital website.

given on the website and formed part of her reflection on her observations and the extent to which they may indicate a diagnosis of obstructive sleep apnoea. Where a symptom did not apply, she reasoned through this, noting other observed behaviour that she saw as potentially related. Thinking with what she was reading, she moved between the signs-as-written, and her embodied sense of her child in the moment and over a longer temporal scale.

Later, she took her son to their family doctor. She played her recording of her son's sleep sounds to the doctor, to aid the diagnostic process. When heard, her doctor said that the sounds were 'obviously' indicative of obstructive sleep apnoea. She reflected that the ability to easily record what she had heard on her smartphone made the diagnostic process simpler because 'he's [doctor] not ever going to hear him unless he comes here for the night and he's not going to do that'. She also kept the recording following the visit, and in replaying the sound, as she did in the interview, she worked on her sense of the sounds and their diagnostic meaning as confirmed by the doctor.

3.2. Jessica

The medical system relies on lay people having a minimum amount of knowledge in order to access care. Mother Jessica (36, Anglo-Celtic, university education, urban) shared her experience in learning to judge respiratory distress through successive presentations to the emergency department and family doctor with her five-year-old daughter. Her daughter had had multiple respiratory issues including asthma, bronchitis, and pneumonia significant enough to warrant hospital presentation. Jessica recalled the sensemaking process leading up to presenting at the Emergency Department (ED) the first time. The parents 'became aware' that their daughter's breathing was laboured. In the interview, she suggested that this awareness emerged from an embodied registration of a change in her daughter's respiration. She demonstrated by placing her hands on either side of her rib cage as a proxy for her child's chest, demonstrating strained breathing by visibly moving her chest and diaphragm as she rapidly breathed in and out in an exaggerated way. She said: 'The feel of her—I remember when I went to pick her up, you know when you hold your baby, you can tell when they're really struggling'.

Jessica said it was her husband who first noticed this. Following this observation, still unsure of the right course of action, they measured their daughter's breathing in a timer app on one of their smartphones. Using the timer was an effort to quantify their observations of respiration, which they imagined would get them closer to an accurate assessment. She explained: 'the quickness of the breaths in comparison to normal—we did actually measure that with the amount of the breaths'. Jessica did not suggest that she knew, in a quantifiable way, what would be a 'normal' rate of breath, but coming together with her device in this way was enough to reinforce her sense that there might be a problem. She said they did not spend much time, if any, attempting to search for symptoms and their meaning online.

In the ED, Jessica received feedback from the doctors about her daughter's condition and its presentation. This feedback led her to refine her diagnostic sense of her daughter's health. While she confessed she was unsure about whether her daughter's condition was serious enough to go to the ED, she said:

I took her to the Emergency Department and I felt silly because she looked happy. I could see she was breathing fast but she looked not that bad. And then we got in there and they did an X-Ray and they're like 'she's got pneumonia'.

The doctor's clinical assessment and the imaging results forced Jessica to re-evaluate the meaning that she had assigned to the rapid respiration that she had seen, felt, heard, and timed before attending the ED. The ED doctors also facilitated a new language to describe her sensory assessments, with tips about what to look for. When explaining

her sensory assessments to Sarah, she gestured to her trachea: 'You can see that the—we have since learnt that it's called the tracheal taut or something, when you see they're really struggling to breathe.' She refined her knowing of respiratory distress as it manifests in another body through touching her own, in the shadow of her memory of her child's body, as well as the doctors' feedback based on the X-Ray result and their seeing/feeling/hearing of the child's body in the clinical exam. Across three bouts of illness and hospital presentations, she said: 'It was more the physical symptoms ... I think at that point you've got to just go to hospital, it's not about Dr Google or anything like that'. She saw her role in the diagnosis as embodied registering of troubling signs, ahead of seeing a doctor. Following the clinical encounter, she searched for asthma online and other respiratory conditions as part of a process of 'rethinking' what this means.

3.3. Steve

Online resources have greatly expanded lay access to diagnostic information. However, searching for signs and symptoms can be difficult, because it requires the searcher to find the right search terms. Father Steve (40, Anglo-Celtic, university education, urban) described facing challenges with respiratory illnesses with his two-year-old daughter and his efforts at searching to understand the potential severity of his observations. He explained that his daughter had been 'showing symptoms that seemed to be abnormal for her'; he saw and felt that she had become 'floppy'.

As Steve described her floppiness, which informed the initial selection of the search term, he moved his own head down analogically, gesturing nodding off. In another attempt to articulate his observations, he described his daughter as 'slack', and as he used this term, he flopped his wrist about. Sarah drew his attention to these gestures. 'I'm trying to supplement inadequate vocabulary on the subject with some physical actions ... I'm not a doctor, so I might not use terminology that's appropriate for it,' he said. These haptic ways of knowing were beyond his language. This presents obvious problems for coming together with digital media to evaluate their seriousness.

In his interview, he only vaguely recalled his diagnostic sensemaking, but a re-enactment of the online search triggered his memory of both his use of the technology and the sensory judgments that were entangled with them.

She was six months old ... maybe 'six month old floppy'. So here's something—that might not be enough, so maybe we say she's very sleepy, and I'll see what that brings back. So straight away people are already talking about some of those sorts of behaviours or symptoms in the context of meningitis, so that'd be something where you'll look up a whole bunch of sites ... because I'd want to rule out preferably anything particularly severe like that early on, or find symptoms to look for which would say there might be a problem that we need to quickly jump on.

Steve's efforts to find a search term that returns results reflects how his relation to the search engine generates agency, contributing to his thinking on what he has observed and its potential diagnostic significance. In multiple passes, he works with his device to find an explanation about the symptoms he has observed. This involves reconfiguring his observation of floppiness as drowsiness, as well as looking for other symptoms that might be present based on the search results. Triggered by what he read, he also used the seemingly 'objective' technology of a digital thermometer to check whether her temperature was elevated as sensed by the device.

3.4. Tom

Tom is a family doctor working in a large Australian city. He runs community groups for new parents, to teach them about common

childhood illnesses. He described his methods for relaying the sensory experiences and signs of disease in these groups:

When I'm teaching patients about asthma ... I'll say if you hear the whistly ... wheezy breathing then that's asthma and that's when you give the ventilator. I say if you have any doubt whether it's a wheeze or not put your ear on your child's chest—because you know, a stethoscope is just an extension of the ear to make it more ... hygienic, so—I don't say that to them, but in reality that's what we were taught, and ... as I'll say—if you hear whistling noises like wind blowing over the top of a milk bottle ... then that's probably asthma—that's probably wheeze ... And they hear wheeze. They'll say 'I gave ventolin last night because I knew he sounded wheezy'. They sleep with their kids and toddlers when they're sick and they hear these noises.

To teach parents embodied diagnostic skills, Tom uses a technique common in medical education, that of metaphor and analogy. He knows that the parents can hear these sounds and he is trying to equip them not only with a particular vocabulary they can use in their clinical encounters (wheeze), but also everyday experiences and sensations they may be able to liken them to (the milk bottle), so that they can be more attuned in their listening. The doctor also tries to help parents distinguish between aural signs:

I'll talk about croup—I'll imitate what a croupy cough sounds like—a barking cough. In fact I'm thinking of actually playing on YouTube on my mobile phone, so I don't have to do that ridiculous imitation of what a barking cough sounds like! Croupy cough is a classical cough. And nothing else sounds like it. I also talk about stridor as important ... to go to the hospital see a doctor straight away. ... I go 'awr awr' like a barking seal for them [for a croup cough] but I say it is the stridor which indicates the severity—so instead of the barking seal cough going 'awr awr' I am also going *breathes in with a closed throat* that's a noise indicating obstruction here in the larynx—so I'll actually imitate that to them. I do it for the mother-baby groups routinely and I get my patients to try and do it.

In this vignette knowing is distributed through voice, recorder and the people involved, each with their various expertise. There is a striking similarity between Tom's account of teaching parents to assign meaning to sensory cues, and the clinical skills education for doctors-in-training, particularly those of Tom's generation. Sounds are presented analogically, and through mimicry, to communicate what a clinical sound 'sounds like'. The widespread availability of digital media expands the possibilities of this teaching to include playing recordings via publicly available platforms such as online video sites, which have the potential to become part of the practice of defining what is diagnostically significant (or not) for parents. Tom is actively guiding caregivers' knowing apparatuses, both in an embodied sense, and in teaching parents how and what digital media to know with.

He has also observed parents recording sensory cues themselves, as with Melissa's recording of her child's sleep apnoea:

Patients record their kid's cough, bring it in and show you. They'll come in and they'll show me all sorts of things on their phone and occasionally it is the snoring, at night, to prove to me that they're snoring. Or they're stopping breathing so they have got apnoea. And sometimes it is what the cough sounded like.

Such cases demonstrate how mobile technologies get entangled with the sensory expertise of the parent and doctor. The device transports what was sensed by the parent at home, into the clinic towards a diagnosis. Once recorded, the sounds take on a new existence, as clinical signs. The recording is not just part of the patient history, but a means to corroboration or co-witnessing of phenomena. Doctor and parent work with the recording to configure the parent's embodied understanding.

4. Discussion

Attending to parents' sensemaking over whether their child has a condition that warrants medical attention reveals the digital-sensory practices that configure bodies inside and outside the clinic. In the words of Barad (2007: 170): 'bodies do not simply take their places in the world'. As she puts it:

We do not merely see with our eyes. Interacting with (or rather, intra-acting 'with' and as part of) the world is part and parcel of seeing. Objects are not already there; they emerge through specific practices (Barad, 2007, 157).

Our vignettes show the need to examine the differential becoming of diagnosing bodies which, inspired by Barad (2007: 149), we see as 'a matter of intra-acting' in digital-sensory work. This is important especially when considering how such diagnostic practices are learned. It is not that the doctor reads information in a textbook, and brings this information to the clinic, nor that the parent draws only from a parental intuitive response. No, each are learning with each other and *with* technologies. They are both part of this world they create together, and what they know is created in a digital-sensory intra-action.

While parents' learning of sensory cues may be more informal than that of practitioners in that they do not learn this in institutions like medical schools, our observations and the accounts of parents capture some similar strategies to those adopted by doctors-in-training, with doctors part of the apparatuses of parents' diagnostic work. We have identified the following seven aspects of these learning intra-actions that seemed most important in our collated ethnographies:

1. *Attention to the change from 'normal'*, in which parents, working from an embodied sense of 'normal' for their child, interrogate potential 'abnormality' in relation to a sensed change.
2. *Testing/searching for signs and symptoms*, as a shared effort to assign diagnostic meaning to what caregivers have observed.
3. *Confirmation and direction from more experienced others*, with stories collected and shared through digital devices and sensory retellings.
4. *Mimicry*, a way of articulating a clinical sign that extends beyond the limits of words, something more easily captured if digital-sensory methods are used in the research encounter.
5. *Analogy/metaphor*, which is closer to words, but still strives for a sensory account of an observation that can be communicated to another.
6. *Digital archiving*, practices of recording and collecting symptoms and signs, for communication and comparison.
7. *Reference to validated recordings of the sound*, which concerns attempts to seek objective renderings and captures of observations for clinical decision making.

The first three of these relate to making a diagnosis of abnormalities in the biomedical paradigm. A parent's principal role is working to distinguish between what might be 'normal' or 'abnormal' for their child (a task which doctors are also trained to do). Parents are more or less continuously connected to the bodies of their children through multiple sensate channels, to the degree that we can observe a blurring of boundaries between bodies (I. M. Young, 1990; Wynn, 1997). They listen in to monitor breath sounds; as parents hold their children they become sensitive to the level of tension in their child's body. This sensory knowing becomes the backdrop against which parents register a change from 'normal'. The practitioner, while developing a patient history, cannot be as responsive to the same changes between normal and abnormal, but can support parents to attend to differences.

Diagnosis is a process of testing and searching (Blaxter, 1978; Jutel and Nettleton, 2011). In moments of parental anxiety about an observed sign and its potential significance, parents may use their devices to search for either symptoms or conditions to check their observations

against. The act of searching is an entangled effort to assign diagnostic meaning. The search results can validate, or force a reconsideration, of the nature of the parent's embodied judgment. *Should I see/feel this degree of floppiness or drowsiness in my child? Is this an emergency situation, or do I need to observe this for longer, to see if it worsens?* If the parent strikes upon a likely diagnostic candidate, the list of associated signs and symptoms can direct the parent's attention to other cues that they had perhaps not attended to—in Melissa's case, feeling sweat, observing mouth breathing.

This diagnostic work among parents does not take place separate from the clinic. Parents take their child to the doctor often on the basis that they have sensed something 'abnormal' (Lauritzen, 1997), but perhaps with trepidation over whether their child is really sick, or sick enough, to warrant medical care (Gunnarsson and Hydén, 2009). In the consultation, doctors form their own sensed judgments, and may also request tests as part of the diagnostic process. Doctors' clinical judgments and interpretation of technological sensing of the body (Maslen, 2017; Schubert, 2011) may serve to validate or force a readjustment of parents' interpretations of sensory cues, or may be informed by them in turn. In the clinic, doctors also explicitly coach parents to assign diagnostic meaning to the signs and symptoms as sensed and digitised, as in the example Tom gave of the sound of croup.

The second set of learning practices relate to communicative strategies to bridge the gaps in knowledge. Sensing clinical signs is the subject of extensive clinical training for medical doctors, including techniques that may appear rudimentary in light of the possibilities of digital media, such as mimicry and analogy (Maslen, 2015; Harris and van Drie, 2015; Rice, 2013). Presented with an aural symptom, parents also use mimicry to begin to conceptualise the nature of the potential problem. Melissa's vocalisation of the sound that she heard reflects an embodied-cognitive understanding of the 'ch' sound as choking (Merleau-Ponty, 1968; see also Barad, 2007, 157). These efforts to get at the clinical sign can be supported by a doctor, who can articulate their own mimicry of a clinical sign that a parent can adjust their expression/conceptualisation against.

The significance of analogy and metaphor is most evident in the account of the doctor reflecting on supporting the learning of parents. Just as he would have learned, he referred to blowing over the top of a milk bottle as like the whistling sign for asthma. In lieu of words, father Steve moved his own body as like the movement of his baby. In this case, gesture becomes a non-verbal analogy (Gallese and Lakoff, 2005).

Last, our data revealed two learning strategies that emphasise the role of digital technologies in diagnostic work. Parents worked between commonly available digital sensors including thermometers, timing apps, sound recording apps, and cameras, alone and in relation to doctors. There is readily available guidance on how to interpret the results of a thermometer and manage a febrile child. However, there is less advice on what to make of quantified rates of respiration (via a timer). Parents turned to this digital media, despite a clear sense of what they should make of the outputs, as a second sense of a cue external to the parent's body. This is not about collecting discrete pieces of information from 'out there' or as separable. Parents were quickly moving between modalities as if the digital was an extension of their own body, with findings from one informing their knowing through another.

As in Melissa's case, there is an awareness that the doctor cannot be there in the night so she is, in effect, collecting the data for the practitioner, as an ethnographer of her own experience (Mol, 2002) or a 'diagnostic agent' (Oudshoorn, 2008). As practitioners co-witness parent produced recordings, they also validate this media use, naming the sample as significant or insignificant to a particular diagnosis. This provides parents with a resource to return to and know with as a point of comparison or remembrance, working to refine their appreciation of the cue in the context of the doctor-caregiver relationship. Doctors 'recapture' (Stevenson et al., 2019) publicly available recordings of clinical signs on videos too, guiding parents on how they might use these resources to inform a decision about seeking of medical care or

administering medication. In doing so, they guide parents' relations to various devices and media in caregiving.

5. Conclusion

An important and increasingly relevant research problem for the social study of health and disease is to understand the role of technologies in the configurations and reconfigurations of bodies. Working closely with Barad, we have developed what we call digital-sensory work. Barad's thinking helps us to interrogate how technologies and bodies come together, highlighting how knowing does not precede an interaction but rather is enacted in the intra-action, between practitioners, parents, sensory knowledge, and devices.

This conceptualisation of digital-sensory work relates to other studies of diagnostic skills in healthcare in a number of ways. First, we focused on learning sensory skills with technologies in medicine, a topic that to date has most extensively focused on doctors and medical students (e.g. Prentice, 2013; Rice, 2013; Hammer 2017; Maslen, 2015; Harris and van Drie, 2015). By looking at caregiver intra-actions we showed that parents also undergo sensory training in their care of their children, a training that uses similar embodied techniques and technologies, such as recordings and mimicry. The re-enactments we conducted as part of our digital ethnographies were helpful in highlighting these learning practices. As parents re-counted a moment of diagnostic sensemaking, they slipped between recollections of their own embodied experiences, and searching for and re-reading of the signs and symptoms online. Their embodied experiences were made real and present as they moved to recreate a sound or a feeling. We recommend such performative, sensory, and creative methods to researchers travelling similar paths.

Another contribution of our article is that it shows that digital-sensory work, and in particular the learning involved by parents as they become diagnostic agents (Oudshoorn, 2008), does not take place separate from the clinic. We showed how doctors guide parents to use their bodies, and digital recordings, to interpret and respond to their child's symptoms in medically condoned ways. Doctors make some matter *matter*, and other matter *not* matter. This also signals a blurring of where diagnosis takes place. We can see something similar happening in other healthcare realms, such as direct-to-consumer genetic testing, where genetic testing becomes a practice that takes place in people's bedrooms and living rooms as well as in clinical settings (Harris et al., 2016). We could say, following from Latour (2004) and Mol (2002), that, just as a genetically-informed citizen is being crafted in the direct-to-consumer genetic testing engagements, so too is a sensorially informed caregiver being configured and enacted in the digital-sensory intra-actions we described. We recommend that researchers interested in digital and sensory practices in healthcare do not separate the clinic and the home, but rather investigate the intra-actions between caregivers and practitioners, between spaces of care-giving, between technologies and bodies, and observe closely how ways of knowing are being enacted in these encounters.

Finally, we also revealed the value of a collaborative approach to making sense of data. While team ethnography (Clerke and Hopwood, 2014) is becoming increasingly common in the social sciences, we also argue for the role of what we call 'collated ethnography', where two or more ethnographers work closely with their own familiar material to find insights that would not have been possible if they worked in isolation. This may take different configurations, and the move towards making ethnographic data open and accessible may shape this further. In our case we worked with sensory and digital ethnographic material. We worked mostly with words and images but we believe this method could be expanded by other researchers, through sharing sound recordings or other sensory material with each other (Harris et al., 2020). Still, by working with each other's material, often online, we engaged in a form of digital-sensory work ourselves as collaborating ethnographers. Our ethnographies had different but related foci, our observations

influenced by our own identities and skills as researchers. By collating our work, we facilitated an intra-action of materials which we hope inspires scholars to also consider what collation, as well as sensory and digital ethnographic methods, may offer their qualitative studies of the complex assemblages of clinical care.

Author credit statement

Sarah Maslen: Conceptualisation, Methodology, Formal analysis; Investigation; Writing – original draft; Writing – review & editing; Visualization; Project administration. Anna Harris: Conceptualisation, Methodology, Formal analysis; Investigation; Writing – original draft; Writing – review & editing; Project administration.

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