Medical Sociology Study Group

Annual Conference Programme

13 – 15 September 2023

University of Sussex

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Presentations taking place AM on Thursday 14 September

Thursday 14 September

09:00-09:30

Room G36 – Diagnosis, Screening & Treatment

Parents, children and health professionals' views on proposed changes to incorporate next generation sequencing into the cystic fibrosis newborn screening protocol

Jane Chudleigh

(Kings College London)

Changes to newborn screening for cystic fibrosis (CF) in the UK, to include next generation sequencing (NGS), could help avoid (i)repeat testing and (ii)reporting carriers. Depending on how this were implemented, it could either increase identification of screen positive cases, including those with an uncertain outcome (termed CF screen positive inconclusive diagnosis, CFSPID), or increase specificity; reducing the identification of CFSPID, but at the cost of missed diagnoses of true CF. This project explored views of various stakeholders on these proposed changes.

Parents of children with CF (n=24) or CFSPID (n=7), and children (n=6) and adults (n=4) with CF were purposefully sampled. Parents and adults with CF (n=35) took part in focus groups, children (n=6) were interviewed. Parents and adults with CF (n=28) and health professionals (n=9) also took part in workshops.

Findings indicated a preference for a more sensitive approach to NGS that reduced the risk of CF cases being missed. This was due to the perceived importance of identifying children with CF as early as possible to enable access to appropriate treatment and improved health outcomes. Identifying children with CFSPID was considered potentially beneficial to avoid a diagnostic odyssey and facilitate early access to treatment if needed. Participants suggested that identifying more children with CFSPID may also support a better understanding of the designation among health professionals and contribute to a developing evidence-base to support its management. Good quality communication with parents and provision of relevant information were seen as pivotal to realizing these benefits whilst minimizing harms.

Room 155 - Health Services Delivery

Between advocacy and discipline: Negotiating experiential knowledge in group clinics

Jackie Van Dael, Claire Reidy, Sara Shaw, Chrysanthi Papoutsi

(Nuffield Department of Primary Care Health Sciences, University of Oxford)

Patient expertise and experiential knowledge have often been studied in the context of patient activist and support communities, framed as means for contesting epistemic claims of medical authorities. However, the concepts are increasingly adopted in mainstream health policy as part of the neoliberal agenda to shift responsibility towards self-managing ‘expert’ patients. In the NHS, group clinics represent a prime example, offering consultations to groups of patients, rather than one-to-one, with the stated aim of improving self-management through peer learning.

Using the case of group clinics, this presentation will focus on tensions and complications that arise when expertise and experiential knowledge are shared in a clinical - rather than peer community - context. We draw from qualitative data collected at three English general practices, including 33 interviews with patients/carers and staff, and ethnographic field notes of 18 in-person, video and hybrid group clinics (menopause, diabetes, cancer). Through an abductive analysis informed by social theories on patient knowledge, identity tensions, and patienthood, we explore what and whose experiences come to count in group clinics, how patients negotiate tensions and distress that arise from (not) identifying with others, and the ways in which group clinics inscribe patients to become carers of themselves and others.

We conclude that policy programmes focused on ‘peer learning and support’ can require complex moral and emotional work, and while they in many cases enable patients to share practical know-how around living with illness, they can also be deployed to place blame on patients and individualise disease progression.

Room 135 - Critical Public Health

Relation Between Environment and Gene Expression: A Sociological Understanding of Epigenetics

Santosh Kumar

(Jawaharlal Nehru University)

Epigenetics refers to the study of environmental influences, such as pollution, nutrition, and anxiety, in relation to gene regulation. In social sciences, epigenetics represents an essential expansion of biological reasoning for many social scientists studying social and political dimensions of biological science. In order to understand how the social environment affects the body and health at the molecular level, the social environment must be taken into account. The research will be based on a qualitative study that attempts to provide historical accounts of epigenetics, a subfield in life sciences. The research will try to trace a history of the recent development in epigenetics and find a relationship between sociology and biology by doing an extensive secondary literature review. The philosophical premise of epigenetics is that the distinction between nature and nurture is becoming obsolete as these two are getting completely intertwined. A debate between nature and nurture appears to be blurred in epigenetics. In this context, it is pertinent to revisit the sociological and historical understandings of nature and nurture brought by sociologists and anthropologists. The subsequent question of the research is the study of nature and nurture, what constitutes nature and nurture. Scientists working in laboratories in epigenetics understand the environment in relation to the human body. For example, food is being quantified as nutrition, and that is permeable to the human body and can have an impact on health and disease.

Room G31 - Mental Health

The cruel optimism of suicide prevention: Imagining socioeconomic conditions and suicide in UK politics

Amy Chandler, Hazel Marzetti

(University of Edinburgh)

Suicide is a ‘complex issue’, yet suicide prevention policies (and practices) tend to centre a mental illness model, focusing on encouraging help-seeking and improving access to mental health care. I argue that this flattening of complexity might be understood as contributing to the ‘cruel optimism’ of suicide prevention. Developed by Lauren Berlant, the concept of cruel optimism refers to ways in which actions aimed at managing the challenges of life, and ‘feeling better’, can perversely contribute to the maintenance of these challenges. Here, focusing on mental health care and individual acts of help-seeking, can divert attention from structural drivers of suicide, such as socioeconomic disadvantage.

One of sociology's early contributions to understanding suicide (via Durkheim) was in demonstrating, and theorising about, the impact of economic conditions on suicide rates. In the UK, suicide is associated with socioeconomic disadvantage, at individual and population levels. I draw on a critical policy analysis of 8 UK suicide prevention policies, published between 2008 and 2019, and a narrative informed thematic analysis of talk about suicide in parliamentary records from all four UK parliaments and assemblies, across the same time period. I focus on how socioeconomic conditions and suicide are 'imagined' - and responded to - in UK suicide prevention policies, and parliamentary debate, unravelling the political contexts in which the 'cruel optimism' of suicide prevention is enacted. I argue for the need for more 'complex' (sociological) theories of suicide, whilst also attending to the challenges such theories face in being taken up politically.

Room G35 - Lifecourse - Reproductive Health: Chronic Conditions; Ageing; Death and Dying

Prolonging life or providing end-of-life care? Mundane technologies in paediatric intensive care

Anna Mann

(University of St. Galle, Switzerland)

The boundary between curing disease and providing end-of-life care in medical practice is anything but given. Medical sociologists and STS scholars have shed light on the ways in which it is shaped, for example, by awareness contexts (Glaser & Strauss 1965), the social organisation of uncertainty (Zusmann 1992) and bureaucratic processes in hospitals (Kaufman 2005). But what about mundane technologies such as parameters and scores? To address this question, the talk presents qualitative data collected in an intensive care unit in a Swiss Children's Hospital. Drawing on the STS concepts of "script" (Akrich 1992) and "repertoires of valuation" (Mol & Heuts 2014), it teases out how the morning round and the schemata A-K-I-N-E-V that was used in it enabled intensivists to optimize the prolongation of a patient's life. In contrast, the ethics meeting in which 'facts' and 'values' were distinguished allowed them discussing a patient's 'suffering' and 'quality of life'. What mattered first and foremost, however, was whether or not intensivists were able to move a patient case from one setting and the parameters that were used in it to another. Through the example of parameters as they are used in daily clinical practice, the presentation sheds light on the ways in which mundane technologies socio-materially organise medical practice. By doing so, it contributes to ongoing debates on, on the one side, health care provided to patients with chronic conditions, and, on the other side, death and dying at the beginning of the 21st century.

Room 118 - Experiences of Health and Illness – Special Event

Adding insult to injury: exploring narratives of unexpected experiences following COVID-19 vaccination

Simon Bailey, Rebecca Cassidy

(University of Kent, UK; University of Oxford, UK; Hamburg University, Germany)

While recognition of Long Covid has been slowly building in medical science and lay populations, the understanding of post-vaccine Long Covid is less acknowledged. In this condition – variously termed vaccine injury, vaccine-induced Long Covid, or post-vaccine syndrome - people experience Long Covid-type symptoms from the Covid vaccine itself, rather than from a Covid infection.

People living with post-vaccine syndrome express their frustration at a 'falling between categories' on two fronts. Firstly, their illness experience does not fit into pre-existing biomedical categories, and they contest diagnoses that simplistically reduce their illness to the psychological (anxiety, depression, PTSD etc). They cite this dismissal and ‘gaslighting’ by the medical profession as the greatest part of their suffering.

Their experiences also do not fit into the polarising categories presented by the larger political vaccine discourses: pro-vaccine or anti-vaccine. They are often banned from online forums of Long Covid patient support groups, as their claims to vaccine injury are interpreted as ‘anti-vaccine’, despite their assertions of support for vaccines. At the same time, their experiences are subverted by anti-vaccine advocates to support anti-vaccine discourses. These polarising categorisation practices leave vaccine injured patients in the middle, “being played in a tug of war.”

This paper draws on interviews with people with vaccine injury, as well as data from an online questionnaire. It explores the ways in which they: contest their right to be included in categories; navigate between existing categories; or attempt to forge their own categories which demand recognition.

Simon Bailey

(University of Kent)

Vaccination is considered the best protection against COVID-19 infection yet there is much that is still unknown about the scope and severity of unexpected events that might be related to COVID-19 vaccines. The payment of the first damages to compensate for unexpected vaccine reactions in the UK in 2023 provides recent evidence of this uncertainty (Wise, 2022). Drawing upon first hand accounts of individuals who have experienced unexpected health events following COVID-19 vaccination, we contribute to the sociological understanding of vaccines by analysing what happens when individuals are not believed when presenting unexpected events to health professionals.

Adopting a narrative approach we show how unexpected experiences of vaccines are shaped by three stories of past, present and future: firstly, the existence of pre-existing conditions, especially past experiences of ‘undiagnosability’ (Franssen, 2020); secondly, the experience of not being believed by a health professional and consequent crisis of legitimacy; thirdly, the lived temporality of the narrative and its orientation to the future and feelings of hope and helplessness.

In discussion we develop sociological accounts of vaccination, which are often framed in terms of belief and trust through people’s hesitancy or anxiety. While this might recognise nuanced forms of agency, it tends to individualise pathologies that might be infrastructural. We counter this by redrawing attention to the reciprocal character of the social contract within which ‘reactions to’ vaccines are situated. We conclude by thinking about how contemporary experiences of vaccines can help us rethink this contract in more inclusive ways.

Anna Dowrick

(University of Oxford)

There are few clear roads to recovery for people affected by Long Covid. Emerging evidence indicates that for some people Covid vaccines can lessen troubling Long Covid symptoms, while for others symptoms can be exacerbated (Sivan et al, 2022). There is also emerging evidence of LC-like symptoms developing following vaccination (Murphy & Longo, 2022).

We examine narratives of changes in symptoms and/or novel Long Covid symptoms following vaccination. We explore how 40 patients made sense of their vaccine response and the subsequent impacts of this on their perception of vaccination in general. We identify three main roles played by vaccines in their narratives - as shield, as treatment and as antagonist. These roles were differently emphasised relative to each participant’s overall recovery narrative. Where vaccines were positioned primarily as treatment, patients were frustrated about their limited access to further vaccines. Where vaccines were seen as a potential antagonist, it was difficult to integrate this role alongside their potential as a shield.

A move to mistrust was possible from both treatment and antagonist positions. Vaccine trust was maintained when uncertainty was engaged with as a form of ‘productive ignorance’ (Gross, 2007), where unexpected experiences were felt to contribute towards an expansion of medical or scientific knowledge about Long Covid. Where professionals did not take ‘known unknowns’ (Knorr-Cetina, 1999) into account this bred mistrust.Through this work we demonstrate the complexity of vaccine positions, building on Brunson and Sobo’s (2017) position that a simplistic pro- or anti-vax polarisation is both inaccurate and alienating.

Lesley Branagan

(Hamburg University)

While recognition of Long Covid has been slowly building in medical science and lay populations, the understanding of post-vaccine Long Covid is less acknowledged. In this condition – variously termed vaccine injury, vaccine-induced Long Covid, or post-vaccine syndrome - people experience Long Covid-type symptoms from the Covid vaccine itself, rather than from a Covid infection.

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Room G22 - Patient Professional Interaction

Patients with a migration background and mental health problems in general practices - A discourse analysis of Belgian GPs' accounts

Camille Wets, Melissa Ceuterick

(Ghent University, Department of Sociology, Hedera)

Despite a higher prevalence of mental health problems such as depression in people with a migration background, recent studies indicate that these patients have more unmet medical needs and are underrepresented in mental health services. In the Belgian health care system, general practitioners (GPs) are central gatekeepers in terms of treatment and referral to specialized mental health care services. However, their recommendations can be influenced by time constraints, unconscious biases and other barriers.

Therefore, through an innovative mixed-method design, the REMEDI project investigates contextual variation in GP recommendations regarding patients with a migration background with mental health problems. The qualitative part of this study comprises a combination of 39 in-depth interviews and 8 focus groups with Belgian GPs. A discourse analysis based on the principles of critical discursive psychology will be performed to examine (1) how GPs discursively construct their decision-making regarding patients with a migration background, and (2) to investigate how GPs' accounts of these patients contribute to the discursive justification, perpetuation and contestation of attitudes measured in the quantitative research part of this project and thus, how this may contribute to possible discrimination.

The ultimate goal is to formulate constructive recommendations based on the obtained results to support general practice, in order to prevent unconscious stereotyping and consequently to remove barriers to access to high-quality mental health care for patients with a migration background.

Room 144 - STS and Medicine

Of mice and men: Interspecies transposition in concussion research

Gregory Hollin

(University of Sheffield)

The last two decades have seen increasing recognition that concussion and other forms of traumatic brain injury may constitute risk factors for Alzheimer’s-like dementias. Unsurprisingly, one consequence of the contemporary ‘concussion crisis’ is the increasing use of animal models aimed at better understanding the neurodegenerative effects of brain injury in humans. In order to better comprehend this emerging field of research, in this presentation I draw upon my observations and interviews with scientists undertaking pre-clinical research and studying brain injury in animals. Following queer theorist Mel Chen, my particular approach is to understand “animality” and “humanity” less as essences that are intrinsically attached to particular species (a mouse, a sheep, a human), than as “sticky” concepts that may-or-may-not be bound to particular bodies. In other words, I seek explore the presence of the human in the animal, and the animal in the human. Based upon my ethnographic work, I suggest that “the human” is ever present in these animal laboratories, not only as an imagined end-point beneficiary of research, but also in the body of a mouse that staggers under a concussive blow, the neuropathological brain slice of a bovine studied under a microscope, and in laboratory protocols stressing a commitment to social justice. I focus in particular upon the raced and gendered implications of these interspecies entanglements, suggesting that while scientists are committed in their progressive political and research agenda, there remain troubling resonances in this particular transposition of human and animal.

Thursday 14 September

09:35-10:05

Room G36 - Diagnosis, Screening & Treatment

“Prostate cancer screening is just a simple blood test” – Norwegian men’s views on screening with PSA.

Marit Solbjør

(Norwegian University of Science and Technology (NTNU)

Screening for cancer has been normalized through slogans as “early detection saves lives” and the implementation of screening programs. Prostate cancer is the second most common diagnosed cancer worldwide, but prostate cancer screening with prostate specific antigen (PSA) is contested due to ambiguous evidence of whether benefits outrun negative consequences. Its low specificity could lead to high numbers of men having a diagnosis and treatment for cancer that would not cause death, and treatment could cause incontinence and impotence. Regardless of this, an increasing number of countries are implementing PSA as a screening test, but not Norway, where urologists are critical towards such screening. Opportunistic screening is frequently done by men at their GPs’, and the Prostate Cancer Association is campaigning for a population program. Such variation of standpoints to prostate cancer screening led us to investigate Norwegian men’s views on screening with PSA. Our data material comprises 10 focus group interviews with a total of 48 men aged 54-85 years old, where seven groups were for men diagnosed with prostate cancer.

Our analysis indicate that these men were positive towards screening for prostate cancer with PSA because they saw early detection as beneficial. But, since “men are men” – i.e. not using health services regularly, having a screening program for prostate cancer was important. Knowledge about the uncertainty of PSA values and overdiagnosis did not influence views on the benefit of screening. The simplicity of screening through a blood sample obscured the complexity of PSA testing of non-symptomatic men.

Room 155 Health Services Delivery

A shift towards the social? Intersex minors and psychosocial care in Europe

John Stephenson, Martin Gramc

(University of Huddersfield)

Intersex minors are born with chromosomal, gonadal, genital or hormonal characteristics that do not fit traditional male/female norms. Also termed (in medical settings) ‘Disorders or Differences of Sex Development’ (DSD), variations of sex characteristics have, since the 1950s, been excised from society via non-consensual medical interventions including non-vital genital surgeries on infants and young children. These socially-driven interventions often have very poor outcomes, including failed surgeries, decreased sensitivity, gender mis-assignment, and serious mental health problems. Intersex activists and human rights bodies are highly critical of them, and they are now banned in some countries, but practice is still prevalent. Existing guidelines support the provision of psychosocial care and peer support to help families and children make decisions about their care pathways.

This paper provides results from a mixed-methods study (literature scoping review, survey across European healthcare professionals and peer support organisations, and focus groups in 6 European countries) funded by the European Commission as part of the INIA: New Interdisciplinary Approaches project (Grant agreement No. 859869). Data has been collected and the study is now at analysis/publications stage.

Taking a sociological perspective in analysing the hegemony of medicalising approaches in contrast to social ones, this presentation shows that there is insufficient psychosocial care provision and peer support, and that where this is present, it is often late or limited. The paper concludes an urgent need for more psychosocial and peer support as part of attempts to bring the 'social' into care settings for intersex minors.

Room 135 - Critical Public Health

Building childhood resilience: engagement to experiencing progress and the embodiment of health.

David Glynne-Percy

(Tutor for progress)

Recent research indicates participation in extra-curricular activities (ECA) is especially beneficial for children from disadvantaged backgrounds. Yet poorer children participate less in ECA than their more advantaged peers. We know much less about how ECA engagement begins and then sustained for less advantaged children. Through twenty semi-structured interviews with school ECA practitioners this article explains the process of successful ECA engagement for poorer children facing adversity in middle childhood. The findings indicate that triggering the ECA is through adult invitation, and sustaining ECA engagement is shaped and guided by adults cultivating conditions where the child experiences progress and increased competency. These findings indicate that resilient outcomes of greater confidence and levels of perseverance for children are a result of proximal processes within their ecology. Resilience is an internal outcome acquired through the enabling presence of external factors. Childhood health is conditioned by sustained environmental access to experiences. Informed by critical realism the research offers a theoretical explanation for these events drawing upon Bourdieu's dynamic of field and habitus and Vygotsky's zone of proximal development. This paper also introduces the notion of resilient habitus to indicate the chameleon qualities that are demonstrated by some children in adapting to contrasting fields and proposes that development of a resilient habitus is optimal in middle childhood, resulting in an embodiment of success that leads to increased levels of well-being.

Room G31 - Mental Health

The Politics of Therapy and the Legacy of Jeffrey M. Masson

Bruce Cohen

(University of Auckland)

Former psychoanalyst, director of the Freud Archives and author of 'The Assault on Truth' (1984), 'A Dark Science' (1986), 'Against Therapy' (1988), and 'Final Analysis' (1990), Jeffrey M. Masson was one of the first scholars to theorize the mental, emotional and physical abuse of clients at the hands of their therapists as being widespread and systematic rather than rare and exceptional, and to ultimately argue for the abolition of all forms of talk therapy. With the forthcoming publication of a Routledge volume dedicated to reflecting on Masson's challenges to psychoanalysis and 'the therapy industry', this presentation will discuss two specific ways in which his work has added to critiques of talk therapy in the sociology of mental health. Firstly, through critical feminist writings on the psychiatric profession from scholars including Phyllis Chesler, Denise Russell, Paula Caplan, and Jane Ussher, it will be highlighted how Masson's work added important research evidence to the critical writings of the 1960s and 1970s in demonstrating psychiatry's 'double-denial' of both the validity of the user voice within the clinical encounter as well as the serious shortcomings of psy-professionals' theories of the mind. And secondly, it will be discussed how Masson's analysis has had an equally important influence on sociological and related critical engagements on the therapeutic encounter (for example, in the work Peter Morrall, Emma Tseris, Paul Moloney, and Frank Furedi), resulting in the theorization of talk therapy as a source of social control in neoliberal society.

Room G35 - Lifecourse - Reproductive Health: Chronic Conditions; Ageing; Death and Dying

'Natural Death' in Care Homes: The Line between Non-intervention and Neglect

Diana Teggi

(The Open University)

Care homes cater for about 30% of all deaths in England. However, sociological studies of end-of-life care (EOLC) practice in English care homes are limited, with the most recent ones appearing about 20 years ago (Sidell, Katz and Komaromy, 1997; Komaromy, 2005). To investigate current EOLC practice, this paper draws on participant observation and interviewing of care home staff in five nursing and residential care homes in the South-West of England between May 2019 and March 2020. The paper argues that care home staff manage residents' dying to achieve what they consider a 'natural', and thus 'good', death on the care home's premises. Crucially, to let residents die 'naturally', staff need to navigate the boundary between non-intervention and neglect that regulates their provision of healthcare, nutrition, and hydration to residents. The paper challenges the assumption that residents' dying is a mere biological, and thus 'natural', process, and interrogates what kinds of deaths are being supported in care homes, thus contributing to the sociology of health and illness.

Room G22 - Patient Professional Interaction

"They're not the ones that should be making the decision": how do clinicians see informal carers' roles and powers concerning anticipatory prescribing?

Louisa Polak, Matt Bernstein, Ben Bowers

(Department of Public Health and Primary Care, University of Cambridge)

Anticipatory prescribing is a complex intervention aimed at facilitating rapid administration of palliative medication at the end of life, thus helping make community care feasible. As May and others have highlighted in relation to chronic illness, shifting care out of hospital increases the burden of treatment borne by the patient and their support networks, including informal carers. In a group interview study exploring what happens after anticipatory prescriptions have been issued, clinicians described carers playing several crucial roles, from collecting medication to requesting that clinicians administer an injection. But the power to decide whether to administer medication is not shared with informal carers: our participants emphasised that it is up to a clinician to make this decision, particularly where the patient can no longer communicate their own preferences. To think about the work of informal carers in this context we draw on Corbin and Strauss' account of the three lines of work through which people manage their own or their spouse's chronic illness. Thematic analysis of our data points to a fourth line, decision-making work, articulating with the other three. Decision-making about anticipatory prescribing requires carers to construct and use various types of knowledge, communicate with multiple stakeholders, and undertake complex relational and emotional work. This onerous workload seems in tension with the limited influence informal carers are offered over choices about medication. Our clinician participants' accounts of carers' roles surface this tension, highlighting the challenge of addressing power imbalances within a decision-making process that guidance emphasises should be collaborative.

Room 144 - STS & Medicine

Biomediatization dynamics of #GeordieHospital: boundary work of healthcare stakeholders' practices of public communication

Gabriel Moreno-Esparza

(Northumbria University)

This paper will cover the mediatization dynamics engaged by a range of healthcare stakeholders who converged on Twitter using the #GeordieHospital hashtag. It will offer initial reflections that stem from a dataset of 2,558 tweets that were posted over several weeks in 2022 when UK-based Channel 4 first put the documentary series Geordie Hospital on air. Reference will be made to the institutional and individual characteristics of actors in the healthcare sector that dominated the activity on Twitter. I aim to argue that the discursive frames, themes, and public communication aims that can be identified in the tweets constitute a substantial case study of biomediatization — whereby the interpenetration of biomedicine into multiple societal structures and multi-actor stage dynamics are channeled through the adoption of media logics. Such dynamics stand apart from previous stages in the mediatization of healthcare, which responded to a medical logic and, later on to a logic of entertainment that is now being replaced by a logic of healthcare that relies on the fluid boundary work of multiple human and non-human actors. This is illustrated by processes of local contextualization in Geordie Hospital and its appropriation by non-media actors on Twitter. This framework will help to account for the significance of biomediatization stemming from one of the UK's largest NHS trusts. In this way, a contribution to the multidisciplinary field of Science and Technology Studies is offered that reflects on how healthcare providers and its stakeholders co-produce social meaning through contemporary practices of the public communication.

Thursday 14 September

10:10-10:40

Room G36 - Diagnosis, Screening & Treatment

Exploring the harms of screening: participant perceptions of atrial fibrillation screening harms

Sarah Hoare, Alison Powell, Natalie Armstrong, Jonathan Mant, Jenni Burt

(University of Cambridge)

That screening may cause harm is well recognised. How screening harms balance against benefits – and whether harms are overstated or under considered – is the subject of continued debate. In this paper we explore the views of participants invited to take part in screening for atrial fibrillation, a common heart condition in older adults that can lead to stroke. The screening, delivered as part of the Screening for Atrial Fibrillation using ECG to Reduce stroke trial, involved using an ECG device four times a day. We interviewed 90 participants and thematically analysed their responses to questions about screening harms. Whilst screening literature finds patients to be unknowledgeable about harms, and especially to overestimate benefit and underestimate harms, interviewees presented considered evaluations about the harms of participating in the screening. They concluded that as the test was non-invasive it was broadly safe for them personally. Their main concern was for 'worriers', other screening participants cast by interviewees as predisposed to anxiety and for whom the screening was anticipated to cause significant psychological harm. Interviewees' perceptions of the otherwise 'safe' screening was linked to their trust in a programme assumed to be delivered by responsible clinicians and therefore to be clinically warranted, beneficial and without significant risks. Our findings highlight the importance of listening to the views of those invited to screening– including when they identify such harms to be limited – and the continuation of rigorous assessment of harms in NHS-delivered screening by national screening bodies.

Room 155 - Health Services Delivery

When is it wrong to ring 999 (again)? Constructing a moral narrative around frequent calls to emergency ambulance services

Alison Porter, Helen Snooks, Alan Watkins, Adrian Edwards, Ashra Khanom, Bethan Edwards, Bridie Evans, Jason Scott, Rabeea'h Aslam, Penny Gripper, Theresa Foster, Rachael Fothergill, Andrew Rosser, Nigel Rees, Anna Tee, Bernadette Sewell

(Swansea University Medical School)

Background - Emergency ambulance services across the UK define a frequent caller as someone who calls 5 or more times in a month, or 12 or more times in a three month period. The STRETCHED evaluation of frequent caller responses in four UK ambulance service areas included a qualitative component to explore the experience of frequent callers and those who respond to them.

Methods - We conducted semi-structured interviews with people with experience of calling 999 frequently (n=16), and with key stakeholders (n=31) providing a response. All interviews were recorded and transcribed. Analysis took a data driven thematic approach.

Results - We explore how concepts of legitimacy and appropriate behaviour were used to construct a disputed moral narrative around frequent calls. Services flag people meeting the frequent caller threshold and aim to reduce calls by: asking people to change their behaviour; limiting future access; offering case management to identify and resolve unmet needs; in rare cases, taking legal action. Response varies across three perceived types of underlying reasons: acute exacerbations; lack of access to appropriate care; and 'nuisance' calls. Callers see their calls as the rational action for their complex needs.

Conclusions - Though there is a strong emphasis in service responses on changing individual behaviour to meet accepted norms of healthcare use, the impulse to calling frequently comes from a breakdown of the wider 'moral determinants of health' (Berwick 2020).

Berwick D (2020) 'The Moral Determinants of Health' JAMA 324:3 pp225-226

Room 135 – Critical Public Health

The impact of changes in China's healthcare system on doctor-patient relationships

Haoyang Liu

(University of Sheffield)

Since the 1980s, there has been a major transition in China's economic system, from a planned to a market economy, at the same time the Chinese government has been reforming healthcare, from administrative centralization to marketization. While the newly established model released financial pressure on the government, the transfer of those pressures to hospitals has triggered profit-seeking behaviour by them and led to patient dissatisfaction. Doctor-patient relationships have changed from active-passive, and guidance-co-operation, to mutual participation and mixed approaches, while patients' complaints about doctors have been increasing at the same time.

This study identified the changes in health policy and doctor-patient relationships in China over the past 73 years (1949-2022), following systematic reviews of the development stage of China's healthcare reform and doctor-patient relationships. The paper begins with an outline of healthcare reform, which highlights the marketization of China's healthcare system and specifically, hospitals, then focuses on the changing relationships between doctors and patients, the reasons for increasing medical complaints and patient dissatisfaction. This research confirms the main problems in China's healthcare system identified by previous research, which includes funding shortages, provider-induced overconsumption of medical resources, excessive reliance on high-tech equipment; and uneven distribution of medical resources among regions, and adds new findings based on the doctor-patient dimensions, those are doctor's workload; asymmetry among interactions; mutual stereotypes and medical costs. These issues reflect the paradox of medical development not leading to increased patient satisfaction as well as some difficulties in the policy implementation.

Room G31 - Mental Health

Trauma as a Sociological Question

Baptiste Brossard

(University of York)

Although trauma constitutes one of the main explanations of negative mental health outcomes in public discourse as well as in professional literature, and a common everyday mode of understanding distress, little has been done to provide a fully-fledged sociological theorisation of trauma. This presentation aims at taking some steps in this direction, focusing on three challenges. First, how to account for the socially constructed dimensions of traumatic narratives while acknowledging the actual effects of trauma in people? A sociological definition of trauma, it will be argued, should consider how the space of narrative possibilities available in a given society partly influences the traumatic process itself. Second, how to overcome the 'deficit narrative', that is, the analysis of trauma only through the difficulties encountered by concerned individuals? Answering this question requires replacing trauma within broader dynamics of socialisation, power and embodiment, in which trauma represents a nonlinear shift of dispositions. Third, how to account for singular life events without adopting a reductively individual perspective? A way of addressing this issue is to conceive human activities as driven by ‘emotional energy’, in which traumatic processes do not limit themselves to a series of event-outcome sequences, but permeate the identities, categorisations and interaction patterns at the core of social life. Ultimately, these theoretical elaborations aim at refining the sociological analysis of traumatic narratives, which will be illustrated with one case study on depression in Australia.

Room G35 – Lifecourse - Reproductive Health: Chronic Conditions; Ageing; Death and Dying

Defamilialising reproduction: intimate labours, public bodies and commercial surrogacy

Aishwarya Chandran

(Department of Humanities and Social Sciences, Indian Institute of Technology, New Delhi, India)

Marxist feminists argue that reproductive labour, traditionally performed by women in the household, and couched within the language of love, affection and altruism, is kept outside the ambit of exchange value or the public sphere. Mies (1986) had famously termed this ‘housewifisation’ or the process through which informal markets rely on the feminisation and domestication of specific kinds of waged work so that it seemingly integrates with women’s conjugal and domestic obligations, thereby making it seem as not work at all. Dalit and black scholars have however noted how the kinds of labour necessary for the reproduction of life have been historically performed by those outside the family, by nannies, slaves, paid domestic workers. Angela Davis (1981) had cautioned against establishing the ‘housewife’ as the enduring symbol of suffering under capitalist patriarchy for it deracialised the politics of reproductive labour and reinforced the structural and ideological separation of the public economy of capitalism from the private economy of the home. Through an ethnography of reproductive labour, as I explore the lifeworlds of women engaged as commercial surrogates and egg donors, the paper hopes to delink conceptualisations of reproductive labour from domesticity and filiality and argue that it must be studied at the intersections of histories of caste-based preoccupations with the management of ‘disorderly’ bodies (Douglas 2002). In the process, I look at how the structural, spatial, and temporal constructs of the public and the private are imagined, regulated, and negotiated with in transactions of intimate, embodied forms of labour.

Room 115 - Open

Dilemmas of pastoral power in the governance of integrated care systems: priests, bureaucrats and ringmasters

Justin Waring

(University of Birmingham)

Foucault's conceptualisation of governmentality is often used to explain how contemporary forms of decentred healthcare governance function through the constitution of self-governing actors operating in market and, increasingly, network contexts. His related conceptualisation of pastoral power further explains how regimes of governmentality are realised through the active cultivation of subjects who internalise prevailing political and economic imperatives and engage in mutually reinforcing technologies of the collective. This paper applies a pastoral power framework to understand the realisation of governmentality in the implementation of regional integrated care systems. The paper draws on the findings of in-depth qualitative research carried out between 2018 and 2022 with three Sustainability and Transformation Partnerships (STPs) in the English healthcare system. It describes the challenges faced by ‘system leaders’ (those responsible for translating and enacting regional policies) in constituting 'system' subjectivities within and across such extensive and heterogeneous communities. It focuses on resistance to: i) the rationale; ii) the pastors, and iii) the practices. In response, system pastors re-introduced hierarchical structures together with segregation of re-localised communities, they cultivated multiple loosely coordinated subjectivities within these re-localised communities, and maintained continuous oversight over autonomous activities. The study highlights the fragility of network governmentality ‘at scale’ and the need for pastors to work at the nexus of sovereign (rule-setting) and disciplinary power (ordering), thereby encouraging closer attention to the topologies of contemporary healthcare governance.

Room G22 - Patient Professional Interaction

Intra-action and Intra-uterine Contraceptives

Adele Moore

(University of Liverpool)

Intra-action, as coined by Barad (2006), describes the ‘mutual constitution of entangled agencies … in contrast to the usual “interaction”, which assumes that there are separate individual agencies that precede their interaction’ (p. 33). According to Barad, ‘agential realism’ is afforded to human and non-human subjects through relationships and intra-actions. Engaging with Barad’s feminist technoscience conceptualisation of agency, this paper will explore the ways contraceptive providers, users and contraceptive technologies interact and intra-act, via the analysis of empirical data collected in a current project exploring contraceptive practice in an area of North-West UK. This data demonstrates a disjoint between the expectations of users and the service which contraceptive providers are able to give. Providers work to offer their patients the best prevention against pregnancy, whilst users are often more concerned by the vast array of potential side-effects (or effects) of hormonal and long-acting reversible contraceptives. In this paper, I argue that the work of contraceptive providers can be understood as interaction, emphasising the individualised nature of contraceptive technologies and the ways they enact users. Conversely, I show how contraceptive users yearn for a more intra-active approach, onto-epistemologically learning about their bodies and contraceptives through experiencing contraceptives and the array of human and non-human entities involved in accessing using them. Engaging with Barad’s work this way, forces us to evaluate and configure the ways we not only understand agency, but also the different ways in which it influences and challenges our understandings of contraception, consent, and reproductive healthcare.

Room 144 - STS and Medicine

Touching fat: skinfold calipers, research protocols and the unbounded body

Jarrah O'neill (Virtual presentation)

(University of Cambridge)

In this paper, I discuss protocols for measuring a fold of skin. These protocols outline the choreography through which measurers grasp up a fold of skin and then, using a pair of specially-designed mechanical calipers, measure its width. The resulting number is interpreted as an estimate of fat. Skinfold calipers are used in a variety of settings, from professional football clubs to longitudinal birth cohort research. This paper, which forms one part of my ongoing PhD research, is based on analysis of contemporary and archival research protocols as well as interviews with researchers. I focus on the choreography of language, gestures, objects, time, and bodies in the moment that skinfolds are measured. In studying this choreography, I ask the question: how is the substance of fat enacted through protocols for skinfold measurement? I argue that touch is central to enacting this genre of fat and, further, that touching fat reconfigures conventional understandings of the skin as the body’s boundary.

Through this argument, my paper contributes to sociological research on the senses and on protocol. Scholars have shown how sensory knowledge is learned and expressed in communities of interest, such as wine-tasting (Shapin 2012), or in educational settings, including medical school (Harris 2016; 2023). By centring my analysis on protocols, I elaborate the tension between the seeming subjectivity of the senses and the disciplined, rationalised practice that protocols demand (Berg 1997). In sum, I show that analysing touch helps uncover the unique capacities of the haptic to materialise substance.

Thursday 14 September

10:45-11:15

Room G36 - Diagnosis, Screening & Treatment

The inter-professional diagnostic work of bacterial infection identification and management in care homes: an ethnographic study

Suzanne Grant, Jane Dickson, Charis Marwick

(University of Dundee)

Antimicrobial use in care home settings is high, which can lead to a range of adverse effects including antimicrobial resistance. Drawing on recent research on the sociology of diagnosis (Jutel and Nettleton 2011), this paper examines the diagnostic work (Buscher et al. 2010) carried out by care home staff (e.g. carers) and clinicians (e.g. nurses, general practitioners) in the identification and management of suspected bacterial infections amongst care home residents, and how this varies across different care home settings. Multi-site ethnographic fieldwork (including non-participant observation, semi-structured interviews (n=44) and documentary analysis) was carried out across seven care home settings with care home staff (including carers, nurses, managers) and general practitioners. Three modes of diagnostic work were identified which care home staff carried out to inform bacterial infection identification and management amongst residents: (1) 'embodied diagnostic work' was carried out by carers based on their awareness of physical changes in a resident (e.g. shortness of breath); (2) 'relational diagnostic work' was carried out by carers and senior carers and involved tacit knowledge of when a resident's behaviour deviated from 'their normal' (e.g. becoming more vocal); (3) 'mediated diagnostic work' involved the subsequent use of formal tests (e.g. urine dip tests, urine culture) as infection diagnostic tools by nurses and doctors. This presentation examines the formal and tacit knowledge held by clinical and non-clinical professionals when diagnosing bacterial infections, the role of perceived resident vulnerability across these different modes of diagnostic work, and wider implications for antimicrobial stewardship in care homes.

Room 155 Health Services Delivery

Remaking Critical Care: Place, Body Work and the Materialities of Care in the COVID Intensive Care Unit (ICU)

Catherine Montgomery, Annemarie Docherty, Sally Humphreys, Corrienne Mcculloch, Natalie Pattison, Steve Sturdy

(University of Edinburgh)

In this paper, we advance sociological ways of knowing care-in-practice, in particular work in critical care. To do so, we analyse the experiences of staff working in critical care during the first wave of the COVID-19 pandemic in the UK. This moment of exception throws into sharp relief the ways in which work and place were re-configured during conditions of pandemic surge, and shows how critical care depends at all times on the co-constitution of place, practices and relations. Our analysis draws on sociological and anthropological work on the material culture of healthcare and its sensory instantiations. Pursuing this through a qualitative interview study of the experiences of forty staff across four intensive care units (ICUs) in 2020, we provide an empirical and theoretical elaboration of how place, body work and care are mutually co-constitutive. We argue that the ICU does not exist independently of the constant embodied work of care and place-making which iteratively constitute critical care as a total system of relations.

Room 135 - Critical Public Health

Care-chronicles: prevalence and socio-cultural risk factors of neural tube defects in Pakistan

Ayesha Siddiqa, Dr. Faisal Feroz Rana

(University of Sargodha, Pakistan)

Children of malnourished women especially with folate deficiency face Neural Tube Defects (NTDs) like spina bifida and Hydrocephalus, and a high risk of disability and death throughout their lives. Present study focuses on exploring incidence of NTDs, socio-cultural barriers affecting maternal health and attitudes regarding nutritional practices, also the challenges faced by caregivers. The sequential explanatory research design (mix-methods) was selected for research in province of Punjab, Pakistan. For quantitative part, Employing Multistage sampling, conducting surveys at public children's hospitals of selected districts randomly, 450 mothers who have at least one child affected with Neural Tube defect (HCP & SB) were selected as respondents through purposive sampling technique. For qualitative part, In-depth-Interviews were conducted using interview guide. Quantitative data was analyzed through SPSS and thematic analysis was used for qualitative data. Major findings highlighted socio-cultural factors showing high significance ($p \leq 0.05$) in prevalence of neural tube defects are: household poverty (family income), education of respondents and husbands, marriage type, women autonomy, maternal health seeking behavior regarding nutritional practices. Four main themes and few sub-themes were extracted through qualitative data as following, 1) Socio-economic determinants 2) Cultural Hazards 3) Quality of life: challenges of a caretaker, role of social support networks 4) Role of Government: Maternal Health Care, NTDs specialized care, Fortified Food. Improved Female literacy & autonomy, poverty elimination, Mass awareness campaigns for maternal folate deficiency, NTDs, prevention through use of supplements and promotion of fortified food for reducing burden of disease in Pakistan are recommended.

Room G31 - Mental Health

Motherhood and mental illness: understanding the stigma(s) experienced by women with a history of severe mental illness

Charli Colegate, Sarah Salway, Scott Weich

(University of Sheffield)

The intersection of the experiences of motherhood and mental illness are complex. Public services, particularly the NHS, provide support to women with histories of severe mental illness (SMI) who are contemplating motherhood, who are pregnant or who are already mothers. If women become acutely unwell perinatally, not receiving care in a timely manner can have significant consequences for women and families. Evidence suggests socioeconomic and ethnic inequalities in access to perinatal mental healthcare exist and some have suggested stigma plays a significant role in this. However, stigma is often used as a taken for granted concept in the literature exploring inequalities in perinatal mental healthcare. Stigma has a long history as a subject of sociological inquiry with recent perspectives on this social process centring power relations.

This presentation will report on findings from a qualitative study, in which 20 women with a history of SMI were interviewed. It presents a rich picture of the nature of the stigmas women both experience and anticipate in the power-settings of the family, healthcare and the workplace. It places an emphasis on how the structures/organisational cultures of these different contexts shape stigmatising practices. It also demonstrates how women are not solely passive 'victims' of stigmatisation, illuminating the strategies that women employ to resist stigmatisation in these settings. Finally, by bringing relational concepts of access to healthcare (e.g: cultural health capital) into dialogue with power-centred concepts of stigma, this paper makes a contribution to addressing a pressing issue in women's health.

Room G35 - Lifecourse - Reproductive Health: Chronic Conditions; Ageing; Death and Dying

Pregnancy in the present: Reconsidering reproductive time through accounts of gestational trophoblastic disease

Emily Ross

(University of Sheffield)

Medical sociologists have shown that an orientation towards the future shapes contemporary biomedical practice, impacting clinical work and patient experience. This is stark within biomedically-managed reproduction. Here, clinical efforts to chart gestation through linear clock-time and other forms of quantification do so with reference to a (future) foetal subject. This reflects a privileging of its anticipated outcome, rather than pregnancy as a process, within biomedicalised settings.

Through attention to experiences of pregnancy that do not end as or when anticipated, social scientists have unsettled dominant framings of reproductive time. This work joins of host of literature considering the complex social and historical factors that have led to the dominance of a ‘teleological’ model of foetal development within biomedicalised health systems. In this presentation I extend these efforts drawing on accounts of gestational trophoblastic disease (GTD), a rare complication of pregnancy that can in some cases require chemotherapy. Drawing on online narratives of GTD, participant observations and semi-structured interviews with patients and healthcare professionals, I demonstrate how the linear narrative of reproduction, and anticipation as an affective state, powerfully shape women’s experiences of GTD and medical work in the laboratory and the clinic. I then suggest that sociological attention to the wide spectrum of reproductive experiences and outcomes beyond a livebirth, including GTD, forces us to confront pregnancy in the present. This provides a means to re-centre gestating bodies, including the maternal, placental and hormonal, with such efforts particularly necessary amid international moves to limit reproductive rights.

Room 115- Open

The ontological politics of benzodiazepines: from prescribing dilemma to knowledge in practice

Melissa Ceuterick, Pauline Van Ngoc, Piet Bracke, Beatrice Scholtes

(Ghent University)

The discrepancy between official guidelines and clinical practice is hardly more pronounced than in the case of benzodiazepines. Using social-constructionist positioning theory, we unravel how health care professionals deal with the dilemma of prescribing benzodiazepines. Our results reveal a prescribing spectrum that is discursively organised around four different storylines used by professionals. The storylines are organised along three axes that are related to prescribers’ opinions on prescribing and the negotiation of the related risks, the power dynamics between provider and patient in the prescribing process as well as to the rhetorical use of arguments. The discerned storylines allow one to explore the emotional and moral side of prescribing and demarcate clinical mindlines -internalised tacit guidelines- that professionals adhere to when they prescribe. By retreating to Annemarie Mol’s conceptualisation of ontological politics, we argue that these storylines also enact multiple versions of this class of medication.

Room 118 - Experiences of Health & Illness

The Shadows of Uncertainty: Experiences of Young Adults Living with Difficult to Diagnose Chronic Health Conditions

Imogen Harper

(The University of Sydney)

Young adults who live with chronic health conditions exist in an emotional, cultural, and medical space where there is limited knowledge and understanding. Often, they have spent significant periods of time without a diagnosis, and relatedly, unable to understand and explain their symptoms. Receiving a diagnosis and accepting the chronic nature of their condition(s) brings a reckoning that not only impacts how they see their future, but which also shifts how they understand their past. This paper comes from research I am conducting for my ongoing PhD. I draw on open-ended interviews with people aged between 18-30 who have been diagnosed, or are seeking diagnosis, for a range of difficult to diagnose and explain chronic health condition. These conditions include auto-immune illnesses, inflammatory conditions, fatigue syndromes, neurological conditions, and chronic pain. Their stories illuminate the tensions, oversights, and biases which exist in our discussion of chronic illness and disability, and in turn reveal the variety of ways that these structural weaknesses burden those who live with chronic health conditions. This paper will explore this ill-defined space that these young adults exist in, the understandings about their bodies and medicine which they reach, and how past oversights in medical care and education continue to influence their lives.

Room G22 - Patient Professional Interaction

Elicitation of ideas, concerns, and expectations in primary care consultations in the UK

Fiona Stevenson, Geraldine Leydon-Hudson

(UCL)

Patient centred care and shared decision making is a core ideology embedded in UK policy concerned with communication in medical practice. ICE (Ideas Concerns Expectations) is one approach used for communication skills training in UK Medical Schools to elicit patients' agendas. Despite this there is a dearth of empirical evidence about how it works in practice.

Conversation analysis of video recorded data from GP consultations is used to understand and critique the application of ICE. Analysis focuses on how patients' ideas, concerns, and expectations are elicited by GPs and how this relates to discussion about medication and prescribing.

Our data set consists of 281 video-recorded primary care consultations collected for the HaRI study, with pre-consultation questionnaires completed by all patients. In the pre-consultation questionnaire 34 / 281 patients indicated they were expecting a prescription. The analysis for this paper draws on these 34 consultations.

The cases under analysis include examples of patients expecting: a medication for a new problem (17), a review of medication (4), and requests in relation to a repeat prescription (12).

Analysis indicates that in practice expectations in relation to prescribing are variously elicited and as such it is vital to take account of the complexity involved in the application of the ICE approach. Through detailed interactional analysis we illuminate the local work in which both patients and doctors engage. Such work is central to understanding how and why prescribing occurs and the consequences for eliciting patient agendas and as such patient engagement in decision making.

Room 144 - STS and Medicine

‘No expectations’: Shifting disease temporalities and negotiating uncertain futures in cancer immunotherapy treatment

Julia Swallow

(University of Edinburgh)

Immunotherapy is an emerging therapy in the treatment of advanced cancer, harnessing or reprogramming patients’ own immune system T cells to ‘attack’ cancer. The promissory discourse attached to these novel therapies is that they will lead to long-term survival: treatment works in the body (harnessing the immune system) for an indefinite period of time, even upon completion, with the potential to extend survival time for patients living with advanced cancer. Immunotherapy treatment can, however, lead to the development of side effects and toxicities, during and post-treatment, and clinical uncertainty remains concerning predicting future treatment success, and how to manage toxicities and the emergence of side effects over time. Drawing on interviews with patients and practitioners in an oncology clinic in the UK, this paper explores how immunotherapy shifts disease temporalities in a wider context of uncertainty concerning patients’ (immunotherapy) futures. Uncertainty around on-going and future treatment side effects and prognosis (re)orients practitioners and patients to the present and also suspends cancer in time with consequences for clinical practice and expectations and experiences of cancer treatment. Situated within a wider context of shifting disease temporalities, this paper argues that patients alongside practitioners negotiate uncertainty concerning future prognosis and side effects in relation to ‘no’ rather than ‘low’ expectations attached to these innovative therapies and the promise of an extended future.

Thursday 14 September

11:20-11:50

Room G36 - Diagnosis, Screening & Treatment

What is the value of an ME (myalgic encephalomyelitis) diagnosis? Exploring epistemic injustice, stigma and the sick role.

Natalie Wotherspoon

(University of Sheffield)

George: "You tell them it's ME and that's the end of everything else. They think it's a life sentence."

Leading psychiatrists (Huibers and Wessely, 2006) have queried whether patients with ME (myalgic encephalomyelitis/ chronic fatigue syndrome) should be informed about their diagnosis due to concerns that ME patients may not try to get better once labelled. This paper draws attention to how, in my study, people with ME felt they were in a double bind of being held responsible for causing their illness yet not always entrusted with their diagnosis.

Accordingly, this paper asks what is the value of an ME diagnosis? To explore this question, 42 in-depth semi-structured interviews were conducted with people who received a clinical ME diagnosis in the UK. The paper considers the epistemic and social implications of holding/withholding an ME diagnosis.

Drawing upon Fricker's (2007) theorisation of epistemic injustice and Parson's (1951) sick role, this paper highlights the medical authority to diagnose and how stigma manifests in the ME diagnosis. The paper identifies how, through experiences of hermeneutic and testimonial injustice, the participants encountered challenges accessing and inhabiting the sick role. My paper argues that, despite ME being a contested diagnosis, holding a label is important for its communicative and narrative value. This remains so even when the label fails to be explanatory, palliate uncertainty or provide full access to the sick role. The paper contributes to the sociology of diagnosis by highlighting the power and value of a diagnosis amidst stigma and epistemic uncertainty.

Room 155 Health Services Delivery

"They seemed to be like cogs working in different directions": a longitudinal qualitative study on Long COVID health services in the United Kingdom from a person-centred lens

Chao Fang, Jd Carpentieri, Sarah Baz, Laura Sheard

(University College London)

Long COVID (LC) has presented significant challenges to healthcare, as people with persistent and fluctuating symptoms often face prolonged uncertainty when seeking medical support. Negative experiences with healthcare systems and trauma from previous health conditions may further compound this uncertainty. To better understand the healthcare experiences of those with LC, we conducted a longitudinal qualitative study with 80 participants in the UK. We collected a total of 153 interviews (with some attrition) in two sets, from November 2021 to March 2022, and from June to October 2022. Adopting a sociological lens of person-centredness that acknowledges and supports interconnected individual, relational, and existential needs in healthcare, we explored LC healthcare experiences across primary, secondary, and specialist integrated care. Through this approach, we identified three overarching themes. Theme 1 focuses on the continued hurdle of accessing the first point of contact for LC healthcare; theme 2 highlights the complexity of navigating secondary care; and theme 3 captures the unique challenges of propagating LC integrated care. These themes were interconnected, with individuals often bouncing between systems and practitioners cooperating across their remits. Using a person-centred lens allowed us to identify the multifaceted needs of LC sufferers and understand how these needs shape individual health and healthcare experiences in a nuanced way, considering their life course as a key source shaping their healthcare needs. The study aimed to explore how person-centred care can be delivered more effectively and sustainably across different healthcare settings and over time to better meet the needs of LC sufferers.

Room 135 - Critical Public Health

‘I thought I was normal’. Children’s views and experiences on weight and body. A qualitative study in Santiago, Chile.

Cecilia Prieto

(University of Edinburgh)

Introduction: In Chile, 58.3% of children are classified as ‘overweight’ or ‘obese’ (JUNAEB 2021). However, there is a limited understanding of children's experiences with their bodies and weight and how these experiences might inform public health policy in Chile.

Methods: 34 semi-structured interviews were conducted with children between 10-12 years classified as ‘overweight’ or ‘obese’ (N=18) and their mothers (N=16). A Reflexive Thematic approach (Braun and Clarke 2022) to analysis has been adopted (ongoing PhD studies).

Results: Children's meanings of body, growth and weight have been affected by medicalisation processes -surveillance, measuring, and monitoring at the clinics-; Children had differing perspectives on their weight and body that were context-specific and shaped by social interactions. The language used by children to describe their bodies differed from those given by the clinicians using medical terminology (‘overweight’ / ‘obese’). Children described their body weight in terms of body size, but not as a disease or chronic condition. Within families and peer relations, children had learned that ‘being overweight’ is a cause of teasing and bullying. For the children, overweight was experienced negatively and perceived as devalued and shameful, undesirable, highly stigmatised, and associated with ideas of abnormality.

Conclusion: Children did not describe themselves with medical labels. The weight stigma associated with those labels made them feel ashamed. These findings are relevant because they highlight the unintended consequences of the current Chilean public policies and surveillance strategies on children based on BMI to classify ‘overweight’ and ‘obesity’ and to reduce overweight.

Room G31 - Mental Health

COMMUNITY HEALTH WORKERS’ EXPERIENCES OF SUPPORTING FAMILY CAREGIVERS OF RELATIVES WITH MENTAL ILLNESSES IN NELSON MANDELA BAY, SOUTH AFRICA

David Morton, Therese Boulle, Natalie Mansvelt, Nomandla Mlungu, Ashwin Navsaria

(Nelson Mandela University)

Globally, community health workers (CHWs) have an intimate knowledge and understanding of the communities they serve. Hence, CHWs are well positioned to provide support to family caregivers caring for relatives with mental illnesses in resource constrained communities. However, they are not always sufficiently equipped to respond to such situations.

The study objectives sought to explore and describe CHWs’ experiences of supporting family members caring for relatives with mental illnesses and to identify the support and training needs of CHWs supporting such family members. A qualitative, exploratory-descriptive research design and methodology was used. The concepts embedded in the Socio-Ecological Model helped elicit insights into the study problem.

The population was all CHWs in Nelson Mandela Bay (NMB), South Africa. Four focus group discussions were conducted at two community health care clinics in townships in NMB. Thematic analysis was used to construct the following themes: Challenges with providing care and support to families with relatives with mental illness; Families have different responses to their relatives with mental illness; Community members have certain cultural perceptions of people with mental illness and CHWs felt that clients with mental illness have certain challenging behaviours.

The CHWs were committed to their work, but certain factors prevented them from providing optimal support to families with relatives with mental illnesses. CHWs avoided certain households with residents with mental illness. They felt ill-equipped to provide effective support to families caring for relatives with mental illness owing to a limited understanding of what constitutes mental illness.

Room G35 - Lifecourse - Reproductive Health: Chronic Conditions; Ageing; Death and Dying

Spectators on life, left behind – people with chronic conditions experiencing loneliness

Karen Willis, Sophie Lewis, Maja Moenstad, Leslie Dubbin, Anne Rogers, Lorraine Smith

(Victoria University)

Loneliness is one of the most pressing and rapidly growing social challenges of the 21st century. Yet we still lack a good understanding of how loneliness is constituted and experienced by those most affected. Our presentation draws on qualitative interviews with 40 people with chronic illness who were experiencing loneliness, to explore what loneliness means to them, and how it impacts in their daily lives. Informed by ideas around liquidity and social bonds, we examine the interpersonal, existential and temporal layers of loneliness. Our analysis reveals the interconnectedness of chronic illness and loneliness in participants' daily lives. Chronic illness shifts temporal orientation and transforms interpersonal relationships both of which contribute to the experiences of loneliness. Participants described the many social conditions that restricted their opportunities for social participation giving them a sense of being left behind and spectating the social life of others. At the same time, a rhetoric of loneliness as a problem and responsibility of the individual was still prominent. Participants described needing to perform social connection, in the absence of meaningful social bonds with others. We found that normative ideals of wellness and positivity circulating chronic illness communities and society more broadly are implicated in, and intensify, the experience of loneliness for people with chronic conditions. We conclude by considering how more expansive representations of how to live well with chronic illness may be important in ameliorating loneliness.

Room 115- Open

"It's a secret in our life" Frontstage and backstage behaviours surrounding the induced abortions in the rural Pakistani community

Rubeena Slamat

(Ghent University)

Induced abortions are highly criticized in the Punjabi-Pakistani community. Induced abortions are considered against the social norms of motherhood and motherhood love. Therefore, induced abortions cause stigma for women who experienced/decided to have induced abortions. Pakistani community considers it socially and religiously negative. It seems that in such a society, induced abortions are not possible, but they exist; this shows a discrepancy in behaviour. This study aims to explore the tension surrounding induced abortions. How do women use their agency to make decisions undergoing induced abortion and avoiding stigma? This study applies the dramaturgical theory of Goffman (2012).

This study is part of a broader research study, ‘maternal health structure of a rural Punjabi-Pakistani Community.’ Data were collected through in-depth interviews, focus group discussions, and observations from the community under study, a religiously diverse village where Christians and Muslims live together.

Study findings are that women express different bahaviours in front, back, and back-back regions. Front region behaviours are staged for face-saving and portray the induced abortions as spontaneous abortions. Backstage regions provide the spaces to decide, making secret plans and behaviours for induced abortions. It involves some support system from family and friends while back-back regions involve behaviours known as top secret. In this region, the women become emotional and ask for forgiveness from God while memorizing the experience of abortion. These regions show different behaviours from each other.

Room 118 - Experiences of Health & Illness

Challenges faced by adolescents and emerging adults with type 1 diabetes mellitus in Delhi-NCR, India: A study on the lived experiences of patients and expert views of paediatricians and diabetes educators

Jyotishmita Sarma

(All India Institute of Medical Sciences, New Delhi)

Type 1 diabetes mellitus (T1DM) is one of the commonest paediatric endocrine diseases whose incidence is increasing globally. It is a complex, exhausting and expensive chronic illness that interferes with almost every aspect of a person’s life. Its incidence is estimated to be very high in India. In spite of this, not much is known about the lived experiences of persons diagnosed with the disease. This study tries to bridge this gap by focusing on the lived experiences of adolescents and emerging adults with T1DM. The study participants (aged 15-21 years) are a part of the PATHWAY Trial, a multi-sited randomized controlled trial initiated by AIIMS, New Delhi in Delhi-NCR to smoothen the transition of T1DM patients from paediatric to adult healthcare provider. This qualitative study was conducted to evaluate the effectiveness of the trial using the RE-AIM framework by randomly interviewing a sub-sample (n=55) of the study population from four major government sites in Delhi-NCR. Using intersectionality as an analytical framework, the study elaborates on the multiple social challenges that individuals with T1DM face in their self-management of diabetes such as diabetes disclosure, peer influences, family support, parent-child conflicts, stress related to school and college work, co-morbidities, aspirations for the future and long term diabetes-related complications. The study explores these challenges through multiple social locations such as age, gender, socio-economic class and place of residence and corroborates these findings through key informant interviews with paediatricians (n=5) and diabetes educators (n=5) of these sites.

Room G22 - Patient Professional Interaction

Communication in optometry: patient resistance to optometrists' treatment recommendations

Holly Dobrzycki

(King's College, London)

Most people in the course of their lives visit an optician where they have their eyesight and eye-health tested by an optometrist. Despite the importance of optometry as a healthcare practice, there are few sociological studies concerned with the interaction in the examination room. This presentation, that is based on my ongoing PhD research, will focus on a particular practice, i.e., the advice regarding the need for particular lenses to correct and improve patients’ sight and patients’ resistance to agree with this advice. Drawing on video-recordings of 62 eye examinations at opticians in England, I will examine the authoritative bases of optometrists' advice and patients' resistance. The analysis will focus on two dimensions of authority – the epistemic dimension concerning knowledge and the deontic dimension concerning rights (cf. Heritage 2012). I will investigate what epistemic and deontic positions optometrists and patients take in the context of shared decision-making, and how optometrists modify their positions in response to patient resistance. Based on the analysis, the presentation will argue that whilst optometrists honour patients' irrevocable deontic authority to reject treatment, they nevertheless treat rejecting treatment as accountable. The analysis is based on ethnomethodology as theoretical framework and conversation analysis as methodological technique. The findings from the research are relevant to sociologists with an interest in patient centred care and shared decision-making in healthcare.

Room 144 - STS and Medicine

The (Anti) Microbial Gaze: Surveillance Meets Resistance

Katherine Kenny

(The University of Sydney)

While disease surveillance has a long history dating back at least as far as the17th century, modern surveillance and audit techniques are now used for a wider range of purposes within healthcare systems. Recently, this has come to include Antimicrobial Resistance (AMR) - a rapidly escalating but often imperceptible global health threat – which is increasingly known through different forms of monitoring. Surveillance, both of resistant organisms and of the antimicrobial prescribing practices that contribute to their proliferation enables prescribing audits, which are routinely deployed to evaluate the alignment of local prescribing practices to established 'best practice' guidelines and thus ensure accountability for 'guideline concordance'. However, governing AMR in this way raises important questions including: how do these forms of monitoring play out in practice, and with what consequences? and; how do they articulate with the machinations and temporalities of hospital governance, and with increasing ambient societal surveillance more generally? Here, drawing on in-depth interviews with 36 participants ranging from ward nurses to hospital executives, we ask what, precisely, this way of monitoring medics and microbes makes visible in the hospital setting, what might obscured, and how this particular way of knowing may delimit what is seen as possible in terms of intervening in the growing challenge of antimicrobial resistance.

Thursday 14 September

11:55-12:25

Room G36 - Diagnosis, Screening & Treatment

Parental Illness Work Across The ADHD Diagnostic Journey

Tom Nicholson

(Northumbria University)

The process of referral, assessment, and diagnosis of Attention Deficit Hyperactivity Disorder [ADHD] within the UK is often protracted, fuelling a rising tide of criticism regarding the perceived failure of the ADHD diagnostic system. Given that parents are often the instigators of the diagnostic process, understanding the experience of parents during this time is sociologically important. Drawing on findings from a longitudinal study, this article explores how the parental experience of the ADHD diagnostic journey can be conceptualised as three significant and distinct forms of 'illness work'.

Twenty-one semi-structured longitudinal serial interviews over a two-year period with seven parents of children on the ADHD diagnostic journey in North-East England. Utilising the sociology of diagnosis and biographical illness work, we present three significant forms of illness work parents engage with: (1) The "Diagnostic Quest", parental work recognising and fighting for their children's needs and selfhood, seeking diagnosis, and engaging with the system of healthcare, (2) "Self-Biographical Illness Work", the personal and individual parental biographical response to the diagnostic journey and (3) "Child Biographical Illness Work and Recontextualising the Child", parental biographical adjustment and re-contextualisation of their children throughout the diagnostic journey. Our research provides novel contributions to sociological literature on ADHD as the first qualitative study to explore the pre- and post-diagnostic temporal time periods alongside parental experience of diagnosis. The theoretical concepts of illness work and biographical work are also applied to ADHD in a novel way.

Room 155 - Health Services Delivery

The development of bio-psycho-social models of fibromyalgia care: a qualitative ethnographic study in the UK

Teresa Finlay, Caroline Cupit, Catherine Pope

(University of Oxford)

Biomedicine has dominated modern health service delivery over recent decades. The limits of biomedicine are increasingly obvious, especially in the treatment of chronic conditions—where pharmaceuticals may provide some change in biomarkers and/or symptom-relief, but do not affect root causes of illness, and often cause harm. Since the 1970s, approaches to care that recognise the psycho-social dimensions of health and illness have been promoted (e.g. the 'bio-psycho-social model'), but have had limited impact on established biomedical service structures.

This paper is based on qualitative findings from the PACFiND study (PAtient-centred Care for Fibromyalgia: New pathway Design) in the UK. We conducted 53 interviews and 200 hours of observation with health practitioners delivering new services for people with fibromyalgia—a condition characterised by fatigue, pain and other symptoms. Drawing on Smith's 'Sociology for People', in combination with a pragmatic formative evaluation approach, we outline an emerging model of care for people with fibromyalgia. Described as a 'bio-psycho-social model' by participants, we highlight the practices that are associated with this approach to care. Particularly important are educational practices that encourage patients to recognise body-mind connectivity (holism), and adapt their own wellbeing and recovery practices in relation to this new knowledge.

We discuss the potential of new ‘bio-psycho-social’ models of healthcare and their fit with existing healthcare services.

Room 135 - Critical Public Health

Products, practices and power: What could/should medical sociology contribute to the Commercial Determinants of Health?

Cervantee Wild

(University of Oxford)

Commercial, for-profit actors deploy power and resources to advance their interests; in doing so, they often determine the distribution of health outcomes (i.e. the commercial determinants of health [CDOH]). The CDoH consider the private sector’s products, practices and power, including how practices shape living environments, consumer preferences and behaviours, and limit labour, social or environmental protections. They also encompass practices undermining the development of public health policies including legislation and fiscal measures through lobbying, political pressure and through misleading research – all areas worth attending to through a medical sociological lens. However, the CDOH field has been dominated by unhealthy commodity industry products like tobacco and alcohol and high-income contexts, largely from a public health perspective.

Referring to Williams’ work on health inequalities and the social determinants, as well as critical Indigenous theories of health, I evaluate the relevance of a CDOH framework for medical sociology, and consider what we could/should contribute to the evolving discourse around CDOH. Beyond questions of healthy lifestyles, non-communicable diseases, and risk factors, a critical medical sociological approach to CDOH could encompass questions concerning food sovereignty, access to clean water and air, environments free of toxic contamination and the right to territory, suggesting the scope should be broadened beyond unhealthy commodity industries.

Room G31 - Mental Health

Children’s Psychological Well-Being in LMIC Countries During COVID 19 school Disruption

Esther Ariyo

(University of Essex)

Literature reports that the COVID-19 outbreak produced mental health stress for children, and negatively impacted their mental health. Albeit, it has been suggested that positive coping mechanisms of family and social support may be important to achieving better well-being outcomes in subsequent or similar situations.

This paper extends the literature by investigating how family and school support influences the relationship between COVID-19 stress and children's psychological well-being across three low and middle-income (LMIC) countries during the COVID-19 school disruption. Based on the transactional model of stress, we hypothesize that children's perceived stress of COVID-19 will decrease children's psychological well-being, but it will be moderated by school and family support.

Data for the study was extracted from the International Responses to Educational Disruption Survey (REDS). REDS is an international survey of grade 8 (Year 8) secondary school students across 11 countries spanning Africa, Asia, Arab region, Europe, and Latin America during the COVID-19 school closure. Data used for this study includes 7429 from three African countries including Burkina Faso, Kenya, and Ethiopia. A sensitivity analysis was used to identify demographic confounding variables was conducted followed by a strobe-compliant structural equation model analysis conducted with AMOS-28.

Although countries of interest had similar cultures and economic status, results show variations in cofounding variables and mechanisms between stress and the psychological well-being of children.

Room G35 - Lifecourse - Reproductive Health: Chronic Conditions; Ageing; Death and Dying

'On a rollercoaster' or 'Going round in circles': a comparison of how metaphors are used to frame experiences across five long-term conditions

Katherine Bristowe, Chris Tang, Emily Heavey, Helen Allan, Vanessa Lawrence, Ruth Williams, Beatriz Santana-Suarez, Lisa Hinton, Karen Gillett, , Anne Arber, Heidi Lempp

(King's College London)

Background: Long-term conditions affect around 25% of the UK population. Enabling patients and caregivers to communicate their experiences, in their own words, is vital to developing a shared understanding of their illness. Metaphors are fundamental to how patients conceptualise and communicate about their condition. Despite extensive research within single illnesses, comparison of metaphor use, and how they may manifest differently, across conditions is rare.

Data: In-depth interviews with n=25 patients, caregivers and parents with lived experiences of five heterogenous long-term conditions (fibromyalgia, mesothelioma, myositis, dementia, and neonatal surgery).

Methods: Secondary qualitative analysis drawing upon Cameron's (2009) Discourse Dynamics Approach to identify the metaphors used, and compare their use across the conditions.

Results: Commonly used metaphors (e.g., Illness as a Journey) and metaphorical vehicles (e.g., Violence) manifest differently, and can be empowering or disempowering, depending on how individual conditions present, are diagnosed, and managed. For example, in the context of incurable illnesses, journey metaphors are often employed to communicate powerlessness and uncertainty as a lack of direction, rather than being destination (cure) oriented. Metaphors are also used to express the negotiation of agency as an illness becomes part of everyday life.

Discussion: Our findings highlight the importance of avoiding assumptions about commonly used metaphors, as they often have the potential to empower or disempower patients depending on the specific condition. Paying attention to how metaphors are expressed by the individual can improve understanding of the nuance of the individual's experience, and enable meaningful dialogue to tailor discussions and care plans accordingly.

Room 115 - Open

Imagery and metaphor in the exploration of the lived experience of healthcare professionals

Sharon Spooner, Deborah Swinglehurst

(University of Manchester)

The delivery of primary care depends crucially on a wide array of working practices that usually remain invisible from patients and public. This work is essential to enabling continuous service delivery; safe, effective, high-quality care depends on it. We have explored the potential of visual images and metaphors to illuminate the full scope of clinicians' work.

Articulating the lived experience of clinicians is challenging due to the inherent complexity of work that is often characterised by exceptions, contingencies, and uncertainties. In a fast-paced working environment that offers little opportunity for reflection and narration, there is also a paucity of vocabulary with which to describe how this work is done. In this paper we demonstrate the value of imagery and metaphor in enabling primary care clinicians to recognise, make sense of, and articulate their 'hidden' work.

Data represented as simple cartoons provided an effective alternative for photo-elicitation, stimulating participants' reflections on hidden work by 'amplification through simplification'. Discussion of evocative metaphors that participants used to describe everyday work, enabled deeper exploration of embedded - often tacit - practices and identification of practices that might be improved.

We demonstrate the value of creative research methodologies to generate, explore and understand complex practices in contemporary health settings where there are limited opportunities for research engagement or for reflection upon adjustments that would benefit clinicians, colleagues, and patients.

Room G22 – Patient – Professional Interaction

Safe from and safe for: exploring the production of remote primary care encounters as spaces of patient safety

Anna Dowrick

(University of Oxford)

This paper explores the relations through which healthcare interactions are produced as spaces in which patients feel safe. There is recognition that healthcare interactions are not de facto safe, but have to be made safe. Examining the work of addressing issues of safeguarding and domestic violence in general practice, we explore the paradoxes that teams of professionals navigate in making patients safe from external harms during interactions, and in making interactions themselves safe for disclosure and, ideally, resistance. We explore this in the context of the move to remote delivery of heathcare, drawing analysis of 40 interviews with primary care professionals about experiences of providing support around safeguarding issues remotely. The rapid uptake of telehealth has required reconfiguration of relations and practices through which safety is produced, as patients are not guaranteed safety in disclosure of violence remotely while in their own homes. Producing safe opportunities for disclosure involves negotiating multiple risks in processes of setting the boundaries of a consultation. This relies on different ways of seeing and hearing risk, first through noticing changes in behaviour and second through paying attention to how things are said, rather than what is said. We conclude that safe interactions are possible on a range of issues in primary care, but are more likely when practitioners are able to 'see' risk through teamwork and to respond flexibly and re-form the borders of interactions to create opportunities for patients to speak freely.

Room G35 – STS and Medicine

Taking care: Collective knowledge practices in antenatal sessions

Leah De Quattro

(University of Manchester)

Knowing Childbirth is a PhD project that asks how people use collective practices to co-produce birth knowledge. The importance of caring emerged clearly from the data, and this paper explores how collective knowledge practices 'take care' of birth knowledge, birthing people and more.

Research included participant observation of community group-led sessions (n=44) and NHS teacher-led classes (n=113). I analysed transcripts using template analysis, alongside feminist ethnography and narrative analysis.

Collective knowledge practices appeared in all sessions, for example in the form of storytelling, intuition, comparing, questions or humour, or lay use of authoritative or procedural knowledges. Notions of care offered a useful framework for understanding patterns in how participants deployed these knowledges, in different settings, regarding certain topics, and alongside other knowledges.

To examine how knowledges ‘take care,’ I engage different facets of care as elaborated by feminist technoscience, including care as material ‘tinkering,’ as both affective and effective, and sometimes as oppressive. I also consider how knowledge-as-care ‘works athwart’ dominant structures or practices, and the phenomenon of care-ful absences.