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Understanding and managing uncertainty in health care: revisiting and advancing sociological contributions

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Abstract In this collection we revisit the enduring phenomenon of uncertainty in health care, and demonstrate how it still offers coherence and significance as an analytic concept. Through empirical studies of contemporary examples of health care related uncertainties and their management, our collection explores the different ways in which uncertainty may be articulated, enacted and experienced. The papers address a diverse range of healthcare contexts - Alzheimer's disease, neonatal surgery, cardiovascular disease prevention, cancer, addiction (use of alcohol and other drugs during pregnancy), mental health/disorders and medical education – and many tackle issues of contemporary relevance, such as an ageing population, and novel medical interventions and their sequelae. These empirical papers are complemented by a further theoretical contribution, which considers the role of 'implicit normativity' in masking and containing potential ethical uncertainty. By mapping themes across the collection, in this introduction we present a number of core analytical strands: (1) conceptualising uncertainty; (2) intersections of uncertainty with aspects of care; (3) managing uncertainty; and (4) structural constraints, economic austerity and uncertainty work. We reflect on the methodological and theoretical stances used to think sociologically about uncertainty in health care, and the strengths, silences and gaps we observe in the collection. We conclude by considering the implications of the insights gained for 'synthesising certainty' in practice and for future research in this area.

Why revisit uncertainty in health care?

One of the most pervasive themes in the sociology of medical knowledge is the role of uncertainty in clinical practice (Atkinson 1984, Fox 1957, 1959, 1980, 2000, Light 1979). In the 1950s Talcott Parsons impressed on Renee Fox the significance of uncertainty in modern medical practice as a 'theoretical concept, an empirical phenomenon and a human experience' (Fox 1980). The concept of uncertainty at that time was a serious challenge to positivistic assumptions of biomedicine and biomedical power, and foregrounded critical thinking on ethics, truth, norms and the essence of medical practice. Fox described herself as a 'watcher, chronicler and analyst of uncertainty in numerous medical settings' and over four decades ago charted changes in both medicine and wider society in terms of expectations and tolerance of uncertainty, and growing concerns about risk and danger. At the turn of the twenty-first century, the enduring relevance of uncertainty was underscored by Fox through her observation that 'Scientific, technological and clinical advances change the content of medical uncertainty, and alter its contours, but they do

not drive it away' (Fox 2000, p. 409). At the time of writing, sixty years on from Fox's first publications, the world is gripped by the Covid-19 pandemic, representing new uncertainties and challenges for healthcare systems across the globe (Simpkin 2020). Pandemics received sociological attention in one of the previous monographs in this series (Dingwall *et al.* 2013) and we anticipate valuable future sociological work exploring how these uncertainties connected to Covid-19 were understood, experienced and tackled.

A substantial body of sociological work has emphasised the importance of studying uncertainty in health care, and responses to it, with studies exploring the training needed to prepare doctors for uncertainties associated with diagnosis, treatment and patient response (Calnan 1984, Delamont and Atkinson 2001, Fox 1957, Light 1979, Mesman 2008, Parsons 1951) and the uncertainties experienced by patients (Gillespie 2012, Pietilä *et al.* 2018). The organisational demands for accurate prediction and effective screening (Warner and Gabe 2004) and the tensions faced by healthcare professionals working with a range of tests and interventions in the face of uncertainty have also been studied (Armstrong and Hilton 2014, Brown and Calnan 2010, Gale *et al.* 2016).

Our intention in putting together this monograph has been to revisit this enduring phenomenon in the context of policy and practice changes and developments. Foremost in our minds here, albeit far from an exhaustive list, were the recent emergence of constructs such as 'overdiagnosis', 'overtreatment' and 'overuse' (Brodersen *et al.* 2018), increasing public anxiety over health and risk of illness, shifting patient expectations on the benefits of scientific innovation and the reliability of clinical expertise, and the growth of organisational and technological 'quick fix' solutions that seek to 'manage uncertainty' (Greatbatch *et al.* 2005, Mackintosh and Sandall 2010). The rapid emergence of new technologies, public awareness of limitations in medical knowledge and pressures associated with grappling with uncertainty at an organisational and health system level are increasingly coming to the fore. Against a backdrop of heightened awareness of uncertainty at a broader societal level (Beck 1992, Giddens 1991), 'personalised medicine' has emerged as a concept which questions to what extent a particular treatment is beneficial for particular patient groups and whether a patient is receiving the right care, in the right place, at the right time, from the right people. Important too is the way in which patients are increasingly encouraged to share in decision-making and 'choose wisely' (<https://www.choosingwisely.co.uk/>) with regard to tests, treatment or procedures because of concerns over potential overdiagnosis and overtreatment. Within the medical literature, there have been recent calls for medical uncertainty to be better understood (Hatch 2017) and for doctors to both move into a therapeutic 'grey-scale space' and change their professional culture to embrace uncertainty (Simpkin and Schwartzstein 2016).

If we look in the journal *Sociology of Health and Illness* over the past twenty years we can see that there has been development of sociological thinking around the concept of uncertainty amongst contemporary researchers across a wide range of research fields including cancer, cardiovascular disease, mental health, well-being and chronic illness, neonatal care, lay experience and medical expertise. We see how it has been theorised in relation to emerging science and technologies (e.g. stem cell technology and genomic sequencing technology), alternative medicine, pandemic preparedness and organ transplantation. Sociological contributions to the field include notions of 'provisional certainty' within a chaotic future for prostate cancer (Pietilä *et al.* 2018) and the development of technoscientific identity (TSI) to enable patients to manage the biomedical and personal uncertainty of breast cancer (Sulik 2009). Identity management is also foregrounded in reactions to physiological risks and social changes accompanying organ transplantation (Cormier *et al.* 2017). For patients engaging with screening programmes, the risk experience in the absence of symptoms, becomes about measured vulnerability (Gillespie 2012). In terms of pandemic preparedness we see the 'potential energy' and 'persistent

unease' associated with uncertainties of when and where threats such as Ebola become real (Herrick 2019) and how modelling methods and calculation practices accommodate these uncertainties (Mansnerus 2013). Within the context of social media and debates about vaccination in a post-truth era, the reflexivity of social actors intersects with certainty and uncertainty (Numerato *et al.* 2019). Timmermans and Buchbinder (2010) introduce the concept of 'patients-in-waiting' confined to a state of diagnostic uncertainty about genetic disease, while Skinner *et al.* (2016) show how the construct of a negative genetic diagnostic result is imbued with uncertainty and contingency as well as optimism, promise, and potentiality for patients and clinicians. In the world of assisted conception and stem cell science, framings of the future are significant (Ehrich *et al.* 2012) while young people show ability to make sense of living with a parent dying, to give meaning to their imagined futures (Turner 2020).

The monograph seeks to bring together contemporary uncertainties, and to add value through the opportunity it provides to think across a collection of contributions. The result, we hope, is a diverse yet complementary set of papers which together help to identify and refine many of the salient sociological questions in this area, reflect on and integrate the various existing literatures, outline useful sociological insights for shaping clinical policy and practice, and identify key priorities for future sociological work in this area. In this introductory article we consider the papers as a whole – highlighting key commonalities and differences between them, as well as drawing out some of the cross cutting analytical themes we observe. We focus in particular on four themes: (i) conceptualisations of uncertainty; (ii) intersections of uncertainty with aspects of care; (iii) managing uncertainty; and (iv) structural constraints, economic austerity and uncertainty work. We conclude by reflecting on the contribution of the collection, including some of the silences and gaps we observe, and identifying ways forward for research and practice. We begin, though, with a brief introduction to each of the papers and its area of focus.

Overview of papers in the special issue

We have a varied selection of papers in this collection, which further our understanding of uncertainty in different healthcare contexts from a range of theoretical and methodological perspectives, and across varied clinical contexts.

In the only non-empirically based paper in this collection, Cribb discusses the idea of 'implicit normativity', and specifically its relevance to the management of ethical uncertainty. He considers in particular the role implicit normativity plays in masking and containing potential ethical uncertainty and the contrast and boundary between implicit normativity and what he terms 'overt ethics'. Using the idea of 'moral settlements' Cribb argues that paying attention to the management of ethical uncertainty shows the critically important contribution that an ambitious sociology of ethics can make to clinical ethics.

Two papers have the neonatal period as their foci. Chandler *et al* take as their focus neonatal abstinence syndrome (NAS), a constellation of symptoms occurring in a baby as a result of withdrawal from physically addictive substances taken by the mother during pregnancy. Through interviews with parents and focus groups with health and social care professionals, they show how the processes of anticipating, identifying and responding to NAS are characterised by significant uncertainty for both groups. They argue that understanding NAS as a social diagnosis, informed by Mol's political ontology of 'multiple' bodies/diseases (Mol 2002), may help to produce clinical and social responses to uncertainty which avoid, rather than promote, further marginalisation of parents who use drugs.

Hinton and Armstrong use interview data to explore the experiences of parents whose babies require neonatal surgery and consider the work these parents do to navigate and cope with the multiple uncertainties they face. The rapid acquisition of experiential and lay knowledge to develop expertise in their baby's condition and treatment options is evident early on, followed over time by the development of the technical and practical competence necessary to care for their babies at home.

Lane takes as her focus the increased demands from patients for formal diagnoses within psychiatry, against a backdrop of continued uncertainty surrounding disease categories as entities and concerns about the pathologisation of emotional distress. Drawing on ethnographic observations of clinical encounters within mental health settings, Lane focuses on interactions where diagnosis is negotiated in order to illustrate the role played by different kinds of diagnostic uncertainty in shaping these negotiations. Lane argues that diagnostic reification plays a key role in the moral categorisation of patients, particularly in cases where uncertainty exists about individual diagnostic status.

Pickersgill's paper focuses on clinical psychologists and their role as both key providers of and gatekeepers for therapeutic services. In particular, Pickersgill is interested in how clinical psychologists facilitate or control access to their services through the patient referral process. Drawing on interviews with this professional group, and with reference to both medical sociology and science and technology studies literatures, the paper interrogates some of the uncertainties around access to psychological therapy, and how decisions made by clinical psychologists involve negotiations of patient, service and professional ontologies.

Swallow takes as her focus the uncertain boundary between the 'normal' process of ageing and the pathological deterioration associated with Alzheimer's disease, and in particular the extension of the latter to include 'mild cognitive impairment'. Drawing on qualitative work including both observations and interviews, the paper examines practitioners' accounts of the complexity associated with constructing and navigating the boundaries between these entities in the clinical setting and healthcare professionals' deliberate invocations of uncertainty as a means of providing what they see as good care for their patients.

In the only paper focused on preventive health care in this collection, Cupit et al draw on an institutional ethnographic (IE) study of cardiovascular disease prevention in general practice, focusing on work of healthcare professionals who are tasked with discussing risk and preventative medications with patients. Paying particular attention to the social organisation of healthcare professionals' knowledge and front-line practices, they highlight the textual processes through which these overrule patients' concerns and uncertainties about preventative medication. Their argument is not that healthcare professionals are necessarily deficient in their practice, but that their work is importantly shaped in ways that orientate towards performance measures and tackling the burden of disease.

Cortez and Halpin explore uncertainty in relation to clinical trials for terminal non-small cell lung cancer, an aggressive and difficult to treat form of the disease. Analysing clinical interactions between doctors, patients and family members, they highlight how uncertainty is a significant issue for terminally ill patients, who must choose between palliative care and participation in research that might postpone their death but also potentially negatively impact in their quality of life. The tensions between high prognostic certainty about their condition and considerable uncertainty about trial participation is explored.

Bochatay and Bajwa take as their focus medical trainees learning to manage uncertainty, picking up a longstanding sociological interest in this area. Using ethnographic case studies of academic medical centres in Switzerland and the United States, they explore the processes through which trainees learn to manage uncertainty, including working under supervision, developing relationships of trust with supervisors, and gaining autonomy to practise

independently. Different attitudes towards uncertainty were developed, with trainees broadly coming to adopt their supervisors' attitudes towards uncertainty.

Conceptualising uncertainty

Having briefly introduced each of the papers, it is useful to articulate the various ways authors within the collection have conceptualised the relevance of uncertainty within contemporary practice. Uncertainty can be conceptualised from a psychological perspective, focusing on an individual's ability to tolerate and respond to it (Hillen *et al.* 2017). Sociological approaches tend to broaden the lens to attend to co-dependencies between 'the affective state of individuals' and 'socio-political and clinico-epistemic infrastructures' (Pickersgill 2019). We highlight dimensions of uncertainty across the papers: (i) epistemological and ontological uncertainty, and (ii) moral or normative dimensions.

Epistemological and ontological uncertainty

As Cribb notes, clinical uncertainty as an epistemic concept relates to the incomplete knowledge of healthcare professionals (including within biomedical sciences more generally) (Cribb 2019). The value and epistemic authority of medicine is open to challenge as medicine has no epistemological essence - there is no single medical model (Rose 2007). In the last decade concerns regarding 'too much medicine' and 'over-diagnosis and over-treatment' are increasingly surfacing in relation to specific conditions and practices (Armstrong 2018). While not necessarily straightforward to define, overdiagnosis and any subsequent overtreatment are terms generally used about instances in which a diagnosis is 'correct' according to current standards but the diagnosis or associated treatment has a low probability of benefitting the patient, and may instead be harmful (Moynihan *et al.* 2012). While initially used largely in the context of cancer screening, more recently concerns about overdiagnosis and overtreatment have spread to a wide range of clinical activities (Welch *et al.* 2011). Uncertainty related knowledge is constituted, negotiated, institutionalised and continually redefined.

In Lane's study, we see how questions over the reliability of clinical biomarkers and the presence of 'fuzzy boundaries' around categories (Fox 2000) threaten the epistemological certainty underpinning psychiatric diagnosis. Epistemological uncertainty provides space for patients to make a case for sought-after diagnoses (e.g. bipolar disorder and autism). It also enables *informal* diagnostic practices by professionals, including diagnostic denial from multi-disciplinary team members without formal rights to assign diagnosis (Lane 2019). We also see ontological uncertainty as the validity of the psychiatric categories and whether they should be conceptualised as disease entities or as reactions to life events is called into question. Assigning a diagnosis is a functional method of securing access to services - 'usefulness' is therefore prioritised - but it entails moving from the practicalities to objective markers, proving the underlying reality of disorder (Lane 2019). This 'essentialist' model of diagnosis presents the 'truth', evidenced in the distinguishable form and nature of disorders. The ontological status of autism as an entity, slips from view despite Lane's insights that an individual may 'have' this disorder and learn how to hide it (Lane 2019).

Within clinical psychology services, the Psychological Mindedness Scale (Shill and Lumley 2002) provides epistemic authority for gaining insight into the self (Pickersgill 2019). The scoring system helps psychologists navigate uncertainty and provides a framework for considering who should receive therapy and why (Pickersgill 2019). Pre-assessments largely occur in the absence of patients; as a result, the ontology of a patient is negotiated at a distance via a

multifaceted biopsychosocial matrix involving demographic data, psychological identifiers, and social and behavioural indicators and networks (Pickersgill 2019).

Swallow draws attention to the epistemological uncertainty associated with AD, as cognitive scores denoting MCI are folded into the category of AD despite ambiguity around whether cognitive decline is attributable to early AD and whether symptoms of MCI will progress to AD. Whilst this diagnostic uncertainty legitimises memory nurses' 'watchful waiting', it also unsettles practitioners looking for evidence as to whether 'you've got AD or you haven't' (Swallow 2019).

Cortez highlights how physicians' use of probabilistic language to describe the efficacy of a cancer trial drug introduces uncertainty, both in terms of specificity of impact (the effect of the drug on the specific patient) and temporality (when the patient might die). Physicians' use of medical terminology serves to reinforce epistemic boundaries as patients grapple to understand the significance of intervention options, their consequences and prognostic certainty from professionalised discourse. Interactional uncertainty surrounding the trial drugs is compounded by the temporal uncertainty of the trial drug side effects, disease advancement and interactions between the drug and the patient's particular form of cancer. Clinical trials also disrupt prognostic certainty within the context of terminal care. Benefits in terms of shrinking or delaying growth of the cancer become re-imagined as offering hope, or a 'silver bullet' or 'lottery ticket' that might eradicate the terminal nature of the cancer (Cortez and Halpin 2020).

Moral/normative dimensions

In addition to epistemic and ontological uncertainty, Cribb also brings into focus the existential element of uncertainty; 'the phenomenological or affective concept relating to the experience of the patient' (Cribb 2019). He calls for normative rather than just descriptive or explanatory thinking to surface underpinning value judgements that intersect with uncertainty work. Cribb's focus on the role of implicit normativity in the management of ethical uncertainty foregrounds ethical uncertainty as a pervasive risk which tends to evade resolution (Cribb 2019). Only some of this uncertainty is surfaced through professional ethics, or other ethics discourses, but 'much is implicitly managed through forms of social organisation and routine practice' (Cribb 2019, p. 2). Ethical uncertainty is argued to be managed through the construction of 'moral settlements', a matrix of norms, social practices, cultures and technologies, and 'the socially embedded dispositions of human and non-human actors' (Cribb 2019).

The moral dimension of clinical uncertainty in front-line practice is made explicit in several of the papers. Chandler's research is situated in the morally laden field of drug use during pregnancy and early parenthood. NAS is identified, monitored and treated in different ways (Hudak and Tan 2012, Knopf 2016, Wolff and Perez-Montejano 2014). Requirement of NNU services emerges across the accounts as a clear signifier of 'severe' NAS' (Chandler *et al.* 2020, p. 10). Admission to NNU has both a moral (a sign of poor parenting) and legal significance (marking the involvement from statutory social work and child protection). Tensions emerge amongst professionals around the significance of 'naming' NAS. Competing narratives highlight on the one hand the importance of communicating this diagnosis to parents to enable them to take responsibility for their drug use versus others that work to avoid stigma, and reduce blame/shame in the face of uncertainties around the label. These moral tensions highlight the 'instability' of NAS, and its shifting form in different contexts of care.

Within the context of ageing and cognitive decline, we see how MCI medicalises memory loss. Normative assumptions regarding the ageing process are reconfigured and behaviours such as 'forgetfulness' are constructed as problematic and pathological. MCI as a formal diagnosis provided a point of distinction for patients from their normal ageing; however, this also works to reinforce pejorative views of cognitive deterioration, dominant social and cultural

imaginings of age, and normative assumptions that to age successfully is to resist ageing (Swallow 2019, Torres and Hammarström 2009).

Doubt over truth telling and legitimacy of parents'/patients' accounts surface within the data in both Chandler and Lane's research. Within the context of NAS, doubts over the validity of drug use disclosed by parents are raised by other parents as well as by professionals (Chandler *et al.* 2020). Within the context of psychiatry, the patient's authenticity and the functional gain offered to them by receipt of a diagnosis, help shape perceptions of their 'fit' with the diagnostic category and legitimacy of their claims. Diagnoses associated with psychosis (e.g. bipolar disorder and schizophrenia) hold greater value than personality disorder or common mental problems (such as anxiety-related disorders and depression), creating a moral hierarchy of diagnosis within psychiatry (Lane 2019).

Moral or normative elements to professional practice are also described. Within primary care, front-line healthcare professionals orientate themselves towards reducing not only the economic but moral 'burden of disease' in terms of lives and costs saved (Cupit *et al.* 2020). Morally inflected professional judgement (Styhre 2013) is apparent in professional accounts of uncertainty work within clinical psychology. Being 'good' means exercising evidence-based clinical judgment (Timmermans and Angell 2001), and demonstrating care within an over stretched service. Preservation of the clinical and moral identity of a psychologist as 'good' links to constructs of patients' readiness for therapy and psychological mindedness which legitimises exclusion from therapy as a form of care (i.e. protecting patients from failure if patient/service misaligned) (Pickersgill 2019). Normative bias (Kugelmass 2016) features 'as a constitutive element of clinical experience that shapes and directs the management of uncertainty and therapeutic (in)action' (Pickersgill 2019, p. 13). Even within structural constraints, psychologists have the power to 'stretch or shrink' a service remit, and facilitate or deny access to particular patients. These flexible service boundaries act as a form of structural discrimination and make it difficult for patients denied therapy to contest this professional decision (Pickersgill 2019).

Having considered how uncertainty has been conceptualised in the various papers, we now explore how the papers address the intersection of uncertainty with specific aspects of care. This is followed by a discussion of different forms of managing or 'synthesising' (Pickersgill 2019) uncertainty.

Intersections of uncertainty with aspects of care

We see through our collection of papers how uncertainty manifests itself and is mediated and negotiated during distinct aspects of care. Focusing firstly on diagnosis, we see how diagnostic processes and products are used as ways 'to interpret, regulate, and mediate various forms of self-understanding and activity' (Brinkmann 2017, p. 170). Lane describes the tensions in mental health, between patient level work to *broaden* diagnostic categories (legitimised by lay narratives related to *underdiagnosis*), and professionals' reliance on categorical dimensions, which enables *tightening* functionality in relation to professional categorisation practices within clinical assessments. Individual diagnostic uncertainty 'bumps up' against reified functional categories and allows for a downgrading to less medicalised categories, shifting responsabilisation of this uncertainty to patients (Lane 2019).

Turning to different settings, we see how a diagnosis of mild cognitive impairment (MCI) offers practitioners the opportunity to *mobilise* uncertainty via deferral, keeping patients on in the system who are classified with cognitive deterioration not yet perceived to be Alzheimer's disease (AD). However, alongside the functional utility of a MCI diagnosis sit practitioners'

doubts about its prognostic value or its ability to mobilise resources or enable access to subsequent treatment (Swallow 2019). Within the context of neonatal abstinence syndrome (NAS), the ‘space of uncertainty’ means that accounts can simultaneously hold the diagnosis and cause of NAS as uncertain while also attributing blame for causing’ NAS or the possibility of NAS. In some cases, ‘NAS was anticipated by parents and some professionals, it was searched for, expected: it retained power as a potentiality even if diagnostic criteria were contested or absent’ (Chandler *et al.* 2020).

If we reflect on *access* to care, in particular access to psychological services, we see that the process of assessment requires the resolution of uncertainty; it involves the clinician appraising the patient’s suitability for therapy and determining the likely gains. Patients and to a lesser extent clinicians are impacted by the certainties psychologists produce at the point of referral or assessment, particularly if decision-making leads to exclusion from therapy (Pickersgill 2019). Within the realms of prognostic uncertainty, we see how clinical trials produce uncertainty in the context of terminal cancer. Trial drugs disrupt the certainty of a terminal cancer diagnosis and the relationship between precision and uncertainty is articulated through medical language and patient–doctor interactions (Cortez and Halpin 2020).

Lastly, turning to uncertainties about treatment and ongoing care we see from Cupit *et al.* (2020) how the social organisation of healthcare professionals’ knowledge and front-line practices highlights the textual processes through which they overrule patients’ uncertainties about taking preventative medication, such that some patients feel unable to openly discuss their health needs in preventative consultations. Healthcare professionals’ activation of knowledge related to ‘evidence-based risk reduction’ serves to frame patients’ queries as barriers to be overcome rather than meaningfully engaged with. In contrast, Hinton and Armstrong (2020) in their paper highlight the varying forms of uncertainty acknowledged by both healthcare professionals and parents in the context of neonatal surgery in order to explore the complex journeys through these uncertainties and how parents navigate these. They demonstrate that uncertainty is an integral part of the experience of parents in this clinical context, taking on different guises as it shifts from uncertainty about whether their baby will survive through to managing uncertainties in their child’s care when they get home.

Managing uncertainty: work to structure and tame

A significant aspect of managing, or ‘synthesising’ (Pickersgill 2019), uncertainty entails engagement with the wider categorisation and classification structures that order medical practice. Categorising patients and medical work is intrinsic to the bureaucracy of healthcare organisations; classification of medical work knits together ‘to form the texture of a social space’ (Bowker and Star 1999, p. 286). All of the papers in this collection highlight, in different ways, processes to tame uncertainty by filtering, ordering, structuring and imposing limits (Cribb 2019). Incentives, social sanctions, performance measures, directives and guidelines all work to shape the environment, construct what good looks like, and set boundaries around what can be tolerated and normalised (Amalberti *et al.* 2006). This section considers three areas related to ‘managing’ uncertainty: (i) categorisation; (ii) scoring systems; and (iii) competencies.

Categorisation

Pickersgill describes how psychologists make distinctions between what qualifies as a mental health issue, and what they perceive as lying *outside* their scope of expertise, such as a social issue (e.g. housing difficulty) or something that requires services distinct from psychological support such as relationship support or chronic pain management (Pickersgill 2019). A key

aspect of psychologists' uncertainty work involves the construction of psychological mindedness. Assessment of this construct involves consideration of both the presenting *issue* and the *individual* being assessed. Access to therapy is in a number of cases contingent on presence of the construct (Pickersgill 2019).

The distinction practices evident in Pickersgill's paper are also mirrored within the assessments undertaken by Community Mental Health Teams (CMHT) in Lane's study. Her data indicate the extent to which reification and adherence to categorical understandings of disorder contribute to the assessment process. The exclusiveness of such categories enables categorical certainty; this in turn allows for gatekeeping practices within mental health care and diagnostic denial (i.e. denying a person's claim to a diagnosis). Patients are required to demonstrate 'enough' symptoms. Hannah's account and her family history, for example, are undermined by an atypical presentation, and Hannah's high-functioning status (particularly career success) leads to doubt about her diagnosis of autism (Lane 2019).

Lane's findings paradoxically highlight how, despite this categorical certainty, the parameters defining the categories are in constant flux. She notes how diagnostic performativity has become part of enacting disorder (Martin 2009) via media and entertainment, leading individuals to identify with popular categories such as bipolar disorder and autism. Lane refers to a moral hierarchy of diagnosis where some conditions and medical categories are more sought after. Practices of diagnostic identification and negotiation contribute to the broadening of diagnostic categories, illustrating Hacking's concept of the 'looping effects of human kinds' (Hacking 1995). This reframing can, in turn, change the way in which such diagnoses are classified (Lane 2019).

Downgrading of patients' conditions to the category of anxiety/stress is also a common feature of CMHT assessments, which foregrounds patients' own agency in managing their mental health. As in Pickersgill's work, categories in CMHT documentation include 'the worried well' as well as the 'seriously mentally ill'. Reframing patients' difficulties as 'life problems' as opposed to serious mental illness enables professionals to shift care 'towards less intensive services and self-management such as primary mental health courses, self-help 'apps', mindfulness and 'bibliotherapy' (Lane 2019, p. 10). As the source of the uncertainty is redeployed within the *individual*, rather than within the mental health *system*, legitimacy is provided to exclude patients from membership of more exclusive and sought-after categories (Lane 2019).

Scoring systems

In Cupit et al's paper we see how elements of uncertainty intersect with the social organisation of CVD prevention within the context of the Global Burden of Disease (GBD) and preventative medicine. 'Within GBD discourse, talk and activity is coordinated through epidemiological metrics, and through the statistical outcomes of clinical trials which inform "evidence-based medicine"' (Cupit *et al.* 2020). Risk scoring and management guidelines offer structure and certainty. Despite the ambiguity inherent in translating population-based risk scoring to the individual level, this uncertainty recedes from view in the clinical encounter. Rather than engaging and staying with uncertainty i.e. articulating uncertainties relative to an individual's particular social situations and working to make sense of these, clinicians prefer to defer to the biomedical authority imbued within the guidelines, and encourage statin adherence and behavioural compliance with lifestyle change (Cupit *et al.* 2020) At an organisational level, general practices are compared across regions using 'accountability circuits' (Griffith and Smith 2014, p. 10) which provide a mechanism to socially organise CVD prevention via multiple, interrelated textual processes, orientated towards quantifiably reducing statistical measures of the 'burden of disease' (Cupit *et al.* 2020).

Key elements in Chandler's study of NAS are the risk stratification and distinction practices operationalised *between* particular bodies; these distinction practices form part of the material

and social production of NAS. Chandler *et al* draw out the tensions implicit when working with uncertainty for practitioners, and managing this for parents, within the wider ordering context of child protection policies and practices (Chandler *et al.* 2020). Good practice involves parental involvement in use of score charts - Finnegan's Neonatal Abstinence Score Sheet or the Lipsitz Scoring Tool - but this is also associated with the threat of losing custody of their baby if they fail to present themselves as 'good enough' parents (Chandler *et al.* 2013, Rhodes *et al.* 2010, Whittaker *et al.* 2019), interested in their baby's well-being. The score charts become a visible means of articulating NAS, guiding care pathways. The uncertainty of NAS scoring features throughout these accounts, with contestation around the interpretation and significance of the scores between parents and staff, which heightens in intensity when the potential threat of admission to NNU is under consideration (Chandler *et al.* 2020).

Swallow's study draws attention to distinction practices in the context of AD as practitioners engage in determining boundaries between physiology (normal ageing) and pathology. The AD category has been extended to include the label 'Mild Cognitive Impairment' despite uncertainty about whether individuals will subsequently develop AD in the future. Cognitive screening processes used to detect and diagnose the initial stages of cognitive decline include the Addenbrooke's Cognitive Examination 111 (ACE 111) and the Montreal Cognitive Assessment, alongside magnetic resonance imaging (MRI) scans, computerised tomography (CT) scans and blood tests. Borderline cognitive scores present practitioners with uncertainty about whether a classification of AD is indicated or whether the scores reflect processes of normal ageing. The memory clinic provides a containment space that allows for 'the imprecise', enabling practitioners to keep patients on in the service for 'watchful waiting' (Petersen *et al.* 2014) so they can involve different clinical teams, e.g. neuropsychology, for further testing. Borderline scores are transformed into a label of MCI which provides a level of functionality (Swallow 2019).

Competencies

The only paper in this collection to focus on non-healthcare professionals' management of uncertainty is that by Hinton and Armstrong (2020), focusing as it does on the experiences of parents whose babies required neonatal surgery. Drawing attention to the practical illness and knowledge production work in which parents engage as they negotiate their roles and the boundaries between the lay and the clinical, Hinton and Armstrong show how in the face of considerable uncertainties, parents develop the technical and practical competence to care for their babies at home, and the knowledge and confidence to be able to interpret signs and symptoms and exercise judgement in whether to seek additional care.

Bochatay's study of medical education indicates the significance of trust and supervisory relationships for trainees' development of psychological safety and autonomy in handling uncertainty. Trainees benefit from a progressive, 'supported autonomy' (Jenkins 2018), and reproduce supervisors' attitudes towards uncertainty (Bochatay and Bajwa 2020). However, Bochatay also draws attention to the structured assessment tools and competency-based systems that have been introduced to standardise medical education and increase transparency (Chen *et al.* 2015, Wallenburg *et al.* 2015). Criteria and measurement tools attempt to categorise what clinicians 'do' as daily work (e.g. entrustable professional activities (EPAs)). However, Bochatay describes how such evaluation tools are used by some supervisors as indicators for improvement regardless of trainees' performance (Wallenburg *et al.* 2015). Working time regulations place trainees in a compromising, ambiguous position as to whether to leave work undone at the end of a shift or to lie about their working times (Szymczak *et al.* 2010).

Bringing these categorisation, scoring systems and competencies together we see that where uncertainties, contradictions and misalignments occur, forms of order are imposed, and

influenced by hierarchies of particular pieces of evidence. Coordination work is required to manage any disjunctures. Multiple markers, metrics and data are used to construct categories of risk, health and illness and to defend gate-keeping practices. Tools and measures embody logics and sets of ethical dispositions and work as ethical actors (Armstrong *et al.* 2018, Gardner and Cribb 2016, Mackintosh and Sandall 2015). We now turn to our last analytical theme which highlights how the papers in this collection illustrate the ways in which uncertainty is intertwined with and shaped by the socio-political context of contemporary health care.

Structural constraints, economic austerity and uncertainty work

A number of the papers note the complex relationship between structural constraints, economic austerity and uncertainty work. In terms of negotiating access to clinical psychological services, the ‘synthesis of certainty’ plays out at a service level within the wider landscape of long waiting lists and pressures to meet service targets (e.g. waiting list targets). Pickersgill describes how exclusion and boundary setting which deny patients’ access to psychiatric services is presented as a rational course of action that reflects ‘the clinical and economic realpolitik of the NHS’ (Pickersgill 2019). Professional boundaries of expertise are ‘drawn and reified’. Patients are encouraged not to self-refer as staff worry about being overwhelmed with inappropriate referrals (e.g. the ‘worried well’) without the protective netting of some form of professional gate keeping. Referral criteria can help manage demand. Other professional services, e.g. CBT therapists, are positioned as *more appropriate* providing justification for this rationing. However, clinicians also exercise individual agency within this context of uncertainty and make case specific decisions about who is most in need of access to psychological care. On occasion, this means accepting patients who they perhaps technically should not, raising concerns about equity of access. Within the wider mental health and social care ecosystem, restrictions and rationing intersect with uncertainty work to create structural inequalities, as some patients are (dis)advantaged over others (Pickersgill 2019).

Similarly, Lane describes how within CMHTs, professional withholding of a diagnosis for those with uncertain medical status is more likely where resources are constrained within the context of economic austerity. This demedicalisation could appear as ‘volitional stigma’ (Easter 2012), as behaviour is interpreted as an ongoing voluntary choice rather than stemming from mental illness. Diagnostic downgrading may have the unintended consequence of driving patients to seek medical help, in efforts to balance such ‘moralising’ (Lane 2019).

Both Lane and Swallow’s studies highlight the functional role of diagnoses as the label mobilises additional resources and access to treatment options (Jutel 2009, Jutel and Nettleton 2011). Lane describes that the stakeholders additionally involved in shaping boundaries around psychiatric diagnoses. Some organisations have a stake in medicalising a condition e.g. pharmaceutical companies, advocacy associations, whereas some individuals stand to gain *functionally* from access to disability-related concessions (e.g. sick leave or disability benefits) or through *acquisition of legitimacy* via a narrative to explain difficulties and differences (Anspach 2011, Lane 2019). Individual negotiation occurs at the micro level as patients present with ‘hybrid diagnostic repertoires’ (Anspach 2011, p. xiv), but these encounters are nested within the wider social and political context. Professionals still retain the power to assign a diagnosis. Access to treatment is contingent on securing a diagnosis and links with clinical guidelines. Keeping the boundaries of diagnostic categories contained is a way for professionals to gate-keep access to more intensive and costly services (Lane 2019).

Swallow’s study is set within the context of a projected increase in prevalence of AD and increasing attention on early detection of AD, constrained UK public funding for social care

and constrained resources affecting the availability of AD care post-diagnosis. Swallow describes how practitioners *resist* use of the MCI label given uncertainties about the added value it provides, either for prognosis or subsequent care (Swallow 2019).

Chandler et al refer to causal uncertainties in relation to NAS which permeates parents' concerns as to whether their baby might 'have NAS' when it is born. Despite acknowledging the unpredictable nature of NAS which does not correlate neatly with the amount and type of drugs taken, practitioners and parents spend time trying to 'tame' this uncertainty by focusing on reducing drug use. Seeing maternal drug use as the cause leads to widespread 'blaming' (by parents and professionals) of the mothers when babies exhibit symptoms of NAS, and questioning of the validity of mothers' accounts i.e. truths about their drug use.

Within this context, diagnosis of NAS is enacted within the wider political, economic, cultural and social context. The enactment of diagnosis is laden with uncertainty, contestation and concern, and power relationships *beyond* the biomedical evidence. Whilst the wider political/economic context and those social structures that shape maternal drug use are not explicitly mentioned in Chandler's interviews, the structural and symbolic violence which contributes to the material and social production of this particular condition can be seen. This wider frame enables our understanding of 'how and why it is identified in particular bodies (and, perhaps, not others)' (Chandler *et al.* 2020, p. 3).

Cribb notes that health care is inherently complex and practitioners do not have the luxury of merely contemplating uncertainty, they *have* to engage with it. As actors intimately involved within the everyday organisation and delivery of health care, they are part of the fabric of care. This raises questions about how far it is possible for them to be reflexive about their role within the wider socio-political context of care. 'Health professionals who are accountable not only for enacting health care, often in non-ideal circumstances, but also for sustaining the broad effectiveness of the systems within which they operate, are not in a position to be continuously and pervasively 'surfacing' implicit normativity' (Cribb 2019).

Conclusion

Contribution of this collection, and its silences and gaps

Looking across this collection we see attention to health and illness categories that can be termed policy 'matters of concern'. These include Alzheimer's disease, cardiovascular disease, cancer, addiction (use of alcohol and other drugs during pregnancy) and mental health/disorders. Concern about these categories is articulated through various means (Moser 2016) including policy initiatives to improve risk assessment and diagnosis (e.g. NHS Health Check appointment), greater research funding to understand causality and experience, together with the provision of additional clinical pathways and services (e.g. dementia services and memory clinics; Improving Access to Psychological Therapies (IAPT)).

The collection highlights the range of approaches that may be used to think sociologically about managing uncertainty in health care. Cribb's use of the construct 'moral settlement' brings implicit normativity and the management of uncertainty to the fore, shifting it from background context to explicitly acknowledge the range and significance of relatively hidden factors that shape the logics of care and how ethical practice is enacted. Cribb's use of moral settlements enables focus on structural features of the ethical landscape i.e. power structures, relationality and care, embodiment and marginal voices (Scully 2017). As a result, ethics emerges as intertwined with underlying social and institutional fields and practices. He draws our attention to those wicked problems (Rittel and Weber 1973) that are subject to heightened and substantial ethical contention and controversy, such as those at the beginning (foetal

monitoring) and end of life (DNACPR). Through his analysis we see how certain practices become valorised while others are marginalised, colonised, obscured or co-opted.

Alternatively a science and technology lens on the nature of things (ontologies) (Mol 1999) enables exploration of how uncertainty is enacted through discursive and practical work. Zooming in and out and switching theoretical lenses (Nicolini 2009) facilitates taking account of both the practical accomplishment of managing uncertainty and the wider social and structural factors that shape this practice. In an effort to 'bring bodies back in' (p. 13), Chandler et al. zoom in by drawing on Mol's 'body multiple' (Mol 2002) and zoom out with Brown's social diagnosis (Brown *et al.* 2011). The lens of 'social diagnosis' enables exploration of relationships and co-dependencies *between* individuals, publics and structural factors (Brown *et al.* 2011).

A number of the included papers used ethnographic methods to gain situated understandings of encounters across a diverse range of clinics (Cortez and Halpin 2020, Lane 2019, Swallow 2019) and ward-based work (Bochatay and Bajwa 2020). Cupit et al's paper illustrates the functionality of discursive power as they draw on an institutional ethnography approach (Smith 2005) to foreground 'ruling relations' and the 'institutional discourse' that displaces localised embodied understandings of CVD prevention (Cupit *et al.* 2020). Rather than embodying the values of involvement and empowerment, the language of 'patient-centredness' and 'shared decision-making' is employed by healthcare professionals to denote the institutional agenda of compliance (Cupit *et al.* 2020).

The monograph brings new insights to challenging intersections between contemporary uncertainties, neoliberal ideologies, biomedical approaches, and broader socio-political contexts. Through drawing papers together in this way, we have been able to explore structural and cultural conditions across a range of healthcare contexts, and question to what extent healthcare professionals and others tasked with managing uncertainty are supported to do (Vriens *et al.* 2016). The collection has extended our understandings of the role uncertainty and certainty play in healthcare trainees' socialisation, knowledge and action (Atkinson 1984, Fox 1957, 1959, Light 1979), and highlighted the significance of social processes such as trust and continuity, and the existential element of uncertainty as part of the implicit fabric of care.

A key focus of many of our papers, and therefore an important way in which the collection and its emphasis on managing uncertainty builds on previous work, is the notion of 'uncertainty work' (Moreira *et al.* 2009, Pickersgill 2011), including its temporal features. This form of work may not be directly experienced or categorised as such by those undertaking it, even though the clinical tasks or activities in which they are engaged are aimed at 'making certain an undefined plan of action' (Pickersgill 2019). While uncertainty might prompt knowledge generation or shifts in social practices, this may not be regarded as satisfactory ends by those participating in uncertainty work (e.g. clinicians) or subject to its effects (e.g. patients). Even if not recognised as particular to and within the rubric of uncertainty work, responding to procedural uncertainty requires skilled judgement (Styhre 2013), and the imagining of alternative futures, social practices and consequences. Movement through uncertainty moments is (psycho)socially productive: action, affects and ontologies are realised through the synthesis and creation of certitude (Moreira *et al.* 2009, Pickersgill 2019, Reed *et al.* 2016).

Previous research has shown how diagnostic practices can provide space for different productions/constructions of illness and bodies (Gardner *et al.* 2011, Mol 2002). It is possible to create 'a sense of a singular, coherent order of things, where different but linked aspects of the same body have been investigated by two separate diagnostic practices', providing a 'patchwork' and 'reifying uncertainty' (Gardner *et al.* 2011, p. 849). Findings from Chandler et al, Lane and Swallow highlight the moral hierarchies within these patchworks enacted through vulnerabilities, labels and claims to legitimacy. The collection foregrounds the labelling and

stigma associated with particular individual behaviours (e.g. mothering), together with moral categorisation around risk and decision-making. Navigating classifications around cognitive impairment for those patients at the borderlines of normality requires managing the uncertainty around progression to AD and anxieties around diagnosis, but also needs to account for socio-cultural discourses around age and cognitive deterioration. At times, practitioners work to 'fold in' to a diagnostic category' (Timmermans and Buchbinder 2010) whilst at other times they actively avoid utilising the diagnostic label in order to contain further ambiguity (Swallow 2019).

Through case studies we see how the degree of uncertainty burden is distributed across multiple disciplines and services within a complex healthcare system. Psychiatrists and nurses in memory clinics (Swallow 2019), and clinical psychologists assessing mental health referrals (Pickersgill 2019) act as boundary actors, managing coordination work and ambiguities over lines of responsibility and accountability (Cramer *et al.* 2018). Managing the uncertainty work of clarifying service identities and ontologies is easier where alternative services are available, and more difficult where there are fewer services to signpost to or where there are gaps in services.

With the exception of Hinton and Armstrong's paper, we note in the collection an absence of papers on patients' and families' experiences of living with uncertainty (Gillespie 2012, Turner 2020).

Whilst several of the papers were based on ethnographic insights of encounters between healthcare professionals and patients (Cortez and Halpin 2020, Lane 2019, Swallow 2019), notable gaps include explicit analysis of the nature of the dyadic relationship *between* health professionals and patients (Calnan 1984), and the actual mechanics of communication, medical talk and decision-making in the face of uncertainty (Pilnick and Dingwall 2011, Pilnick and Zayts 2016). Other absences include consideration of the role of less formal modes of knowing i.e. gut feeling, tacit knowledge and intuition to make decisions about risk, diagnosis and help seeking (Locock *et al.* 2016, Urbane *et al.* 2019).

We also noted that most of the papers focused at a micro level (patient-professional) and that analyses of response to or tolerance of diagnostic, prognostic and treatment uncertainty at meso (organisational) and macro level (system) were missing. Only Bochatay and Bajwa (2020) included an assessment of different health systems (US/ Switzerland) which limited our ability to compare and contrast societal expectations, policy logics, organisational dynamics and healthcare delivery in the face of differing types of uncertainty (Power 2008). Also missing were media representations of certainty and uncertainty related to diagnosis, prognosis and treatment (Clarke and Everest 2006). Particularly pertinent given the current crisis of COVID-19 is the silence within the collection regarding analyses of efforts to manage and stabilise sources of uncertainty linked to societal challenges such as antimicrobial resistance (Gröndal 2018, Will 2018) and epidemics/pandemics (Nerlich and Halliday 2007). 'Emerging diseases are sources of instability, uncertainty and even crises that can make visible features of the social order ordinarily opaque to investigation' (Dingwall *et al.* 2013, p. 1).

Ways forward for research and practice

We see through the varied contributions to this collection that uncertainty still offers value as a sensitising concept (Strauss 1987) and analytical tool. Uncertainty is an inherent feature of health, illness and care practices. 'It is never possible to know with certainty whether a particular diagnosis is final, whether a procedure will produce the desired result, whether a patient will follow the treatment plan or whether an apparently stable and safe situation remains so' (Pedersen 2016, p. 9). In health care, uncertainty co-produces and is bound by the dialectic between structure and practice.

The papers in this collection suggest future avenues of empirical sociological inquiry that can usefully use uncertainty as an important starting point for analysis, providing us with a means through which to understand what in health care is recognisable and what is invisible, and how hegemony and countervailing powers co-exist in its management. Research into the social, symbolic and technical aspects of managing uncertainty, together with its implications for medical training across both the formal and so-called 'hidden' curriculum (Lempp and Seale 2004), would help inform the development of practical support systems to enable health-care professionals to meet these challenges (Vriens *et al.* 2016).

Among the key insights from the selected papers are the ways in which uncertainty moments may be *productive* as they enable and enhance the care of patients, and how patient outcomes are *recursively patterned* as 'professional ontologies and the praxis of uncertainty work are reciprocally constituted' (Pickersgill 2019, p. 12). However, synthesising certainty intersects with context in sometimes complex ways. A future focus of sociological study on the (re)production of forms of structural discrimination within clinical practices such as diagnosis, assessment and referral (Pickersgill 2019, Swallow 2019) would be valuable.

In terms of significance for practice, we see from the papers that while uncertainty regarding individual diagnosis *is* expressed, ontological uncertainty at the level of diagnostic categories largely remains hidden and unarticulated. A shift in what is explicitly shared with patients may offer a way forward. Lane for example argues that given the frequency of diagnostic uncertainty within psychiatry, sharing with patients the lack of clear boundaries between diagnostic categories will arguably provide potentially helpful information for patients. A move towards 'dimensional models which emphasise severity, incorporate heterogeneity and emphasise individual symptoms as opposed to categorical status, may be more appropriate within clinical communication, particularly for those on the boundaries of a diagnosis' (Lane 2019).

'Good care' involves healthcare professionals and patients working together to 'try, adjust and try again' within the context of uncertainty about what is possible and/or desirable in what might be constantly changing circumstances (Cupit *et al.* 2020, Mol 2008, p. 22). Interactional work is also needed to police epistemic boundaries between patients and clinicians (Hinton and Armstrong 2020), in order to ensure interpretive divides do not lead to a form of 'epistemic injustice', as certain knowledge claims are dismissed (Cetina 1999, Fricker 2007). Placing value on *people* rather than *behaviours or tasks* to emphasise the social elements of diagnosis may offer a way to reimagine care, and could offer space to flatten hierarchies and acknowledge lay/professional differences (Chandler *et al.* 2020). This approach has been used with promising initial indications in family-focused approaches in adult drug services (Orr *et al.* 2014).

In terms of death awareness, clinical trial interactions provide a space for both professionals and patients to move from active open awareness (i.e. explicit acceptance of a terminal prognosis) to uncertain open awareness, with a focus on possible positive outcomes associated with cancer trials. Cortez and Halpin suggest the importance of moving *beyond* quantitative language to denote risk and uncertainty to acknowledge the limits of medical knowledge. Consideration of temporalities, priorities and the quality and quantity of their remaining life may help patients prepare for decision-making and their uncertain futures (Cortez and Halpin 2020).

Lastly, a refocus away from accountability *mechanisms* to the wider structural and cultural *conditions*, the 'spectrum of axes of social difference' and practical *support systems* would allow us to see how professionals meet the challenges of uncertainty work. However a word of caution in our reframing; 'the more that implicit normativity is made explicit the greater the danger that the lived experience of ethical uncertainty will become difficult to manage' (Cribb 2019). Continuity in medical education appears significant as is the need to explicate how processes such as working under supervision, developing relationships of trust with supervisors and gaining autonomy enable medical trainees to learn to manage uncertainty. Future strategies

may include exposing trainees to ‘the phenomenological lived experience’ in order to develop ‘comfort with uncertainty’ (Bochatay and Bajwa 2020, Ilgen *et al.* 2019, p. 4).

We began this introductory paper to the special issue with a quote from Renee Fox on the enduring relevance of uncertainty. We turn to her again as we conclude our introduction, this time to capture what can be gained through the study of uncertainty: ‘Our current preoccupation with medical uncertainty, error, risk and harm is a symbolic language through which we are communicating some of our deepest questions about the cognitive, moral and the metaphysical foundations of our cultural tradition and outlook’ (Fox 1980, p. 45). Through this introductory piece we have sought to draw out and synthesise the contributions each of the individual papers makes and the deeper questions, to use Fox’s language, that each raises and explores. We hope that you will enjoy reading them as much as we have.

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