



Seeking help for atrial fibrillation: the role of the body in distributed decision making

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ABSTRACT

We adopt Rapley's (2008) concept of distributed decision making to explore the role of the body in people's decisions to seek medical care. We conducted in-depth interviews with patients diagnosed with atrial fibrillation (AF) who were taking long-term anticoagulants to prevent stroke. We interviewed seventeen patients recruited from English anticoagulant clinics using the biographic-narrative-interpretive method, and conducted thematic, structural and metaphorical analyses. This pluralistic analysis focused on how distributed decision-making was enacted through a range of socio-material, relational and embodied practices. Participants told how they experienced AF-related sensations that fluctuated in intensity and form. Some had no symptoms at all; others experienced sudden incapacitation – these experiences shaped different journeys towards seeking medical help. We draw on work by Mol (2002) to show how the body was differently observed, experienced and done across contexts as the narratives unfolded. We show that as part of a relational assemblage, involving social, material and technological actors over time, a new *body-in-need-of-help* was enacted and medical help sought. This *body-in-need-of-help* was collectively discussed, interpreted and experienced through distribution of body parts, fluids and technological representations to shape decisions.

RAPLEY T., 2008. Distributed decision making: the anatomy of decisions-in-action. *Sociology of Health & Illness*, 30, 429–444.

MOL A., 2002. *The body multiple: ontology in medical practice*. Duke University Press: Durham.

1. Introduction

Atrial Fibrillation (AF) is a common cardiac arrhythmia which affects 1.5–2% of the population (Camm et al., 2012) and increases the risk of ischaemic stroke. Often the first step towards a diagnosis of AF is a decision to seek medical help, typically prompted by a person experiencing altered sensations in the body, which may or may not be related to AF. Rapley's (2008) model of distributed decision-making offers insights into how people make health-related decisions but *how* the body figures in this decision-making is, by Rapley's own admission, poorly articulated. In this paper we explore the role of the body in distributed decision making at the point of help-seeking, focussing on Atrial Fibrillation as an exemplar.

Rapley's (2008) theory highlights the ways in which many human and non-human actors - distributed across time and space - constitute a decision-making assemblage. He proposed the notion of a *decision-in-a-series* whereby decision-making *unfolds* across a trajectory of care (Rapley, 2008), subject to the possibility of change as contexts and social

interactions evolve. The patient can thus be thought of as a *collective patient* (Rapley, 2008) within a network. Goodwin (2014) has argued that clinical decision-making is “*intrinsically collaborative, both thought and work, practical and embodied, distributed and relational*”. She highlights that autonomy is neither necessary or sufficient for participation in decision making; non-human actors shape decision making (Goodwin, 2009). Neither are people necessarily at the centre of decision-making, even if their best interests are the central concern. For example, ethnographic research on multidisciplinary teams providing cancer care has shown that much of decision-making takes place backstage between healthcare professionals, before a more limited set of options is presented to the patient (Hamilton et al., 2016). Medical documents, policies and technologies (such as the internet) are also key actors in distributed decision making (Makanjee et al., 2018; Bussey and Sillence, 2019).

Some aspects of distributed decision making in health care remain neglected. Existing research focuses almost entirely on what happens in clinical settings (Bussey and Sillence, 2019; Makanjee et al., 2018; Hart

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et al., 2015; Hamilton et al., 2016), overlooking the decisions that lead people to go to the clinic in the first place. There is recognition that a person's decision to seek medical care is often prompted by a process which begins with altered subjective bodily feelings becoming privately acknowledged as potential symptoms, until a person's capacity to make sense of these sensations by whatever means is exceeded (Heath, 2019). Hay (2008) differentiates felt, embodied sensations from symptoms, defining symptoms as socially informed and constructed cognitive interpretations occurring through engagement with biomedicine. Offersen et al. (2016) describe a continuum of sensations representing illness potentiality, ranging from normal to not normal, which are culturally and morally contingent, and emerge in the everyday. Making sense of new sensations involves drawing on personal experiences, socially informed illness repertoires and socio-cultural health beliefs (Macdonald et al., 2016). The boundary between the significant and the insignificant, or the threshold at which feelings become symptoms is 'aided and abetted by a variable combination of sensibility, preoccupation, fear, denial and stoicism' (Heath, 2019). AF patients have described this experience as a 'turning point', where normalised sensations suddenly became too much to bear or ignore (McCabe et al., 2011). Horlick-Jones (2011) illustrates how patients' 'everyday health competence' in distinguishing between normal and abnormal bodily sensations can be disrupted by an episode of serious illness. Fear of recurrence and being seen as an informed and responsible patient create additional anxieties about interpreting bodily signs. As Horlick-Jones' example demonstrates, interpretation of bodily sensations and decision making about care together constitute displays of responsibility and therefore invoke moral work. For instance, Polak and Green (2020) have shown how decisions about medicine become narratively framed as the 'right thing to do' in patient accounts. The social and moral dimensions of judging whether someone 'needs' to seek medical help has been characterised as the 'identification of candidacy': a dynamic, relational, socially situated process influenced by social disadvantage, fear of blame from professionals, normalisation of symptoms within deprived communities and negative views on personal health (Dixon Woods et al., 2005; Macdonald et al., 2016). Even when experiencing new bodily sensations and identifying a need for help, people may be reluctant to seek help over concerns of being seen as a time-waster or malingerer (Goode et al., 2004). How to interpret and make sense of new bodily sensations is learned anew through engagement with social and moral discourse, medical services and illness experience.

Mol and Law (2004) identify the body we *have* (body-object) which is observed and sensed through the medical gaze, the body we *are* (body-subject), which is our embodied, fleshy situatedness, and the body we *do* (body-in-practice), which we enact through our daily actions (Mol and Law, 2004). Drawing on stories of hypoglycaemia, they show, through attention to practices, how the body is not only observed, sensed and known, but also *done* differently in different contexts. In earlier work, Mol (2002) reminds us that everyday existence is a fleshy affair, and that whilst patients may interpret bodies, they also live in them. Through her ethnography on atherosclerosis, she shows how the practicalities of diagnosis in the hospital setting result in multiple enactments of the disease that come to 'hang together' to produce a 'patchwork singularity' (Mol, 2002). As part of a diagnostic practice, she illustrates how clinicians draw on social considerations, alongside other forms of knowledge from an array of actors, to make decisions about diagnosis and treatment. Following Mol, Gardner et al. (2011) illustrate how clinician and patient in the clinic collaborate to 'patch together' these multiple enactments and coordinate to create coherence in the diagnostic process through interaction with technological actors. These technological actors, images and test results inform patient decision making through the construction of certain forms of knowledge that lead to the enactment of new bodies or conditions. These new bodies may be predisposed to technological surveillance within and outside the clinic (Gardner et al., 2011; Lupton, 2013). Blaxter (2009) has demonstrated how technologies can shape decision making for patients: through a case

study she illustrates how clinical tests and images provided insight and reassurance for the patient. However, the process of translating these images into clinical records (and the wider clinical system) contributed to alienation of the patient during the co-production of the diagnosis with clinicians and technologies.

Here, we adopt Mol's (2002) conceptualization of the body (as multiple and enacted in practice) as our point of departure for tracing the role of the body within distributed decision making. As a break from the literatures explored above, we will show how this plays out in non-clinical settings as people decide whether, when and how to seek medical help prior to diagnosis of a condition known as atrial fibrillation.

To achieve this, we analyse patient narratives of atrial fibrillation (AF) to illuminate decision making around seeking medical help. Diagnosis of Atrial Fibrillation can be tricky. It is categorised by doctors as either 'permanent', 'persistent' (lasts more than 7 days) or 'paroxysmal' (occurs in episodes but returns to normal sinus rhythm within 7 days) (Zoni-Berisso et al., 2014). The bodily sensations experienced by a person at home may disappear by the time they arrive in clinic or undergo clinical tests. This can translate into difficulties securing either diagnosis or appropriate care. Sometimes the diagnosis arises opportunistically via pulse checks or an electrocardiogram (ECG) reading when people are undergoing routine or emergency care for other conditions. In this situation there may be no felt sensations at all. In others, the diagnosis is prompted by sudden severe incapacitation. Once diagnosed with AF, people may be offered preventative anticoagulants to reduce their stroke risk. Anticoagulants can also increase risk of bleeding (including haemorrhagic stroke) so deciding whether to take them entails careful deliberation. Given the complex relationship between bodily sensations, symptoms and diagnosis in AF we recognised the potential that patients' narratives might hold for examining the contribution of the body to distributed practices of decision making. In this paper we present empirical evidence from our analysis of how these complex relationships manifest in everyday life.

2. Methods

We explore help seeking decisions amongst AF patients through narrative analysis. Narratives are an important way in which humans make sense of, and account for their life-worlds and illness trajectories. They are also occasions in which biography is made and told, revealing situated practices, motivations, values and illness beliefs. Narrative research acknowledges the co-constructed nature of such accounts. It brings into focus the interaction between narrator(s) and listener(s), the context, time and place of the interview. Narrative interviews invite people to narrate their whole illness experience. Interviewees choose where to begin and what to include. The richness and narrative form of the data allows for in-depth exploration of illness experience, including the people, encounters, technologies and material artefacts involved.

We have published our methods in detail elsewhere (Hawking et al., 2020). In summary, we conducted a narrative interview study with seventeen adult patients who had been diagnosed with AF. We recruited participants opportunistically from outpatient anticoagulant clinics in five English hospitals serving diverse populations. Participants provided informed consent and we sampled purposively, guided by concepts of information power (Malterud et al., 2016), including a variety of self-reported attributes: exposure to medication (type of anticoagulant, whether they had switched medications); gender; age; ethnicity; history of previous cardiovascular events. A patient advisory panel discussed ethical issues, reviewed patient-facing materials, provided feedback on project design and delivery, and piloted the interview schedule. Interviews were held by MH in English in participant homes (n = 10) or a university office (n = 7) and were guided by the Biographic-Narrative-Interpretive Method (BNIM) (Wengraf, 2001). The audio-recorded interviews had three sub-sessions: an initial question to invite narrative; a follow-up using cues from the initial telling; then

semi-structured questions. We kept reflective notes and transcribed interviews verbatim. All participant names given in this manuscript are pseudonyms.

We adopted a pluralistic narrative analytical approach that combined structural (Labov and Waletzky, 1997), thematic (Braun and Clarke, 2006), and metaphorical (Lakoff and Johnson, 2003) lenses. We performed these analyses initially sequentially and then integrated these different ways of interrogating the data across cases and with a commitment to retaining the coherence of whole story. A process of familiarisation included checking the transcripts for accuracy and repeated readings. MH classified key segments of the initial narratives according to six categories of clauses (Labov and Waletzky, 1997) and plotted the main events in a timeline, noting how narrators shifted positions and reflected on their actions. Transcripts were coded by hand, before transferring to NVivo software for data management (QSR International PTY LTD, 2012) in six stages of thematic analysis (Braun and Clarke, 2006). Metaphors related to the body and its parts (e.g. heart, brain, blood, circulation system); clinical processes (e.g. diagnosis and healthcare interactions); drugs; and other health-related experiences were identified line-by-line and grouped conceptually according to vehicle (subject). We were sensitised to moments of decision and practices around these. At each stage preliminary analytic insights were shared with DS as a focus for in-depth discussion, development of analytic ideas and exploration of relevant theory with which to engage in iterative rounds of ongoing analysis across the dataset. To refine the analysis and ensure rigour, we worked as 'critical friends' offering alternative interpretations and undertook three analysis 'panels' with 4–6 academic researchers, focussing in depth on three diverse transcripts (Wengraf, 2001).

2.1. Findings - the body in distributed decision making

Our structural analysis identified three common narrative threads or storylines that featured in people's illness trajectories around seeking help for AF. We characterised these as the 'big event', the 'chance find', and the 'long road'. The 'big event' was typified in the accounts by a sudden, significant, often unforeseen and disruptive event - an emergency - resulting in seeking medical care and then diagnosis. The 'chance find' storyline involved help seeking via a pre-planned clinical appointment for an unrelated concern, such as diabetes, infection, or routine screening, which then led to a surprise diagnosis of AF. The 'long road' was characterised by longer, more difficult trajectories towards securing a diagnosis, with repeated attempts to seek help. Some people wove more than one type of thread in their overall illness story. In the following section we outline three ways the body figured in distributed decisions about seeking help in these narratives. We focus on decision-making in relation to whether, when and how to seek medical attention, as an example of a key decision-in-a-series in illness trajectories.

2.2. Bodies-in-need-of-help

People drew on shared or collective interpretations of what was *normal* or *abnormal* in a relational process whereby a potentially ill body emerged and was collectively experienced. Through observations, sensing, knowing and being of the body, as well as actions and discussions, a body-in-need-of-help was enacted.

In order to convey the abnormality of felt sensations, some participants invoked metaphors for the heart including: out of control or escaping 'flapping', 'flying' animals - one participant Jim likened his heart in AF to a 'rabid dog' - or, alternatively, mechanistic metaphors including pistons, 'racing' cars or spinning motors in 'overdrive'. Kristen said her heart in AF was 'racing' so fast she felt it would stop, and Margaret described it thus: 'it thumps, it thumps and bangs, [makes a fist and gestures towards her chest as if beating it] it's almost as if it's trying to get out, you know. It jumps around'. However, some participants did not experience new or different sensations in their heart, but initially sought

help for other reasons. One such example is provided by Michael. Michael lived alone and was diagnosed with AF after seeking help for symptoms of a transient ischaemic attack (TIA). He started his story describing an instance when he fell off his bike and cracked his ribs. He described the pain as being so severe, it may have caused a 'shock' to the heart. However, when he attended the Accident and Emergency (A&E) department for treatment, it was too busy for him to be seen so he returned home. He then described visiting his sister and brother-in-law soon after in order to fix their computer and television. Whilst in the pub together that day, he began slurring his speech, and he made sense of this in collaboration with his brother-in-law. He felt sensations, they both observed, and together they judged whether what he was experiencing could be caused by being drunk, or something else:

"I didn't put it down, I was very curious about it, but to be honest I had no explanation. I asked him, do I sound drunk? And [he] said, yes. Oh. I couldn't, if you start sounding slurring and sounding drunk after drinking beer, obviously one thinks of being inebriated. But no way could it have been. But I couldn't attribute it to a heart problem or a stroke or anything like that." Michael

His own perception of what was happening - slurring his words - was not enough for a definite conclusion, and so he sought a second opinion from another person, someone who knew what was normal for him and who could hear and see the way he was talking from an outsider perspective. Even though he 'sounded drunk' and his past embodied experience did not support the possibility of being 'inebriated' after 'three pints of beer', collectively they concluded that they could not attribute it to serious illness in that moment and they did not act on this. Later on, as he was eating the dinner his sister had prepared, he noticed he couldn't 'use my left hand, the fork, which was quite worrying' and then he 'didn't really worry about it' and went to bed early. Whilst walking home the next day, Michael attended A&E. He said: 'on the way back I thought to myself, well, better go and get it checked out. I walked to [hospital]. And [doctor] said, oh, hemispherical TIA. Whoa, I thought, I must admit I thought you got a stroke and there's only one level of stroke, it just curls you up.' Michael's decision to seek medical attention was clearly distributed over time (his previous experience at A&E, daytime, dinner/evening, the next morning) and geographic locations (his sister's house, the pub, the walk home), as well as involving multiple human (his sister and brother-in-law) and non-human (the television and computer, the three beers, the fork) actors and their collective actions (drinking, eating, observing, sensing, discussing, understanding). This case shows that a body-in-need-of-help - that Michael knows, embodies and enacts - was central to, and emergent from, this relational and distributed decision-making process.

The involvement of others in the interpretation of new sensations and the decision to seek medical care could help allay worries expressed by people about being seen by others as someone who inappropriately accessed care or called on medical services when they were not justified. Like others, Sarah experienced a 'big event' - a 'heart attack' that led to her seeking help and then eventual AF diagnosis. She described the process of deciding what to do in that moment:

"Because I do look back and think, why didn't I just call an ambulance? It's so important. But I think I was worried about wasting someone's time, that perhaps I could have got my, I'd even thought about driving to be honest. But luckily enough my daughter came in. But it was just thinking, oh perhaps, you know you hear about people that think they're having a heart attack and they're told it's indigestion or something like that. So that was one of the things in my mind thinking, cor, imagine an ambulance turning up. And I end up, oh it's just either a few palpitations or something." Sarah

Sarah's daughter arrived and together they decided her sensations were likely not just 'a few palpitations' or indigestion, and that urgent medical attention was required, but rather than call an ambulance, her daughter drove her to the emergency department. Sarah's enacted body-

in-need-of-help was informed by moral and social expectations and concerns that needed to be managed through collaboration by mother and daughter.

The relational process of deciding to seek medical help can recreate the body-subject, shifting how the body is experienced by the patient, and de-centring the patient such that the majority of the distributed decision-making is done by people *other than* the patient. For AF patients, this occurred when participants either experienced no AF symptoms (often a feature of ‘chance find’ storylines), or their symptoms were so severe that they were incapacitated (for instance, in ‘big event’ threads that included cardiovascular events, stroke etc). In these contexts, particular assemblages of material and non-material actors combined to focus attention on the body, bringing it to the fore and changing the possibilities and potentialities of the illness. An example can be found in Helen’s story. She was a married retiree who described herself as ‘independent’ and a ‘getter on-er’, and she had sought help from her GP with a cough and pain, which she described thus - “*this cough was the sort of cough where you think, oh when is it going to go? Anyway, and I don’t know whether that was making the pain, I don’t know but anyway, I went to him about that*”. During the consultation, she described how the GP “*tested my back and put the old thing on and everything and he said, I think you ought to have an X-Ray, just in case you’ve got an infection, we’ll take some blood, we’ll do some blood and I want you to have an ECG. So, I said, oh OK then.*” Following this, Helen was referred to A&E for further tests, so she caught a bus to the hospital with her husband. Once at A&E, Helen recounted being ‘forced’ into a wheelchair, a bed and a gown:

“*She gave me this form, started to fill in and then I, next thing I knew there was these two nurses they was, they wasn’t porters, two nurses with this chair and they said, ‘sit down’. I said, I can walk you know! [laughter] And they said, ‘we know but sit down’ and I was still taking it all in really because it was all happening so, what the, on earth is going on? Anyway, they wheeled me into a bed and gave me a gown and my husband was sitting there. Next thing I know I’m strapped up to all sorts of things and cannulas in and whatever and it just went from there.*” Helen

Helen’s dramatic retelling and reference to multiple hospital objects, including the ECG machine, wheelchair, bed, gown, a ‘form’ and ‘all sorts of things and cannulas’ construct a serious clinical space and sense of urgency which identifies the escalation of her diagnosis journey as an acute medical emergency that did not make sense (*what on earth is going on?*) in the context of the bodily sensations that had led her to the GP (*‘the sort of cough where you think, oh when is it going to go?’*). The clinical emergency, however, bought her body to the fore – a new body was enacted in the clinical space, which *felt* the same to her but was now redefined as a body-in-need-of-help in that moment. She went on to recount how this process ‘shook’ her confidence and temporarily disrupted her trust in her own embodied knowledge. She described how she became hypervigilant for any signs that might point to serious illness, using a mirror to watch for visible signs of stroke and as a tool to interpret bodily sensations:

“*So, that did go through my mind a bit when they were mentioning strokes and I’m a little bit, not so much now, but I got a little bit obsessed with the advert on the television where it keeps telling you about the FAST, isn’t it? Is it Face, Arm, I can’t remember what the S is ... Speech and then Telephoning. I did get a little bit, looking, when I was having these headaches I did, I kept, when it was on I kept looking and in fact I went to the mirror and thought, is my? I did get a little bit, but that’s gone now, I’m over that now.*” Helen

After this episode, Helen *does* her body differently. Previously a ‘getter-oner’, she told how she ‘holds on’ to her husband now, in the next instantiation of her body-in-need-of-help. She also observes her body differently, with a mirror, and checked for signs that she previously did not monitor – surveillance work that she didn’t undertake before. A new body, one in ongoing need of help emerges from the decision-in-a-series, in the trajectory from cough to AF. This body is socially and temporally

situated and enacted differently in these new contexts as time goes on. Others enacted their bodies in new ways too. Margaret said: *‘I’d lost my confidence, I was very, um, wary of going out, so I had to take little short journeys to start with on my own’*. Tracy used army related surveillance metaphors about ‘keeping an eye’ on her body – you ‘know the drill’ – after her diagnosis. Michael described purchasing a ‘finger dongle’ to record his heartrate at home and reflected: *‘it’s, just looking at it on paper it’s quite startling. As against, shall we say, a crazy, seismic line going up and down, and afterwards [after undergoing a cardioversion to return to normal rhythm] just a smooth ripple going along’*. The earthquake and calm water metaphors dramatically convey the different way he now understands, observes and *does* his new body.

2.3. Distributed bodies

The lived body which participants accounted for in their narratives was a body that included senses, parts, organs, fluids and bodily secretions. Particular to the narratives was metaphorical talk about sticky, heavy, thick and treacle-like bodily fluids, blockage and flow. The metaphors for blood conjured images of obstructed and clotted ‘pipes’ and ‘plumbing’ in the body. The following example, from Rose and her daughter, Katrina, offers some relevant insights into how these fleshy parts, fluids and secretions figured in distributed decisions to seek help. Rose retired with chronic illness which she attributed to working long hours in a physically demanding job and bringing up her children. Her daughter, whom she described as ‘*the best thing in her life*’ lived nearby, so that she could assist her mum with housework, managing her illness and treatments. In their narrative, which included elements of ‘big event’ and ‘long road’ threads, they recounted together a collective decision to re-consult after an unsatisfactory response to earlier help-seeking for a cough. They describe how this decision was distributed over their friends and neighbours, via the passing, storage, showing and discussion of bodily fluids.

“*Katrina: Right, that was to do with, when my mum got a cough, she used to cough and bring up.*”

Rose: *A lot of water like that. [indicates small clear plastic bottle of water]*

Katrina: *Yeah but dusty water. So what she did, she kept the bottles and every time we went to the doctors or to the hospital.*

Rose: *We bring, because they were not taking me serious [...] Uh huh, uh huh, every family, everybody thinking it is a cancer causing it. Is it a cancer, is it a, and then I would pass one of them little bottles [indicates 500 ml bottle] every night. I used to sleep with it and I have a plastic, small plastic cup when I put cough.*

Katrina: *Every bottle had that phlegm in it, you’d come in.*

Rose: *Because I was only saving it to show ...*

Katrina: *To show everybody.*

Rose: *To show the medical people because they was not taking it serious, you know.*

Katrina: *Everybody. Everybody down the road knew about that bottle of phlegm.*

Rose: *Every family. Every friend and one of my friends.”* Rose and Katrina.

The ‘*bottle of phlegm*’ - shared, observed and discussed - acted to reveal Rose’s embodied discomfort for peers and provided evidence for medical assessment. Beyond this, the practice of carefully preparing bottles, passing and saving bodily fluids, formed an important stage in the journey to re-consultation. This sustained effort meant that bottles of fluids were distributed throughout the house. As material-corporeal actors they prompted conversations in social and medical spaces. The

leaky boundaries of Rose's body allowed family, friends and neighbours to experience her suffering body, jointly constitute the seriousness of this suffering and thus engage in the distributed decision-making process. This decision was narratively constructed by mother and daughter through references to serious illness (cancer) via the reported experiences of friends who had experienced similar symptoms with a 'frightening' outcome. Consequently, a collective, relationally distributed decision that Rose's symptoms should not have been brushed off by the previous medical professionals she had consulted, and that she legitimately required further medical attention resulted.

The extent to which a decision gets distributed over others is varied. In situations judged to be emergencies, decisions to seek help were often led by other people, often family members, but sometimes friends and even strangers who were nearby. In an example of a 'big event' that led to emergency care and diagnosis of AF, Margaret describes how others decided to seek medical attention when she became unwell in the street:

"Well I'd been to the chiropodist, and I was just walking along, and I was going to catch the bus, and I, the next thing I knew, I was on the pavement with my face covered in blood, and could hear somebody saying 'where's that blasted ambulance?' So I don't know how long I was unconscious for. And um, then unfortunately I had to wait another hour and a quarter for the ambulance." Margaret

In this scenario, others had a more significant role in the distributed decision-making process when Margaret passed out and was badly injured. Her body was done differently at this point – with limited cognitive processing, her injured body and secreted bodily fluids - her 'face covered in blood' - nevertheless shaped the resulting decision that medical attention was required. Through the relational interaction, her bodily distress became collectively experienced - strangers who attended her expressed frustration on her behalf at the long wait for help to arrive.

In these examples, other people shared the decision about seeking help, helping to assess and enact the body-in-need-of-help. The stories that were prompted by sharing of Rose's bodily excretions provided possible explanations, that could be collectively assessed and considered. In the case of emergency, others stepped in to contribute to the decision making when Margaret did not have the capacity to do so. Through the hanging together of bodies, bodily secretions, family, friends, neighbours and strangers, the collective decision that help seeking was required was made.

2.4. Technological bodies

One of the narrative threads around seeking help that we identified from people's accounts was termed 'the long road'. These storylines were characterised by a process of 'achieving' an AF diagnosis through gathering biomedical evidence of symptoms and repeated, often challenging, contact with the health service over a prolonged period of time and multiple encounters. For instance, Sarah described herself as being in 'limbo' about her AF: "because my diagnosis isn't a proper one. Well, it is from the hospital, not from the GP. It's, I don't really know where I stand". Central to her decision to keep making repeated attempts to seek help was a strong sense that the sensation she was experiencing was 'different'. She said: "I did know it was a different pain. That's the strange thing. And I think the pain wasn't overwhelming. But it's because it wouldn't go away that I knew it was different".

In these storylines, technological representations of the body came to the fore as important actors in the distributed decision to seek help or diagnosis. This was particularly important for patients who had symptoms which were later diagnosed as paroxysmal AF, and who struggled to prove that the sensations they felt (when they were experiencing AF) were in some way pathological. Unless the arrhythmia was recorded using monitoring technologies, it did not fully exist, and was certainly without diagnostic label. Jim described this process: "[the doctor] wanted to catch it when it was flapping around so that they could put the, test me out but of course every time I got it [AF sensations] it lasted and then by the time I

got to see somebody it had died down.' If this occurred, people resorted to repeatedly seeking help, often in the face of resistance from health care professionals who were involved in their care. These bodily representations – created through Holter monitors, ECG machines and other scanning technologies - provided legitimacy to consultation practices which could otherwise be dismissed by healthcare staff. For Sarah, the Holter monitor posed a problem when it failed to represent her embodied experience: 'it doesn't always pick up on the, you have the Holter monitor and you don't experience palpitations when you're having it. So it's, like, you feel it's not a true representation really of how you're feeling'. Similarly, Ruth described feeling 'like a fraud' when she was sent for tests because by the time she went to the doctor, her heart felt like it had returned to normal.

Kristen's narrative demonstrated how technological actors played a decisive part in her need to repeatedly seek help before reaching a diagnosis:

"I went along and they did an ECG, which of course I wasn't in an episode at that time, so it didn't show anything up. And I was told that I was quite sensitive to my heart. It would appear that I was someone that was very sensitive to the beatings of my heart, and I was probably getting myself anxious about the speediness of them." Kristen

She was upset about this characterisation of her felt sensations and concerned that the ECG was unable to 'capture' them. However, as both the GP and cardiologist said there was nothing wrong, she decided to sign up to a charity race, which resulted in a 'big event' at the end of the race:

"Suddenly I felt very, very poorly. [...] I don't remember what went between saying to one of my family members, I don't think I feel very well, and then the next thing I knew, the paramedics were there, and they were moving me into the ambulance. I was in the ambulance for a long time. They put me on a monitor. One of the paramedics was actually tapping my face, and he kept saying, you're having a panic attack, you need to stop worrying, you're having a panic attack. And he was doing this. And actually that made me feel worse, because I know I don't have panic attacks. I'm an anxious person, but I know I don't have those. So that, it did scare me a bit, because I felt really uncomfortable inside still. And then the other paramedic suddenly said, Kristen, are you undergoing investigations for a flutter on your heart? [...]. So, she said, we're seeing traces of a flutter. [...] She said, I'm going to take a readout now. And she said, and she held it up and she said, this is yours and you mustn't lose this. This is proof that this is showing up that you are." Kristen

Like others, Kristen metaphorically likened the sensations of her heart in AF to an escaped 'flying', 'flapping' animal that needed to be 'caught' by medical professionals. In the face of resistance and dismissal from previous healthcare professionals, Kristen's decision to press on and continue to consult about her bodily sensations was facilitated through the production of a technological-material actor, a 'readout' that acted to provide 'proof' of Kristen's embodied experience. The AF heart could then finally be seen, or 'captured' under the medical gaze and Kristen's fleshy reality communicated in an alternative way, incorporating distributed elements that went beyond her private embodiment. Through engaging with the readout, enabled through medical practices involving machines, monitoring and printing, Kristen enacts a different body, one that has the potential for an AF diagnosis where it previously did not. The coming together of distributed actors – medical (paramedics, ambulance and ECG machine) and body-in-practice (running, sensing, passing out, monitoring) result in a changed decision-in-a-series that leads Kristen towards re-consultation and eventual AF diagnosis.

3. Discussion

In this paper we have drawn on Rapley (2008) and Mol (2002), to show the ways in which the body figured in patient's accounts of distributed decisions to seek medical attention for altered sensations or

out of the ordinary circumstances, which led to an eventual diagnosis of atrial fibrillation. A key strength of our work is our pluralistic analysis and attention to narrative elements including metaphor and structure to pay attention to how embodied experience comes to the fore in these decisions.

Offersen et al. (2016) describe how bodily sensations can either be absorbed into ordinariness, or have illness potentiality, and these sensations are given meaning according to cultural, moral and everyday contingencies. Bodily sensations can come and go, and shift in intensity and form, particularly with AF which can be paroxysmal, so that it is difficult for patients to make sense of and difficult for clinicians to diagnose. Scarry (1987) has argued that the 'body in pain' (she refers to 'pain' in its broadest sense i.e. suffering) resists language. For patients with AF, pain/suffering may be minimal, or not exist at all. They may not feel any bodily changes (in asymptomatic AF) or may not know, or immediately feel, bodily changes in cases of sudden loss of consciousness. In between there is a wide range of experience and wide range of possibilities for interpretation, decision-making and action. Whether through communicative actions, technological representations or sharing of bodily parts and fluids, we have shown that distributed decisions to seek help involved body-work to articulate and make sense of sensations that were not yet 'knowable'. Through this body-work, body parts and fluids (e.g. in the case of Rose's *phlegm*) or representations of the body (e.g. in the case of Kristen's *readout*) could be distributed, observed, saved, shared, discussed or foregrounded as evidential proof in medical and non-medical spaces.

These practices were one way of overcoming or circumventing the constraints of language as a mode of expression of felt embodied realities. Different enactments of the body contributed to the eventual decision to seek help. At the same time, these practices also involved moral-discursive (i.e. language) work to communicate the 'abnormality' of bodily sensations, establish the need for clinical attention and to provide legitimacy to decisions. The use of metaphors, including out of control animals and cars in *overdrive* were examples in our data. Reventlow et al. (2008) outline how metaphors can shift the perceptions and meaning of health risks and bodily capacities for people when interacting with others. In our study, metaphors contributed to shifting the collective discursive construction of 'need' by enabling people to more persuasively communicate their embodied experience. Metaphors, as a linguistic device, highlight some aspects of an experience and obscure others. They invite listeners to think about one thing in terms of another and are thus effective in filling 'gaps' left behind by more literal language and facilitate shared meaning between the actors involved in decision-making. Through this discursively informed, socio-material practice, a new body (a body-in-need-of-help) is enacted.

The interpretation of new bodily sensations and changes is a relational accomplishment, where a new body-in-need-of-help is enacted through distributed decision making. Previous research has highlighted the role of significant others in decisions to seek medical attention – and how this can both slow down (Dhand et al., 2019) or speed along (Pattenden et al., 2002) the process. For example, events that occur amongst close networks of relations can result in delays to seeking help in cardiovascular emergencies, compared to events that occur in spaces where strangers are present (Dhand et al., 2019). In our study we have shown how the leaky boundaries of the body, and the distribution of its parts and representations can result in the collective identification of candidacy (Dixon Woods et al., 2005), a validated decision to consult, and a new emergent body-in-need-of-help. Friends and neighbours shared in this decision to consult through their own intimate knowledge of the patient, their bodily tales and interpretations of what was normal or abnormal.

It may also be necessary for the body to act for itself when sensations are ignored or the potential for illness is unrecognised. Where illness progresses without intervention or develops suddenly, an AF emergency can occur, often leading to incapacitation or loss of consciousness. This may result in the emergence of a greater role for others in the distributed

decision to seek help – such as in the case of Margaret – but the body contributes to and shapes this decision by displaying pathological signs that social, material and technological actors respond to. Goodwin (2009) argues that agency can emerge even from an unconscious body when connected to clinical life support machines. In this scenario, the patient and machine become an organic-technological cyborg that can communicate about its status with clinicians in the vicinity who must respond. A body may thus act for itself when cognitive processing is limited, through relational interactions with actors in the socio-techno-material assemblage.

Whilst we have been able to show how social groups collaborated to construct legitimate help seeking and to distribute accountability for decision-making, our analysis does not enable us to shed light on situations in which the distribution of decision making contributed to a decision *not* to seek help. Nor does our analysis speak to situations in which a decision was made to seek help, but no diagnosis ensued. Our approach to recruitment (from a secondary care clinic), sampling and narrative elicitation did not readily facilitate such storying; it is also possible that these stories are less tellable (Norrick, 2005). Do the leaky boundaries of the body also allow for the distribution of responsibility for 'poor' decision making or unjustified help seeking? Patients who consult 'inappropriately' might risk being labelled a time- or resource-waster in the context of NHS scarcity narratives (Goode et al., 2004). This was a particular struggle for some participants who narrated 'a long road' storyline and had difficulty reaching a definitive diagnosis. Recent work has shown how 'rejected candidacy' when seeking medical care left people angry and defeated, compounding their struggle to receive care with their illness symptoms (Maclean et al., 2023). Others have outlined how the route to diagnosis, particularly when marked by disbelief and denial, impacts the way illness is then experienced (Jeske et al., 2024). Our analysis confirms the presence of similar experiences (for example in the cases of Sarah and Ruth) and it is possible that diagnoses such as AF (in which symptoms may be fluctuating, non-existent and difficult to communicate) are especially prone to these kinds of moral concerns and social evaluations. Our participants were all patients with established AF reflecting on their transition from 'not-knowing' to 'knowing' their diagnosis so we cannot draw any firm conclusions about peoples' alternative courses of (in)action.

We conducted context-specific interviews with patients who all currently took anticoagulants. They had therefore constructed illness narratives based on their perceived need for medication in the context of their AF diagnosis. Furthermore, as regular attenders at the anticoagulant clinic, they may have had numerous opportunities to rehearse, retell and reshape their narratives. These narratives may therefore be presentable stories, shaped by the need to talk about taking medicines as the 'right' thing to do, a phenomenon which previous researchers have identified (Polak and Green, 2020). This moral and performative work therefore could impact narratives about seeking help in this context. Further, the narrative approach may overlook some important elements of the distributed decision-making process by virtue of its reliance on accounts rather than direct observation of practice. Despite these inevitable limitations, narrative provides opportunity for narrators to engage in hermeneutic sense-making practices, to position and re-position themselves within the evolving storyline, and to draw on plot, character and metaphor to display how complex processes of decision-making unfold and become presentable to the curious listener.

3.1. Implications for theory and practice

Our key contribution is to build on the existing scholarship on decision-making and symptom interpretation to show key points of intersection between these literatures by foregrounding the role of the body within the model of distributed decision making. We thus broaden the reach of Rapley's original theorisation. In particular, we show how the body both shapes, and is shaped by distributed decision making, even in cases where there are no felt sensations or the capacity of the

patient is limited. Paying attention to the multiple ways the body-in-need-of-help is *done* and how help-seeking emerges from relational socio-techno-material assemblages enriches understandings of how decision-making takes place in community settings and what prompts people to seek help.

For clinicians our work offers a fresh perspective on the notion of 'shared decision making' (Thomas et al., 2021). Decision-making is shared not only between clinician and patient (perhaps with the incorporation of decision-making tools and professional guidance), but rather extends to a widely distributed assemblage of human and non-human actors across time and space. This brings salience to the importance of enquiry as to *how* and *why* a patient is consulting with a particular concern at a particular point in time – a threshold moment. The clinical consultation is an opportunity to focus on this intersection between evolving biology and evolving biography (and continuity of care as a means of continuing this engagement). The potential of narrative to convey this - especially in the context of policy calls to conduct more consultations via digital means - should not be underestimated. Our research also highlights examples of patients adjusting to new ways of trusting and interpreting their own bodily sensations. This opens up new avenues for fully appreciating the consequences of receiving a new diagnosis as patients adjust to these new ways of being and doing, especially in the immediate aftermath of a new diagnosis. Furthermore, the significance of the relational networks that patients may draw on in deciding to seek care may also provide important insights that are relevant to ongoing treatment and care.

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CRediT authorship contribution statement

Meredith K.D. Hawking: Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Deborah Swinglehurst:** Conceptualization, Formal analysis, Methodology, Supervision, Writing – review & editing.

Declaration of competing interest

None to declare.

Data availability

The authors do not have permission to share data.

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References

- Blaxter, M., 2009. The case of the vanishing patient? Image and experience. *Sociol. Health Illness* 31, 762–778.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 77–101.
- Bussey, L.G., Sillence, E., 2019. The role of internet resources in health decision-making: a qualitative study. *Digit Health* 5.
- Camm, A.J., Lip, G.Y., de Caterina, R., Savelieva, I., Atar, D., Hohnloser, S.H., Hindricks, G., Kirchhof, P., ESC Committee For Practice Guidelines, 2012. 2012 focused update of the ESC Guidelines for the management of atrial fibrillation: an update of the 2010 ESC Guidelines for the management of atrial fibrillation. *Eur. Heart J.* 33, 2719–2747.
- Dhand, A., Luke, D., Lang, C., Tsiaklides, M., Feske, S., Lee, J.M., 2019. Social networks and risk of delayed hospital arrival after acute stroke. *Nat. Commun.* 10, 1206.
- Dixon Woods, M., Kirk, M.D., Agarwal, M.S., Annandale, E., Arthur, T., Harvey, J., 2005. Vulnerable Groups and Access to Health Care: a Critical Interpretive Review. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO), London.
- Gardner, A., Dew, K., Stubbe, M., Dowell, T., Macdonald, L., 2011. Patchwork diagnoses: the production of coherence, uncertainty, and manageable bodies. *Soc. Sci. Med.* 73, 843–850.
- Goode, J., Greatbatch, D., O'Cathain, A., Luff, D., Hanlon, G., Strangleman, T., 2004. Risk and the responsible health consumer: the problematics of entitlement among callers to NHS direct. *Crit. Soc. Pol.* 24, 210–232.
- Goodwin, D., 2009. Acting in Anaesthesia: Ethnographic Encounters with Patients, Practitioners and Medical Technologies. Cambridge University Press, Cambridge.
- Goodwin, D., 2014. Decision-making and accountability: differences of distribution. *Sociol. Health Illness* 36, 44–59.
- Hamilton, D.W., Heaven, B., Thomson, R.G., Wilson, J.A., Exley, C., 2016. Multidisciplinary team decision-making in cancer and the absent patient: a qualitative study. *BMJ Open* 6, e012559.
- Hart, R.I., Foster, H.E., McDonagh, J.E., Thompson, B., Kay, L., Myers, A., Rapley, T., 2015. Young people's decisions about biologic therapies: who influences them and how? *Rheumatology* 54, 1294–1301.
- Hawking, M.K.D., Robson, J., Taylor, S.J.C., Swinglehurst, D., 2020. Adherence and the Moral Construction of the Self: A Narrative Analysis of Anticoagulant Medication. *Qualitative Health Research* 30 (14), 2316–2330.
- Hay, M.C., 2008. Reading sensations: understanding the process of distinguishing 'fine' from 'sick'. *Transcult. Psychiatr.* 45, 198–229.
- Heath, I., 2019. Subjectivity of patients and doctors. In: Dowrick, C. (Ed.), *Person-centred Primary Care: Searching for the Self*. Routledge, London.
- Horlick-Jones, T., 2011. Understanding fear of cancer recurrence in terms of damage to 'everyday health competence'. *Sociol. Health Illness* 33, 884–898.
- Jeske, M., James, J., Joyce, K., 2024. Diagnosis and the practices of patienthood: how diagnostic journeys shape illness experiences. *Sociol. Health Illness* 46 (S1), 225–241.
- Labov, W., Waletzky, J., 1997. Narrative analysis: oral versions of personal experience. *J. Narrat. Life Hist.* 7, 3–38.
- Lakoff, G., Johnson, M., 2003. *Metaphors We Live by*. University of Chicago Press, Chicago.
- Lupton, D., 2013. Quantifying the body: monitoring and measuring health in the age of mHealth technologies. *Crit. Publ. Health* 23 (4), 393–403.
- Macleane, A., Hunt, K., Brown, A., Evered, J.A., Dowrick, A., Fokkens, A., Grob, R., Law, S., Locoock, L., Marcinow, M., Smith, L., Urbanowicz, A., Verheij, N., Wild, C., 2023. Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: validated, diverted and rejected candidacy. *SSM Qual Res Health* 3, 100207.
- Macdonald, S., Blane, D., Browne, S., Conway, E., Macleod, U., May, C., Mair, F., 2016. Illness identity as an important component of candidacy: contrasting experiences of help-seeking and access to care in cancer and heart disease. *Soc. Sci. Med.* 168, 101–110.
- Makanjee, C.R., Bergh, A.M., Hoffmann, W.A., 2018. Distributed decision making in action: diagnostic imaging investigations within the bigger picture. *J Med Radiat Sci* 65, 5–12.

- Malterud, K., Siersma, V.D., Guassora, A.D., 2016. Sample size in qualitative interview studies: guided by information power. *Qual. Health Res.* 26, 1753–1760.
- Mccabe, P.J., Schumacher, K., Barnason, S.A., 2011. Living with atrial fibrillation: a qualitative study. *J. Cardiovasc. Nurs.* 26, 336–344.
- Mol, A., 2002. *The Body Multiple: Ontology in Medical Practice*. Duke University Press, Durham.
- Mol, A., Law, J., 2004. Embodied action, enacted bodies: the example of hypoglycaemia. *Body Soc.* 10, 43–62.
- Norrick, N.R., 2005. The dark side of tellability. *Narrat. Inq.* 15 (2), 323–343.
- Offersen, S.M., Risør, M., Vedsted, P., Andersen, R., 2016. Am I fine? Exploring everyday life ambiguities and potentialities of embodied sensations in a Danish middle-class community. *Medicine Anthropology Theory* 3, 23–45.
- Pattenden, J., Watt, I., Lewin, R.J., Stanford, N., 2002. Decision making processes in people with symptoms of acute myocardial infarction: qualitative study. *BMJ* 324, 1006–1009.
- Polak, L., Green, J., 2020. Rethinking decision-making in the context of preventive medication: how taking statins becomes “the right thing to do”. *Soc. Sci. Med.* 247, 112797.
- QSR International PTY LTD, 2012. NVivo Qualitative Data Analysis Software Version 10.
- Rapley, T., 2008. Distributed decision making: the anatomy of decisions-in-action. *Sociol. Health Illness* 30, 429–444.
- Reventlow, S.D., Overgaard, I.S., Hvas, L., Malterud, K., 2008. Metaphorical mediation in women’s perceptions of risk related to osteoporosis: a qualitative interview study. *Health Risk Soc.* 10 (2), 103–115.
- Scarry, E., 1987. *The Body in Pain: the Making and Unmaking of the World*. Oxford University Press, New York.
- Thomas, E.C., Bass, S.B., Siminoff, L.A., 2021. Beyond rationality: expanding the practice of shared decision making in modern medicine. *Soc. Sci. Med.* 277, 113900.
- Wengraf, T., 2001. *Qualitative Research Interviewing: Biographic Narrative and Semi-structured Methods*. SAGE Publications Ltd, London.
- Zoni-Berisso, M., Lercari, F., Carazza, T., Domenicucci, S., 2014. Epidemiology of atrial fibrillation: European perspective. *Clin. Epidemiol.* 6, 213–220.