Medical Sociology Study Group

Annual Conference Programme

13 – 15 September 2023

University of Sussex

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Presentations taking place PM on Thursday 14 September

Thursday 14 September

14:00-14:35

Room G36 - Theory

A cognitive interpretation of healthcare and health technologies? Medical sociology joining forces with cognitive linguistics

Edison Bicudo

Department of Sociology and Policy, Aston University

This paper argues for a combination between medical sociology and cognitive linguistics, so that sociologists can incorporate linguistic and cognitive factors in their analyses.

Linguistic practices in health and illness (such as the use of metaphors and the importance of discourses) have been explored in medical sociology and STS. However, these analyses not always seek a deep conversation with linguistic theories. This paper highlights the importance of such conversation, putting forward a possible combination between sociological theory and cognitive linguistics.

The main idea of cognitive linguistics is that people act based on their understanding of the situation being dealt which. In this way, people's practical actions are the result, but also the source, of cognitive processes which are, to a large extent, articulated in linguistic and lexical terms. Phenomena such as metaphors and metonymies are not merely devices used by poets and novelists: they are everyday forms of reasoning.

This paper claims that social actors, when dealing with practical issues (such as the development, implementation, and delivery of medicines and health technologies) necessarily formulate and disseminate certain understandings. Frequently, this takes the form of metaphoric and metonymic reasonings which frequently oppose each other, thus generating disagreements that manifest themselves in conflicting projects for regulation, models for therapy development, organisation of healthcare services, and others.

This paper gives some examples of how these cognitive and linguistic conflicts emerge in the fields of medical-related software, as well as cell and gene therapies.

Room 155 - Health Services Delivery

Jurisdictional challenges and ownership of the deteriorating patient: An ethnographic exploration of a patient-led escalation system

Liz Sutton, Peter Mcculloch, Lesley Booth, Nicola Mackintosh

(University of Leicester)

Detecting and responding to patient deterioration following surgery is a continued threat to poor patient outcomes and mortality. Patients and their relatives are now encouraged to be part of hospital monitoring and response systems through patient-led escalation systems. Our research draws on boundary and distinction work as a useful theoretical resource for the study of escalation. We consider how jurisdictional challenges related to ownership of the 'deteriorating patient' become visible via patient-led escalation systems.

We utilise data from an ethnographic evaluation of the implementation of a programme of interventions focussing on improving response to patient deterioration following surgery in three surgical units in

hospitals in England. One of these interventions was a patient-led escalation system. It enabled patients and their relatives to call a hospital telephone number in the event that they had a concern about their health.

Drawing on fieldwork and interviews (clinicians, managers, patients and relatives), we highlight the tensions created by introducing such a system. Our findings illustrate the importance of institutional contexts. We highlight the prominence of different staff group 'buy in' in the organisational structure along with the extent of relational effort involved in both implementing and using the system. We see how jurisdictional claims over management of the acutely ill are linked to occupational and organisational boundaries between staff groups, and ward and critical care services. Data differences between sites reflect wider political and socio-cultural influences, notably the legitimacy of user involvement in rescue trajectories, and trade-offs between safety, quality and efficiency in practice.

Room 135 - Critical Public Health

The social lives of the COVID-19 vaccines among people of black ethnicities in London

Emily Jay Nicholls, Denis Onyango, Vladimir Kolodin, Zoë Ottaway, Lucy Campbell, Rob Horne, Frank Post, Shema Tariq

(University College London)

Medicines have social lives and meanings beyond their biological effects. In this paper, we follow the social lives of the COVID-19 vaccines by drawing on a series of focus group discussions with people of black ethnicities, most of whom are also living with HIV. People of black African and black Caribbean ethnicities were among the groups most likely to acquire COVID-19, and to develop serious infection, but were also the least likely to have received a COVID-19 vaccine. In the course of our discussions, the COVID-19 vaccines emerged not simply as agents with the (sometimes contested) ability to protect from severe COVID-19 disease. Nor was a decision to get vaccinated driven solely by travel requirements or a broader aim of returning to 'normal', although these were often key motivators. Rather, the COVID-19 vaccines were bound up in, and entangled with, complex social and cultural meanings for our participants. Painful histories of medical experimentation on black people emerged anew in the context of concerns regarding the safety of the vaccine, as well as the present realities of medical racism and global vaccine inequity. Moreover, familial, religious, and cultural expectations were ever present in decisions about whether to be vaccinated. For participants living with HIV, longstanding trusting relationships with HIV physicians were key in building confidence around the vaccines. We untangle these complex webs of meaning to understand the temporal, geographical and interpersonal relationships which play into and form part of the COVID-19 vaccines, and their social lives and symbolic meanings.

Room G31 - Mental Health

From brain "scar" to "bat shit crazy": Negotiating the madness of sexual violence discourse

Emma Yapp

(Birkbeck University of London)

In this paper I examine how people who identify with psychiatric diagnoses in the UK make sense of and talk about their experiences of sexual violence. I interrogate the dominant discourses with which they engage, as well as the consequences of these engagements for subjectivity and opportunities for 'speaking out'. I analysed in-depth semi-structured phenomenological interviews (n=9) using a thematic, reflexive discourse analysis. Participants engaged with two dominant medicalised discourses – a binary discourse of trauma as psychological normality/abnormality, and an associated discourse that conceptualises psychological normality on a spectrum. For all participants, the value of these discourses was dependent on the testimonial landscape within which they were operating. I examine how participants move away from occupying the subject position of 'victim' or 'survivor' and its

associated speech imperative, and towards a desire to live a life outside of the violence of others. This shift was precipitated by the impossibility of speaking about their experiences – either due to fears of being branded 'mad' or the psychological consequences of speech itself.

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

Ageing men: intersections of health, age and gender

Iva Smidova

(Masaryk University)

Men are often not named as a gendered category in research on ageing. Intersections of power/dominance and (absence of) care for own health form the core analytical axis in the paper. Its goal is to help us understand categories of age and gender in men´s narratives on health (performance, able-bodied-ness, achievement vs. illness, powerlessness). The critical approach to the process of gendered ageing, situated in the context of a post-socialist country - the Czech Republic, aims to fill in gaps in topical research and enrich current international knowledge.

The paper addresses the process of ageing as a reflected gendered practice in the dynamics of relations in later lives. Inequalities, marginalisation as well as relations of power of men as they age get scrutinised together with caring and being cared for. Several social environments have been explored in the fieldwork; the paper elaborates intersections of health, age and gender in detail on narratives of three specific groups of participants: homeless men, men in health-care professions and "balancing" men (attenders of workshops designed for men to "look back" on their life-courses).

The paper is based on a current sociological research project Institutions of Aging Men (fieldwork and analysis ongoing), using face-to-face in-depth interviews with men in selected social environments as the primary analytical source of data. Ongoing qualitative data analysis is based on feminist and critical studies on men and masculinities approaches.

Room 115 – Open – Special Event

Sociology and critique: the Cost of Living blog as a natural experiment in public sociology

Simon Carter

(Open University)

Sociology, by its very nature, has the potential to offer cutting insight and critique into the ongoing social issues. However, all too often, this potential is blunted or even lost, but the prevailing scholarly contexts in which the majority of sociology is written and discussed. There is a clear need for sociological commentary to be conducted in more accessible, public fora in order to enrich debate in those fora, to bring an often absent sociological framing to those debates. In this regard, the Cost of Living blog can be characterised as a natural experiment in public sociology. Blogging is a powerful tool for sociologists to connect with a broader audience and contribute to public discourse. This session explores how issues of public sociology can be developed and utilised to enhance public sociology by bridging the gap between academic research and the general public, amplifying marginalised voices, promoting dialogue and participation, and fostering social change. Whilst sociologists can utilize the accessibility of blogs to share their research findings, theories, and perspectives in a more engaging and approachable way, it is imperative that this is accomplished in a way that directly develops public understanding of sociological critique. This is imperative because the current political climate, both in the UK and further afield, is one where the opportunity and possibility for critique appears to be reducing. Public sociology offers an vibrant and important opportunity to keep critique alive. By weaving personal stories, relatable examples, and anecdotes into their writing, bloggers can effectively communicate complex sociological

concepts to a broader audience, encouraging critical thinking and social awareness. In this symposium we outline both the present and the future potential for public sociology in the context of continued hostility to critique.

Room 118 - Experience of Health & Illness

The spatial and place dimensions of loneliness: Experiences of those living with chronic illness

Leslie Dubbin, Maja Moensted, Karen Willis, Lorraine Smith, Sophie Lewis

(University of California, San Francisco)

In this paper we explore the spatial and place dimensions of loneliness. Drawing on in-depth and walking interviews with 40 people experiencing loneliness and living with chronic illness, we explore the ways in which spatial situatedness and place are implicated in the experience of loneliness. Through Bourdieu's concepts of collective habitus and habitus clivé we examine the complexity of the relationship between sense of place and feelings of loneliness, including interconnectedness between self, other people and the natural and built environment. Our analysis reveals how the deep connections people make with the natural environment, regular visits to green spaces, and being known and seen in the community fosters a sense of connectedness, particularly in the absence of interpersonal relationships. Many participants described the importance of green space in lessening their experience of loneliness and supporting their social wellbeing. In contrast, participants who lived in social and/or insecure housing, a discourse of disconnectedness was notable. Poverty, transient living and unsafe neighborhoods merged to exacerbate feelings of social isolation. And while these participants exhibited a strong sense of belonging to their neighborhood, these spaces also hindered engagement in activities to enhance their sense of social connectedness. Findings highlight the critical importance of creating places that support ways for people vulnerable to loneliness to meaningfully connect with nature, the built environment, and with others.

Room G22 - Patient - Professional Interaction

Biomedicine still reigns supreme: women's accounts of antenatal care

Hannah Miles, Clare Whitfield, Julie Jomeen, Una Macleod

(Hull York Medical School)

Objectives - The antenatal period is a time of immense transition for women, and in a western context this is increasingly marked by a set of social and cultural expectations, one of which is the engagement with antenatal care. This can lead to a complex web of expert and lay discourses that require mindful interaction and negotiation. Language and communication within the antenatal and birthing space form an important part of this process. Particularly when we take into account the growing call for more personalised women-centred care.

Method - This was a qualitative, ethnographic doctoral study, underpinned by a feminist praxis. This paper draws on interview data from 45 in-depth interviews with 33 mothers, living in low-socioeconomic areas, who were either pregnant, or had their child in the previous two years, prior to taking part in the research.

Results - Findings indicated that within these interactions medical knowledge displaces women's knowledge of their own bodies, and women's lived expertise is marginalised in favour of dominant biomedical discourses. Data captured demonstrates that these negative experiences can be not only disempowering, eroding trust between women and health professionals, but at times traumatic, and influencing how women see the best start for their child / children. This can be amplified for those women who have already experienced trauma, for example child loss.

The Implications of these findings show that we are only part way to fully achieving true women-centred care.

Thursday 14 September

14:35-15:05

Room G36 - Theory

Are we treating care home residents like 'dirt'? Deteriorating residents as 'matter out of place' in the care home and the hospital

Fawn Harrad-Hyde, Natalie Armstrong

(University of Leicester)

The last decade has seen extensive focus on reducing 'inappropriate' hospital transfers, including for those living in care homes. Despite much policy discussion, there is a lack of agreement about what constitutes an 'inappropriate' transfer for care home residents, both in academic discourse and amongst healthcare professionals who support residents.

Drawing on 30 semi-structured interviews with staff across six purposively sampled care homes, coupled with 113 hours of ethnographic fieldwork in three of the homes, we use Mary Douglas' (1966) work to critically examine constructions of '(in)appropriate' approaches to caring for residents whose health is deteriorating.

Care home staff expressed a strong preference for continuing to care for residents in the home, rather than seeking a transfer to hospital, yet there were times when staff felt unable to meet deteriorating residents' needs in the care home. Staff felt that hospital was often not the 'right place' for residents, due to concerns that residents may not receive adequate support in a busy hospital environment and be discharged in a 'worse' condition or without satisfactory investigations.

Using Douglas' work, we suggest that current discourses frame deteriorating care home residents as 'out of place' in hospitals. This in turn leads to residents being portrayed as both a risk to healthcare services and at risk from using healthcare services. This may reflect concerns for residents' and their health but could also reflect the marginal position that care home residents hold in society and a desire to create and maintain boundaries around stretched healthcare services.

Room G31 - Mental Health

Behind the posts – social media and UK undergraduate-student mental health and wellbeing

Heather Sutherland, Gabriel Moreno Esparza

(Northumbria University)

Increasing rates of university student mental distress continue to be recorded. Current explorations and declarations pertaining to the issue draw most heavily on quantitative approaches; qualitative understanding is afforded less space, resulting in conversations where personal agency is frequently overlooked. As a particular element, research considering UKHE students' use of social media frequently focuses on posted (presented) content. This has implications for how 'student mental health and wellbeing' specifically might be interpreted, understood, and acted upon (notably by academic institutions).

This presentation draws and reflects on data generated via free association narrative interviews conducted with 21 undergraduate students at one UK university. Included in the research process was social media employed as 'student mental health and wellbeing' elicitation tool. Referred to in the stories/comments shared were aspects such as personal reasonings behind multiple-account use; employment of social media for 'grounding/memory-banking', 'self-tracking', 'venting' and 'drafting';

uses of social media in relation to ideas of self-safety/security etc. Such elements, amongst others, signify new or underappreciated facets of the issue to consider - the significance of social media in reference to 'student mental health and wellbeing' may lie not in what is visible but rather in what is not. When social media is employed as a methodological tool, and a shift in thinking about social media towards 'backstage(s)' is implemented, a more granular, in-depth understanding of 'student mental health and wellbeing' (which may aid enhancement of support for those experiencing distress at university) may be realised.

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

Deathbed Events: A Challenge to Bureaucratic Care?

Rachel Cummings

(Goldsmiths, University of London)

Deathbed events are 'spiritual' experiences that happen in the last days and hours of life to both patients and those around them. Reports include seeing deceased relatives, believing oneself to be on a journey or observing meaningful coincidences (Fenwick et al 2007; Claxton & Dunnett 2018). These events are discussed within palliative care circles but little-known beyond (Kessler 2010; Lamb & Finucane 2022). This presentation will consider how such experiences challenge 'bureaucratic care' (Stevenson 2013). Based on ethnographic research on a hospice in-patient unit, it will compare the formal and informal discourses that circulate around such events among patients, carers and palliative care workers. It will trace the differences within professional and social hierarchies over how the phenomena are understood and the clinical responses they should or do illicit. It will explore how staff manage the tension between 'folk' and 'official' knowledge in day-to-day clinical practice. Using situated examples the presentation will suggest that extraordinary events provide an alternative stance from which to understand contemporary debates around the medicalisation of death and the medical management of profound ontological difference.

Room 118 - Experiences of Health & Illness

Contested illnesses: An exploration of experience and understanding

Lucy Skingle

(Royal Holloway University of London)

Contested illnesses are illnesses without identifiable etiology. These conditions have no well-defined treatment or therapeutic intervention, are subject to significant societal and medical debate over symptom causation being psychological, physiological, or psychosomatic, and their legitimacy are widely challenged medically, popularly, and politically. This paper centralises patient experience to investigate the lived experiences of those who suffer with Myalgic Encephalomyelitis (ME), Fibromyalgia (FM) and Morgellons Disease (MD), marking the first scholarship about MD from the perspective of sufferers.

Recent scholarly accounts have noted an increasing popularity of online illness communities. Due to the limited information and support available, many contested illness sufferers turn to online illness communities to abate uncertainties, create community, and generate knowledge about these conventionally poorly understood conditions. Using three online ethnographies, fifteen online video interviews, and fourteen instant message interviews that have been conducted on Facebook, this project explores how the use of online communities not only eases the isolation of sufferers, but evidences how patients are self-generating accessible knowledge about illness through collectivisation.

Building upon existing concepts of medical and existential uncertainty, this paper attests that contested illness sufferers must additionally navigate uncertainty regarding their psychological wellbeing and concept of self-morality. The difficulties faced, and uncertainties experienced by those who suffer with ME, FM and MD has caused many to turn to social media for information and support.

Room G22 - Patient - Professional Interaction

"What are you complaining about?" – How patients and care professionals make sense of informal complaining in care encounters

Jelmer Bruggemann, Ann-Charlotte Nedlund, Lisa Guntram

(Linköping University)

Patient complaints have a central place in the organization and development of health care systems. In line with consumerist trends in many health care systems, complaints are increasingly used as a tool for organizational learning, and quality assurance and development. Its importance is mirrored in a growing body of literature studying how health care systems can effectively collect, analyse, and act upon these complaints. This literature almost exclusively deals with so called formal complaints, while there has been little attention to informal complaints, e.g., the kind of complaints made verbally to care professionals. Following Mulcahy and Tritter (1998), in this paper we zoom in on informal complaints, not as mere untapped potential for formal complaints, but as a distinct phenomenon, drawing attention to the everyday ways in which patients' concerns manifest in care encounters. In particular we study how patients and caregivers make sense of informal complaining and how this shapes and is shaped by their understanding of care and patienthood more broadly. Theoretically, our paper is inspired by sociological work on good/bad/difficult patients and Ahmed's (2021) recent conceptualizations of complaint. We will present preliminary analyses of interviews with 19 individual patients and three focus groups with care professionals in Sweden.

Room 144 – STS & Medicine

Behind the 'digital front door': triage as distributed decision-making in general practice

Natassia Brenman, Michael Gill, Sara Paparini, Sara Shaw, Sophie Spitters, Sharon Spooner, Deborah Swinglehurst, Joseph Wherton

(University of Oxford)

Many GP practices in the UK have continued to use triage systems introduced during the Covid-19 pandemic to manage demand for face-to-face care. These are often supported by digital platforms, which filter patient requests through online forms, to be assessed by practice staff before appointments are booked. This has expanded the digital and material spaces in which decisions are made about who gets what kind of care, including in-person or remote modes of consultation: the focus of our study. Drawing on ongoing ethnographic research in three GP practices in the South of England, we map the distributed decision-making processes involved in technology-supported triage. Whilst NHS England has emphasised enabling access via the "digital front door," we are interested in following spatial understandings of providing access to care beyond this, charting the movement of patient requests through systems that span different spaces and relationships. Building on ethnographic scholarship on the spatial features of triage, as well as classic STS work on the ethical stakes of "sorting things out", we describe how various clinical and non-clinical staff contribute to, negotiate, and adjust triage decisions across the practice. We argue this disrupts conventional understandings of triage, reflecting a primary care landscape in which clinical decision-making responsibilities are increasingly diffuse across people and technologies. In the presentation, we speculate on the implications these preliminary findings may have for practice, such as the increasingly complex conditions needed for 'good' decision-making and inclusion—beyond simply getting patients to the digital front door.

Thursday 14 September

15:10-15:40

Room G36 - Theory

The selectivities of pharmaceutical spending containment: social profit, incentivization games and state power

Ben Main, Piotr Ozieranski

(Durham University)

State government spending on pharmaceuticals stands at 1 trillion USD globally promoting criticism of the pharmaceutical industry's monetization of drug efficacy and health injustice. This paper elucidates the dynamics of a state-institutional response to this problem through the sociological lens of the strategic relational approach to state power. I draw on 30-expert interviews, legal and policy analysis in explaining how New Zealand's state elites have contested their pharmaceutical spending containment policy. The theoretical explanation of how elites have effectively contested the policy is made of three elements. First, a strategic context consisting in relationships between the state bureaucracy's pricing strategies and the industry. I (re)conceptualize anti-competition in commercial and state actor relations as an incentivization game played by industry and state actors. For example, the pricing strategy, of "bundling"- packages of drugs that combine older and newer patented products - is interpreted as a means by which state actors continuously create "field positions" between themselves, industry actors and pharmaceutical products (current and in-development). Second, I describe a protective context to be comprised of legislative-judicial responses to the strategic context. Third, drawing on an analysis of the phenomena of increased pharmaceutical mix despite stable spending I theorise that the state defends a "social profit". In contrast to scholarly views that neo-liberalism drives the pharmaceutical policy making process I hold that state actors are largely antipathetic to neo-liberals. The argument is contextualised with discussion of the specificities of fictitious commodities of health and problematisation of Abrahams neo-liberal-corporate-bias model in pharmaceutical policy theory.

Room 155 - Health Services Delivery

A critical evaluation of cultural competence in medical sector: perspectives of ethnic minority cancer patients and local healthcare professionals in Hong Kong

Pui Yan Flora Lau   (*Virtual Presentation*)

(Department of Sociology, Hong Kong Shue Yan University)

Cultural competence in the context of healthcare is a well-recognized concept worldwide. In Hong Kong, relevant healthcare recommendations such as the promotion of infusion model of teaching cultural competence in tertiary education, enhancement of on-the-job training, institutional changes, establishment of culturally competent lens for program delivery and policy making, are actively proposed in recent years (EOC, 2019). Cultural competence should be particularly important to patients with critical illness such as cancer because communication among different stakeholders, healthcare literacy and emotional support are all vital in the process of healing and recovery.

However, the existing recommendations have the following insufficiencies. First, they are all based on a top-down approach which lacks an emergence of any voices and suggestions of service users. Second, cultural competence admittedly improves the cultural sensitivity of healthcare professionals but there is no evidence to show that cultural competence training of healthcare staff improves patient adherence to therapy, health outcomes, and quality of services across ethnic groups.

Drawing on qualitative interviews with thirty cancer patients and eight healthcare professionals in 2022-23, this presentation aims to articulate the perspective of service users and evaluate the existing capacity of culturally competent healthcare delivery in Hong Kong with reference to the capacity assessment model (United Nations Development Programme, 1998). Among all essential findings, cultural competence holds a different meaning for different people and it may be that cancer patients have taken a different approach as to what cultural competence means to them, which varies from a top-down education or policy approach.

Room 135 – Critical Public Health

"The world seems a bit of a better place" – Idealised femininities and alcohol consumption at midlife

Kate Kersey, Antonia Lyons, Fiona Hutton

(Victoria University of Wellington)

Background: Midlife women in Western countries are increasingly drinking at at-risk levels. Public health messaging focussing on individual responsibility to manage alcohol consumption has had little effect, and research shows that alcohol use remains embedded, pleasurable and functional within their lives. We need to understand the roles and meanings alcohol has in women's lives, considering their gendered social, cultural and economic environments.

Methods: 50 women aged between 35-60 years in Aotearoa New Zealand who self-identified as past or present drinkers took part in interviews (n=17) and friendship groups (n=33) to discuss drinking alcohol. Information on their life circumstances and drinking behaviours were also collected. Interviews and discussions were transcribed verbatim and analysed discursively.

Findings: The women utilised three main discourses in accounting for their alcohol use: 'alcohol as enhancer', 'alcohol as enabler', and 'knowledge and awareness'. These discourses all referenced wider social and cultural meanings around idealised femininities, individual responsibility for health and wellbeing, and notions around 'appropriate' alcohol consumption. Feelings and sensations such as stress, pleasure, and remorse prior to, during, and after drinking co-produced meanings around alcohol as well as drinking experiences. While the women drew on these discourses to legitimise their own drinking, tensions arose around ensuring they were maintaining appropriate gendered drinking behaviours and leading responsible, successful feminine lives.

Discussion: The findings add understanding as to how various factors combine to produce diverse gendered meanings around drinking behaviours, experiences and potential harms, contributing to the development of more nuanced approaches in alcohol research and policy.

Room G31 - Mental Health

Mental Health Apps and the Self: A Computational Analysis of Public Discourse

Mark Hill, Vince Miller, Tiago Moreira

(University of Kent)

Symptoms of mental disorders are on the rise while a shortfall of service provision persists. Within this context a mental health app (MHA) market has emerged. One 2021 estimate suggests there are as many as 20,000 apps, and our research shows that downloads are growing. This has resulted in increased attention from experts. The NHS has 19 recommended MHAs (including six for staff) and the APA has an "App Advisor" supporting professionals assess suitability. Additionally, research has emerged around efficacy and condition-specific applicability. However, there has been little reflection on the impact MHAs have on users' understanding of themselves more broadly. This paper addresses this by empirically investigating how users report their use of MHAs, asking: Do MHAs change the relationship between 'self' and emotional states?

To answer this question we make use of detailed public discussions taken from online reviews and forums. While this data is in the public sphere, its abundance and diversity makes analysis difficult. We, therefore, make use of computational methods (NLP) to extract and investigate these sources. Initial findings quantitatively identify distinct discourses, and substantive discussions can be found in which MHAs are used for self-betterment (they add to the self) and are used to address specific conditions (they minimise/overcome an issue within the self). Our initial hypothesis, therefore, is that MHAs can both a) help externalise emotions, encouraging users to see them as separate from themselves, and something to be reflected upon/controlled; and b) be internalised/become integral to the self, and self-management.

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

Sex, truth and lies: Investigating the psychosocial experience of people learning 'not parent expected' news from an at-home ancestry DNA kit

Rob Whitley

(McGill University)

According to recent estimates, over 30 million people have taken at-home ancestry DNA tests to learn more about their ethnic ancestry. This is sometimes known as recreational genetics; and is marketed as a fun, harmless and exciting process of discovery. For a fee, individuals can order a testing kit from a company such as AncestryDNA or 23Andme. Once a saliva sample is received, the company provides an estimate of ethnic ancestry, while also detailing biological relationships between users on its database. This process can throw up sudden, unexpected and completely surprising news for individuals. The most shocking may be a 'Not Parent Expected' (NPE) discovery, where an individual learns that an assumed parent (typically the father) is not a biological parent. In this presentation, the author will report the results of a qualitative research study aiming to document the psychosocial experience of people receiving NPE news from ancestry DNA tests. This involved over 50 semi-structured in-depth interviews with affected individuals, which were analyzed using thematic analysis. Results indicate that learning NPE news is typically a deeply disturbing discovery creating a severe biographical disruption, with negative implications for (i) physical and mental health; (ii) familial relationships; and (iii) sense of self. Participants also reported an inadequate response from psychological therapists and clinicians, who reportedly reacted with bewilderment and fascination, but were considered ill-equipped to help. This study indicates that an NPE discovery can have serious psychosocial consequences for affected individuals, and that this growing but oft-ignored population may need specific supports.

Room 115 - Open

The role of 'administrative concepts' in the globalisation of autism: how have Japan's welfare and education systems mediated western knowledge?

Sawako Shinomiya

(University of Exeter)

This paper explores the cross-border transfer of knowledge about autism, with a focus on non-medical fields such as education and welfare. The medical concept of autism entered Japan in the 1950s, and Japanese doctors have reported as high diagnostic rates of autism as Western countries. In contrast with this relatively smooth transfer of the autism concept in medicine, the education and welfare systems have seen more complex processes to establish support for autism – the government has often shown reluctance to use the term autism and instead has coined original disability categories to launch support schemes that covered autism. These 'administrative concepts' are 'children with mobile severe motor and intellectual disabilities', 'emotional disturbance', 'extremely disruptive behaviours', and

'developmental disabilities'. These concepts substantially referred to autistic people but served as more suitable categories for the Japanese administrative context. These categories helped the foreign-derived concept of autism enter the local context, functioning like drills to make holes into the thick wall of locality. This paper will analyse historical documents and interview data on administrative concepts to reveal why they were needed instead of direct use of the concept of autism. This research will contribute to existing literature by shedding light on non-medical aspects of a psychiatric concept that face more barriers to flow into a different cultural context. Scholars have discussed how successful – and thus how invasive - the globalisation of psychiatric concepts is, but this paper will show that non-medical support does not move as fast and globally as medicine.

Room 118 - Experiences of Health & Illness

Towards resilience: examining complex and hybridised coping strategies used by NHS workers experiencing Long COVID illness

Nicholas, Norman Adams, Emma Maciver, Nicola Torrance, Virginia Hernandez-Santiago, Diane Skätun, Flora Douglas, Catriona Kennedy, Aileen Grant

(Robert Gordon University)

NHS workers faced an increased risk of contracting COVID-19 during the pandemic and many now experience long COVID (LC). Over 10'000 NHS workers are estimated absent from work due to LC. LC represents a complex, dynamic, and often serious condition, for which unclear case-definition or diagnostic criteria exists. Common LC symptoms such as fatigue, brain-fog and breathlessness are debilitating, unpredictable and can significantly impact life and ability to work. Understanding factors supporting positive coping with LC are important for informing successful workplace supports. This study draws on two phases of longitudinal qualitative interviews, conducted six–months apart, with a range of NHS workers from Scotland with LC (50 interviews at first interview and 44 at follow-up). A structured, mixed inductive-deductive thematic analysis revealed workers engaged in complex, iterative and multi-faceted strategies to approach coming to terms and coping with LC illness; intertwining processes of 'illness work' and 'emotional work' to generate novel conceptualisations of resilience. Strategies included reframing LC as long-lasting but temporary, 'accepting' LC recovery as 'a journey' with 'highs', 'lows' and often frequent 'setbacks', and 'letting go' of past established (pre-LC) benchmarks of health and wellness. Corbin and Strauss' notions of Illness Trajectory Theory are applied as a sociological framework to interrogate linkages between participant's reimagining of LC illness and their journey's towards developing coping and resilience. Some meaningful outcomes for structuring workplace supports are presented, drawing on participant's narratives of 'what works', and pathways are spotlighted for advancing theory and further scholarship within this important research domain.

Room G22 - Patient - Professional Interaction

A glimpse behind the organisational curtain: A dramaturgical analysis exploring the ways healthcare staff engage with online patient feedback 'front' and 'backstage' at three hospital Trusts in England

Lauren Ramsey, Laura Sheard, Jane O'Hara, Rebecca Lawton

(Yorkshire and Humber Patient Safety Translational Research Centre)

Healthcare staff are encouraged to use feedback from their patients to inform service and quality improvement. Receiving patient feedback via online channels is a relatively new phenomenon that has rarely been conceptualised. Further, the implications of a wide, varied and unknown(able) audience being able to view and interact with online patient feedback are yet to be understood. We applied a theoretical lens of dramaturgy to a large ethnographic dataset, collected across three NHS Trusts during 2019/2020. We found that organisations demonstrated varying levels of 'preparedness to perform' online, from invisibility through to engaging in public conversation with patients within a wider mission for transparency. Restrictive 'cast lists' of staff able to respond to patients was the hallmark of one

organisation, whereas another devolved responding responsibility amongst a wide array of multidisciplinary staff. The visibility of patient-staff interactions had the potential to be culturally disruptive, dichotomously invoking either apprehensions of reputational threat or providing windows of opportunity. We surmise that a transparent and conversational feedback response frontstage aligns with the ability to better prioritise backstage improvement. Legitimising the autonomous frontstage activity of diverse staff groups may help shift organisational culture, and gradually ripple outwards a shared responsibility for transparent improvement.

Room 144 - STS & Medicine

Unruly surveillance: navigating reassurance and risk in at-home fetal Doppler use

Sabrina Keating, Sharon Dixon, Jennifer Maclellan, Abigail Mcniven

(University of Oxford)

Fetal Dopplers are handheld devices that use ultrasonography to listen to an unborn baby's heartbeat. A wide variety of commercial options are available, often with the advertised promise of checking in on the fetus's safety and feeling more connected. In recent years, multiple medical regulatory bodies and charities have issued warnings around the use of at-home fetal Dopplers and discouraged their use in domestic settings. Concerns include misinterpretation, potentially delaying seeking necessary care, and the cultivation of undue anxiety through frequent monitoring.

While health bodies and charities discourage Doppler use, this messaging co-exists with broader pressures around self-surveillance of the 'risky' pregnant body and notions of responsible mother/parenthood (Lupton, 2011). An existing qualitative study by Middlemiss (2020) highlights the navigation of multiple, contradictory discourses in pregnant people's decision-making on Doppler use. Middlemiss also flags the role of prior experience of miscarriage or stillbirth and limited access to pre-natal care as key considerations in Doppler usage.

This talk will present preliminary findings from a qualitative interview study of 15 people with experience of decision-making regarding fetal Doppler use. It will consider pregnant people's negotiation of the tension between the promise of technologically-moderated reassurance, neoliberal expectations of self-surveillance of the pregnant body, and the growing taboo towards a potentially unruly technology. Building on existing literature on the routinisation of ultrasonography (Roberts et al, 2015; Thomas et al., 2017, etc), we explore fetal Dopplers' ambiguous role in providing technological reassurance towards pregnancy-related risk.

Thursday 14 September

16:00-16:30

Room 155 - Health Services Delivery

Maternity staff experiences of asking for help using escalation visual management tools: the significance of colours and their meanings for supporting shared decision-making

Helen Elliott-Mainwaring, Nicola Mackintosh, Nicola Bateman   (Virtual Presentation)

(University of Leicester)

Visual management tools (VMTs) in healthcare are used to relay information quickly for shared cognition. They can include quality improvement display boards, and coloured corridor markings. This doctoral study focused on 3 types of VMTs to investigate their role in the context of acute illness and escalation of care in maternity settings. Methods included interviews with 55 maternity staff to explore their experiences of asking for help using VMTs, in particular how the content and design of escalation VMTs contributes to team decision making in maternity services.

This research evidenced the importance of colour in healthcare visual management for shared understandings. Where RAG ratings (Red/ Amber/ Green) were employed, red was observed by users to create noise, providing permission for staff to shout loudly. This focusing of attention empowered staff to bypass hierarchies of accountability and initiate rescue. Amber was seen as a middle of the road colour which might buy staff time in delaying escalations, but which came with an increased workload in terms of repeated observations. White shaped professional levels of engagement, providing reassurance that doctors could move on to the next patient. Colour specificity was a factor in escalation, and colour was seen as a tool for learning in an industry with a heavy reliance on locum staff with geographical mobility.

This research highlights the significance of VMTs for efficiency (allocation of resources), shared repertoires (shared language), and for providing legitimacy for staff voice in bridging hierarchical and professional boundaries.

Room 135 – Critical Public Health

Striving for 'good' as a family: the doing of collective healthy lives

Meredith Hawking

(Queen Mary University of London)

Families face much public health advice about how best to collectively modify their behaviour to lead a healthy life, particularly those which include young children identified as having excess weight through mandatory surveillance programmes such as the national child measurement programme. However, these universalising health and weight related guidelines may conflict with their own normative notions of what it means to lead a healthy and happy life, and the lived realities of complex social contexts such as the cost-of-living crisis, housing overcrowding, lack of accessible green spaces and fuel and food insecurity.

This paper draws on qualitative data (interviews, photos, child drawings and diary entries) collected with families in East London boroughs about their everyday lives and household practices. Underpinned by empirical ethics, it describes the multiplicity of health related social normativities, or 'goods' related

to child health and weight, and considers how these are imagined/ intended, enacted, prioritised and negotiated collectively in everyday practice.

I will discuss the process and potential of realising impact from empirical ethics work through local public health policy. As a form of empirical comparative re-imagination (Aula, 2022), 'telling cases' from the findings, co-produced as vignettes with community members, will be presented to public health stakeholders to challenge and encourage reflection on alternative framings of 'good' health practices for households in these contexts.

Room G31 - Mental Health

Food insecurity and mental health during the first uk covid-19 lockdown

Marina Kousta, Karen Glaser, Rachel Loopstra

(King's College London)

The link between food insecurity (FI) and mental health is well-established. Prior studies have mostly focused on vulnerable groups such as those on low incomes. Evidence suggests that FI levels rose during the first UK Covid-19 lockdown given movement restrictions and widespread food shortages. We hypothesised that FI during this time could have extended beyond those who usually experience FI. We examined the association between FI and mental health, and assessed whether broader socio-economic groupings capturing being at risk for FI mitigated this relationship. We used an online survey conducted in the end of the first UK lockdown. FI was based on a validated measure from the U.S. Department of Agriculture, but it was adjusted to also capture non-financially driven FI. Two validated mental health measures were examined; GAD-7 and PHQ-9. We found that FI increased the likelihood of reporting anxiety and depression, regardless of the level of FI risk. However, those at higher FI risk, were also at increased risk of reporting poor mental health, regardless of their FI status. Our results suggest that FI is linked to poor mental health, but its effect is more important for less vulnerable groups. They also suggest that although FI contributes to poor mental health among more vulnerable groups, the magnitude of the effect was smaller. It is likely these vulnerable groups experience additional life adversities, which can independently contribute to poor mental health, regardless of whether they are experiencing FI.

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

Flowers and the management of death

Emma Saunders

(Serendipity Research)

Throughout western history flowers have played a prominent role in the management of death. There is a gap in the literature concerning the role of flowers and death practices, in particular a lack of regard for the taken-for-granted experiences of flowers, interaction and emotion as important components of human well-being and culture. It is this gap that my research addresses. I identify the relationship between people and positive emotion stimuli, well-being, and flowers, as well as the external interactive relationship between flowers and the social-emotional experience. The research used an ethnographic approach, applying case-study methods. When Goffman's dramaturgical framework is applied to the ritual of the funeral alongside Hochschild's (1979) concept of emotion work and Gordon's (1981: 563) definition of sentiment, flowers can be identified as multifaceted institutionalised props with interchangeable meaning, assisting in the management of a positive sentiment identity.

Flowers are an intrinsic component in the management of sympathy and grief, becoming part of the process of grieving as transient markers in the bereavement process. As temporary objects they assist

in a momentary cathartic state, supporting the bereaved in a transitory expression of grief – hence the expression 'life goes on'. Fresh flowers aid the transition from the space of grief back into daily routines and practices. On a practical level, as institutionalised props, flowers decorate the coffin and the funeral stage. On an emotional level, their evident 'sentiment' use-value assists in the management of emotion and well-being.

Room 115 - Open

Transgressing biomedical boundaries: the "enticing and hazardous" challenges and promises of self-managed abortion

Rishita Nandagiri, Lucia Berro Pizzarosa

King's College London

Globally, abortion has largely been understood, researched, and regulated within a medico-legal paradigm. The medicalisation of abortion functions across three different levels: how abortion is defined medically, how it is addressed, and the kinds of treatment available and by whom. This is evident in how abortion is framed within laws (e.g., the need for doctors' approval), how it is theorised within the rubric of medical safety (e.g., definition of unsafe abortions) and addressed (e.g., "minimum medical standards"). This gives rise to narratives of safety and risk in abortion access, care, and provision, and is linked to constructions of "authoritative knowledge" and expertise, and whose knowledge is valued or not.

However, self-managed abortion (SMA) questions the centrality of these heavily medicalised paradigms, as well as the presumed individuality of abortion decision-making that it is predicated on. SMA offers an "enticing and hazardous" (Donnan & Magowan, 2009, p. 9) challenge to traditional legal and biomedical understandings of and approaches to abortion, as well as to social, religious, (pro)creative conventions.

In this paper, we detail how abortion remains exceptionalised and deeply medicalised, setting conditions for "permissible transgressions". We explore how SMA fundamentally challenges and alters meanings of abortion care and abortion provision: from whose authority and knowledge is valued and centred, to the environments that abortion is possible in, to issuing a broader challenge around how abortion itself is understood and depicted, and how SMA, thus, represents a deliberate move towards new ways of making meaning and (re)imagining abortions.

Room 118 - Experiences of Health & Illness

Temporalities of the dementia journey: insights from the IDEAL programme

Alexandra Hillman, I.R Pentecost Jones, C Quinn, C Stapely, L Clare

(Wellcome Centre for Cultures and Environments of Health, University of Exeter)

This paper explores perceptions of past, present and future amongst people living with and affected by dementia. Our analysis draws on longitudinal qualitative interview data with 5 married couples, where one partner is living with dementia, spanning a five-year period. We address the temporal frames in our participants' accounts that enable them to make sense of both the continuities and changes they experience as a result of their dementia symptoms, as well as the complex associations these have with the wider contexts and circumstances of their everyday lives. Building on long-standing contributions from medical sociology, highlighting the connections between time, identity and illness, we provide new insight into the journeys and trajectories of those living with and affected by dementia. Our analysis identifies three key themes from our participants' accounts: firstly, that fearful futures are managed through adaptations and orientations to the present; secondly, that participants' present circumstances frame their perceptions of the past, present and future; and thirdly, that perceptions of

what is possible to live with (or not live with) continually shift. Finally, throughout our analysis, we highlight how temporal frames are integral to managing identity and a changing sense of self. This research contributes to ongoing policy questions regarding points of crisis and transition in the lives of those living with dementia and their implications for meeting care needs.

Room G22 - Patient - Professional Interaction

"I'm through with having to prove who I am": Physicians' use of time as a resource to practice flexible professional authority

Leeor Shachar

(Tel Aviv University)

Increased accessibility to health information via the internet has created a surge of knowledgeable patients and has radically altered the doctor-patient relationship. Drawing from 35 in-depth interviews with Israeli physicians from four specialties (family medicine, cardiology, oncology, and surgery), this study explores the role of temporality in doctors' accounts of relationships with their patients, describing the ways in which doctors make use of different timelines when interacting with internet-informed patients. Results show that doctors make use of three different timelines: their own seniority, the duration of their relationship with the patient, and the consultation time. I argue that doctors use time strategically, as a resource that allows them to move flexibly along an authority continuum, as deemed necessary by the context. This flexible authority facilitates their adaptation to a new reality of internet-literate patients with more knowledge, and consequently different expectations of the doctor-patient engagement.

Room 144 - STS & Medicine

From necropolitics to a feminist ethics of care: human rights abuses and ageism in the COVID-19 pandemic

Bethany Simmonds   (Virtual Presentation)

(Aberystwyth University)

As a feminist researcher, I start with a political commitment to use my personal experiences to highlight injustice and bring about change to address discourses, institutions and practices of discrimination. My experiences of being 'extremely clinically vulnerable' to COVID-19, and the associated feelings of isolation, invisibility and discrimination, have provided a sense of affinity with other groups, like some older people, who may have had similar lived experiences. This positioning has informed this paper and the theoretical framing of the arguments.

The pandemic has highlighted necropolitical decision-making and modes of exception that meant that some older people were left to die, as utilitarian medical philosophy would consider this a 'societal need'. Techniques were employed, such as triage tools, to deny life saving treatment, and spatial control of these populations in residential care homes or hospital wards enabled necropolitical decisions. These abuses of the human rights of those most in need has been justified via economic and biological reductionist discourses, employed by neoliberal governments to justify cuts to public spending, including the health and social care system in the UK.

This paper starts with discussing the exceptional practices and necropolitical decision-making that led to intensifying the rationing of care to older people in the UK during the pandemic. It then goes on to propose a new way of conceptualising care, using feminist care ethics. Finally, in this paper, I aim to reframe the debate of ageing, health and social care towards radical alternative systems that resist neoliberal marketisation.

Thursday 14 September

16:35-17:05

Room G36 - Theory

Breathtaking discipline: a sociological examination of the debate on critical care guidelines during the coronavirus pandemic

Matthias Benzer

(University of Sheffield)

This paper presents a sociological examination of a far-reaching debate conducted during the coronavirus pandemic regarding guidelines by the British Medical Association for decisions on access to scarce critical care resources. The examination proceeds from a qualitative text analysis of over 100 documents – publications by the British Medical Association, health professionals, ethicists, legal professionals, patient advocacy organisations, disability organisations, journalists, professional bodies, and regulators, among others – which formed that debate between March 2020 and April 2021. The documents variously contain foundations, statements, explanations, endorsements, and criticisms of the Association's guidelines. The paper configures and details four overarching themes surfacing from the data: the mismatch between needs and resources, the aims of guidance, the objectives of decision making, and acceptable ways of arriving at a decision. In contradistinction to contemporary interpretations of problems arising during the pandemic as illustrations of wider problems created by neoliberal politics, the paper attempts to demonstrate that the controversy on access to critical care manifests three major problems concerning social relations raised by social theory: the limitations of "resistances" in power relationships (Foucault 1981: 96); the way in which a "diagram" congruent with a "social field" qua "immanent cause" comes to be "realized" by a "concrete assemblage" qua "effect" (Deleuze 1999: 30-34); and how "clouds of sociality" end up constrained to answer to the standard of a "system's" optimal "performance" (Lyotard 194: xxiv). The problems are contrasted with the concept of a "universal right to breathe" (Mbembe 2020).

Room 155 - Health Services Delivery

Culture and trust in renal centres: ethnographic findings to support person-centred dialysis choice

Kerry Allen, Karen Shaw, Jenna Spry, Sarah Damery, Iestyn Williams, Lisa Dikomitis

(University of Birmingham)

Our NIHR multi-disciplinary study (InterCEPt) aimed to understand renal centre variation and socio-cultural inequalities in the uptake of home dialysis. An initial ethnographic work package focusing on the interplay between health professionals, patients and carers/families and organisational culture allowed insights into decision-making about treatment and setting (home or hospital), through non-participant observations and interviews at four renal centres in England with above average home dialysis uptake rates. Findings showed people's treatment decisions are typically based on trust in: staff; technology; self-efficacy; and personal relationships.

Centres where trust was high displayed common aspects of culture, beliefs and practice:

-There was recognition of the holistic impact of dialysis on each person's life. Renal teams incorporated non-clinical specialists and involved family/community. Sites engaged with inequalities and welcomed greater investment in people's social, psychological and cultural needs.

-Treatment eligibility was fully explored, with tailored education and training. There was a focus on 'the right dialysis for the right people' rather than on increasing home therapy uptake per se. This involved transparency about all treatment options, helping to manage uncertainty, plan early, anticipate barriers, find solutions and build them into future working. Bespoke training was provided which promoted and supported self-management via training materials, shared care and peer support.

-All staff shared a positive belief in the benefits of home dialysis for patients, not just those in 'home therapies' roles. This included home dialysis champions and ongoing work with the public, colleagues and charities. Improvement and learning were built into routine working.

Room 135 – Critical Public Health

A viral pandemic: understanding the role of social media in the Mpox outbreak as a new challenge for public health preparedness

Jaime Garcia Iglesias, Tom May

(University of Edinburgh)

Since March 2020, the UK has experienced an unprecedented outbreak of Mpox. In the absence of timely and effective government-issued information, community members and organizations turned to social media—most frequently Twitter—to share health promotion information, personal experiences, or encourage vaccination. Some shared their experiences of contracting Mpox—frequently with images of their lesions—with unprecedented numbers of people. The effective use of social media has already been identified as a defining challenge for public health in the 21st century. Considering this, we ask: how did the characteristics of social media mediate community responses to and activism about Mpox in the UK?

We engage with scholarship on social media and health, and science and technology studies, to critically analyse the promise of social media for public health, and situate the Mpox outbreak in a broader historical context of health activism. We argue that social media allowed for rapid, cost-effective health promotion and allowed individuals to share their lived experiences easily. However, it also generated problems due to material conditions, algorithmic visibility, homophobic stigma, and reliance on pre-existing networks—all of which limited the access of historically underserved groups. Relying on both social media analyses and the experiences of activists, clinicians and policymakers, we conclude that social media transformed the Mpox response in the UK, generating new dynamics around collaboration and personalization, but also creating unique ethical and practical challenges. We suggest how enhanced preparedness is needed to harness the potential of social media for future outbreaks.

Room G31 - Mental Health

An African and African Caribbean perspective of the barriers and solutions to accessing mental health services in Nottingham – an art based approach

Penelope Siebert, Ana Souto, Clive Foster, Akudo Ekwenye

(Nottingham Trent University)

We present insights from an art-based project, that was underpinned by principles of emancipatory research to elicit understanding of mental health service use amongst those with African and African Caribbean heritage living in Nottingham. A total of 90 individuals attended 7 community based interactive workshops held between February and June 2022.

This art based participatory approach identified the importance of building a sense of trust and ownership in research with those who have been marginalized as a result of inequalities and discrimination. The project clarified the importance of faith leaders and trusted community members from these communities having a key role in designing and leading the project and activities during the workshop. Those who participated openly discussed and shared their perceptions and understanding

of mental health and did illustrations to visually share stories of their mental and emotional health journeys and experiences. During the workshops participants expressed their level of frustrations of health professionals' insufficient knowledge and understanding of the ethnic, social, cultural, and economic factors that influence the mental health and emotional wellbeing of those of African and African Caribbean descent. This responds to the way mental services are communicated and provided locally.

Importantly, those who participated contributed to the generation of knowledge, and evidence and solutions that reflected the cultural and social sensibilities of those from minoritized communities to be shared and disseminated to local mental health providers.

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

(Body) mapping the menopausal journeys of LGBTQ+ people

Rebecca Simmons

(University of Leeds)

Although menopause has enjoyed a renewed focus in recent years including considerable feminist based research already written on the topic, attention to LGBTQ+ experiences of menopause is negligible. This research therefore hopes to uncover those neglected life experiences and utilise them to completely reconfigure the bio-psycho-social picture of menopause and the multiplicity of experiences that abound within it by centralising marginalised perspectives. Drawing upon cross-cultural research into menopause, such as that of Margaret Lock (1986, 1993, 1998) and those academics investigating health inequality along racialized lines (e.g. Trawalter, Hoffman and Waytz, 2012), this research will work redraw the picture of menopause experience not just to include marginalised voices as an afterthought, but as the centrepiece and focus of the picture. Utilising a phenomenological investigation of queer experiences of menopause, participants are invited to use body mapping, or a similar arts-based research method to explore their experiences through both visual and linguistic methods, and to tell their stories and control their own narrative. Body mapping will be followed by a semi-structured interview which is analysed through reflexive thematic analysis (Braun and Clarke, 2019) in order to centre researcher subjectivity and the importance of reflexivity throughout the research process. This ongoing research project seeks to consider the ways in which sexuality and gender identity affects one's experience of menopause and the potential for positive experiences of embodiment. Key concepts and themes such as queerness, disrupting Western binaries, medicalisation and the (im)materiality of "the" body will be explored.

Room 115 - Open

Confined by the Market: An Ethnographic Account of (Adverse) Health Practices in Taxicab Drivers

Salman Khan

(Durham University)

Prior research on taxicab drivers has drawn attention towards a range of 'behaviours' and 'stressors' that predispose workers in this occupation to poor physical and mental health, including but not limited to: long, unsocial working hours; unpredictable earnings; and the ever-present threat of violence and abuse, including racism. Studies have examined the prevalence of these behaviours/stressors as well as associations between them, in turn arguing for interventions such as ergonomic safety, tackling discrimination against minoritized drivers, and promoting behaviours like healthier eating and exercise. Drawing on findings from an ethnographic study based in North-East England, this paper presents a localised, situated account of the world of work wherein these behaviours/stressors unfold, together

with drivers' own understanding of this world – one that they must continue to inhabit. Placing these findings in conversation with Cohn's frame of 'health practices', it underlines the centrality of one factor that is seen by drivers to affect all others: the necessity to attune themselves to the temporal rhythms of a fierce, deregulated market. Analysis of data gathered from hackney carriage and private hire/Uber drivers demonstrates variations of how this attunement acts as an intractable constraint, one that effectively confines them into practices known to be adverse for physical and mental health. The paper ties this constraint to Marmot et al.'s high demand, low control model, and concludes with some emergent insights into how the concurrent worsening of both is linked by actors to agencies which, to borrow a phrase from Latour, 'act at a distance'.

Room 118 - Experiences of Health & Illness

Trajectories and temporalities: exploring Long Covid experiences overtime drawing on interviews from a qualitative longitudinal study

Sarah Akhtar Baz, Laura Sheard, Jd Carpentieri, Chao Fang

(University of York, Health Sciences)

How has Long Covid (LC) been experienced over time? In addressing this question, here we present preliminary findings of a qualitative longitudinal study where people with LC, drawn from cohort studies and the wider community, have been interviewed over three points in time (from November 2020 to April 2023) presenting their LC 'health trajectories' (Henly, Wayman and Findorff, 2011). A total of over 200 interviews have been undertaken over time. This is the first qualitative study within the UK to do so. There were three different trajectories and patterns of LC illness found: firstly persistent, exacerbated and relapsing symptoms overtime, secondly LC becoming normalised as part of everyday life, and finally for some recovery from LC. These trajectories will be illustrated drawing on the pen portraits longitudinal analysis approach (Sheard and Marsh, 2019), presenting case studies of participants' LC experiences in relation to aspects such as self-management of symptoms overtime, adapting everyday life, inequalities and (dwindling) resilience, with a particular sociological focus on diverse 'temporalities' of chronic illness (Bell, Tyrell and Phoenix, 2017). This approach allows for rich exploration and understanding of individual experiences of temporal phenomena like LC. In taking a longitudinal approach the study aims to provide a better understanding of how LC develops over time. It also has important practice implications for supporting people with LC as the illness progresses. Finally, it shows the value of presenting in-depth interpretive accounts in applied health research over the traditional emphasis on quantity and 'quantitative empiricism' (Sheard, 2022).

Room G22 - Patient - Professional Interaction

'Once you get under…that umbrella, you feel that someone has your back' : A qualitative study of older people's experiences of person-centred care (PCC) in an integrated care context (PCIC)

Sarah Murphy, Dr Martha Doyle, Dr Niamh Gallagher

Atlantic Technological University

While most evaluations of integrated care often focus on systemic or clinical outputs, theoretically informed research emphasising the values, preferences and voice of older persons in relation to the experiential dimensions of person-centred integrated care (PCIC) is less prominent.

This paper presents initial findings of a multiple qualitative case study exploring older persons' experiences of PCIC in an integrated care programme in Ireland, NICPOP. Conceptual underpinnings of PCC and of McCormack and McCance's Person-Centred Practice (PCP) framework were used as a sensitising framework to interpret data generated in 23 interviews with service users across 3 heterogeneous NICPOP sites.

Key findings point to the centrality of relational care processes and the extent to which patient/service provider interactions lead to PCP person-centred outcomes of 'a good care experience' and 'feelings of wellbeing'. Relational processes engendering PCP included 'having a sympathetic presence'; 'working with the person's beliefs and values'; and 'engaging authentically'. Findings also reveal the importance of the care context on the care relationship. Specifically, they suggest that a home-based, as compared with clinical hub based, model of care enables relationship building, which provides for a greater insight into the social contexts of the older person, revealing their vulnerabilities, priorities and needs, and facilitates more tailored holistic care. The findings reflect on key components within the PCP framework such as holistic care and a healthful culture and consider how these are differently experienced by older people depending on their own complex life stories and health and social care needs.

Room 144 - STS & Medicine

"body in pain": Chinese female labour pain from the perspective of body politics

Qiuyue Lin   *(Virtual Presentation)*

(Xi'an Jiaotong University (Bachelor of Arts in Sociology) / University of Oxford (Master of Science in Sociology)

China's three-child policy has brought the issue of childbirth to the forefront of debate. Labour pain could be viewed as a social construct beyond physical sensation. It involves a process of power and metaphorical operations. Based on the theoretical framework of Foucauldian body politics, this study used qualitative in-depth interviews to demonstrate women's subjective experiences during childbirth. By analyzing their narratives about labour pain, the study explored the symbolic social meanings of labour pain and discovered that the experience of medical power, as well as the body's response and adaptation to it, constitutes a dynamic interactive process. Women's bodies are not completely passive, and they cope with pain by interpretating metaphors. This research reveals the complexity of fertility practices and pain narratives. It contributes to the understanding of women's willingness to give birth under the three-child policy and sheds light on the high rate of Caesarean sections in China, while also reflecting on the misuse of medical technology for pain relief. The study's focus on women's subjective experiences will facilitate the exploration of their subjectivity in childbirth.

Thursday 14 September

17:10 - 17:40

Room G36 - Theory

The critical (micro) political economy of health redux

Nick Fox

(University of Huddersfield)

In the plenary address to the BSA Medical Sociology conference 2017, I outlined a new materialist and posthuman perspective on the sociology of health and illness. This paper revisits these approaches in the light of my subsequent work in political sociology, political economy and analysis of the health inequalities manifested during the pandemic. The new analysis is founded upon an affective re-working of Marx's exegesis of capitalist social relations in Capital. It offers a radical more-than-human insight into capitalism and health inequalities, and a powerful critique of neoliberal policies on health and welfare.

The starting point for this critical micropolitical economy of health is the Deleuzian question 'what does capitalism do?' Capitalism is re-analysed using the relational, monist and post-anthropocentric ontology of the new materialism as two core assemblages: a production-assemblage and a market-assemblage. This discloses not only the affects that transform labour-power into capital (Marx's focus), but also a flow of non-human matter and associated affects that produce 'supply and demand' phenomena and unintended consequences of run-away growth, waste and social inequalities. Capitalism is a 'black hole' from which none (neither workers nor 'bosses') can escape.

With this micropolitical economic perspective established, the paper considers the implications for human health, in terms of a) health inequalities and b) the neoliberalisation of health and welfare in contemporary social and economic policy.

Room 135 – Critical Public Health

Vaccine-mediated nationalism: a comparative analysis of how governmental communication in the UK and China framed vaccine activities during Covid-19

Yumeng Guo

(The University of Sheffield)

Building upon Ulrich Beck's conceptual development of 'risk society', this paper presents initial findings from research that investigates how governmental actors use social media to promote their efforts in Covid-vaccine activities. As part of a doctoral project, the paper analyzes 2002 tweets and 3093 Weibo posts from government-related accounts in the UK and China (e.g., state ministry accounts, political figures' accounts, and hospital accounts), between January 2020 and March 2022. In particular, this paper zooms into vaccine-related activities at the state level (i.e., vaccine R&D, international vaccine distribution).

Data shows that national vaccine R&D capacities and global vaccine access are two key concerns in the governmental framing of vaccines. Domestically, vaccine R&D in the UK is connected to national pride and its medical science advancement, while the narratives of China-made vaccines reflect China's role as an emerging global player in the public health crisis. Internationally, both depict responsible global images by strengthening their contributions to vaccine distribution (largely through cross-national donations). But the dynamics between vaccine donors and recipients reflect the pre-Covid regional

solidarity: as the UK's donation points to its historically colonized countries (now as the Commonwealth), Chinese donation aligns with developing and African countries.

Conceptually, this paper suggests 'vaccine-mediated nationalism' to reconsider vaccines as empirical vehicles to redefine 'vaccine nationalism' in Covid. It argues that governmental discourses of vaccines narrate the concepts of 'nationalism' and 'cosmopolitan solidarity' parallelly, but finally, the promises of sustaining cosmopolitanism are ephemeral into particular solidarity between countries.

Room G31 – Mental Health

Trends in the use of benzodiazepine receptor agonists among working-age adults in Belgium from 2004 to 2018

Lisa Colman, Katrijn Delaruelle, Piet Brache, Melissa Ceuterick

(Ghent University)

Introduction. Belgian studies have identified educational differences in BzRA use among working-age adults. These educational differences may be partially attributed to differences in work status. However, while work status is an important factor to consider, this has not yet been empirically investigated. Therefore, this research aims to assess to what extent work status explains educational differences in BzRA use. However, considering medicalisation processes, where non-medical factors, such as work status, are increasingly associated with medical mental health care-seeking behaviour, this research also aims to assess to what extent work status explains educational differences in BzRA use, regardless of mental health status.

Methods. Data from the Belgian Health Interview Survey (BHIS) spanning four waves (2004, 2008, 2013, 2018), with a sample size of 18,547 respondents aged 18 to 65 years old, are analysed using Poisson regression models.

Results. Work status acts as a partial mediator, explaining educational differences in BzRA use regardless of mental health status. Unemployed, (pre-)retired, and sick or disabled individuals, regardless of their mental health status, exhibit higher levels of BzRA use compared to employed individuals.

Discussion. Work-related uncertainty leads to increased prescribing and medication use, regardless of mental health. Medicalisation and pharmaceuticalisation processes detach social problems from their social roots and treat them as personal failures. The marginalization of the social roots of unemployment, sick leave and pre-retirement has led to a personalization of responsibility. Negative feelings arising from such work statuses may cause isolated, non-specific symptoms for which medical treatment is sought.

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

Fertility and Foucault; Revealing the Man Behind the Curtain in Femtech Advertising

Kathryn Sheridan, Sue Ziebland, John Powell

(Department of Primary Health Care, University of Oxford)

A small but rapidly growing section of the digital health market is "Femtech", or digital technology targeting women. Proponents of Femtech frame it as a women's empowerment movement seeking to revolutionise digital care; its critics argue industry uses the moniker to popularise platforms that surveil reproductive data for profit. This presentation reports a study of a subset of tools that illustrate this tension; digital interventions for managing infertility.

This research uses an inductive approach to conduct a discourse analysis of fertility mobile application advertisements to assess the framing of control, medicalisation, and biopower. Though fertility trackers are widely advertised and downloaded by users, they remain loosely regulated, and are criticised for false advertising and targeting ads towards children (Hough et al., 2018). Many of the most popular apps have capitalised on feminist empowerment rhetoric to market their platforms, strategically using language to frame women as socially responsible for conception (Gilman, 2021; Healy, 2021). In doing this, they play a carrot-and-stick game, placing the complex burden of reproductive labor on women's shoulders while offering a digital reprieve for a fee.

This language isn't limited to industry; it sits within a wider political landscape committing to pro-natalist policies encouraging (some) women to procreate as birth rates fall. This analysis builds on research by Deborah Lupton, Josie Hamper, and Maryam Mehrnezhad to discuss the results in the context of these movements, and makes conclusions on the dangers of women being coerced by the tech giants claiming to empower them (2015; 2020; 2022).

Room 115 - Open

Menstrual tensions: A multi-modal discourse analysis of menstrual product advertising

Lucy Frost, Sharon Dixon, Francesca Dakin, Maria Tomlinson, Alice Roberts, Sue Ziebland

(University of Oxford)

Background: Over half of the UK population menstruate within their lifetime. Despite the commonality of this experience, there is dissonance around how and when to talk about menstruation, allow it (or its signs) to be visible, and at what point it becomes 'abnormal'. Increasingly, commercial agents influence these conversations, through advertisement of menstrual products.

Aim: To explore menstrual product advertising messages in social media.

Methods: Multi-modal discourse analysis was undertaken on advertisements from 13 prominent menstrual product companies on Instagram and TikTok over a 1-month period, to explore explicit and tacit messaging. Five researchers captured posts, stories and sponsored advertisements through social media algorithms in regular use.

Results: Menstrual product brands advertised to diverse audiences through co-opting and commodifying discourses of menstruation, including those from medical and advocacy spheres. Tensions are raised in doing so, adding complexity to how people make decisions about how best to manage menstrual symptoms. We focus particularly on tensions of normality and abnormality, freedom and limitation, pride and shame, empowerment and judgement, advocacy and advertisement. To explicate these, we draw on sociological theories of biomedicalization (Clarke et al 2003) and doctorability (Heritage and Robinson 2006).

Conclusions: Menstrual products advertisement reflect the varied discourses surrounding menstruation more broadly, with different brands seeking to align themselves to different (sometimes multiple) positions through curating brand identities that match the proliferation of identities within neoliberal markets. This is likely to have implications for how people understand menstruation, their bodies and whether, how and when to seek clinical support.

Room 118 - Experiences of Health & Illness

The physical and psychosocial impacts of Iatrogenesis following treatment for Head and Neck Cancer

Sasha Scambler, Anna Rajakumar

(King's College London)

Head and neck cancers [HNC] are the sixth most common group of cancers worldwide, with rates rising amongst men and women. The majority of people diagnosed with HNC are male and from deprived areas with 1 in 5 from a black or minority ethnic group. When compared to other cancers HNC has received relatively little attention, treatment outcomes for some HNCs remain poor, and there is a dearth of literature on the experiences of this group of patients. Drawing on Illich's concept of iatrogenesis, this paper presents the results of a qualitative study exploring the experiences of people receiving, or having received, rehabilitative care following treatment for HNC. Treatment usually involves combinations of surgery, chemotherapy and radiotherapy, which can result in permanent effects on basic human functions such as breathing, swallowing and speech. Together these treatment effects, exacerbated by facial disfigurement, can have a significant and ongoing impact on quality of life. Analysis suggests that the ongoing issues experienced emerge from both active treatment of the cancer itself, and from risk mitigating procedures provided prior to treatment. For the majority of those interviewed the cancer produced very few symptoms but clinical and cultural iatrogenesis following treatment was often severe and ongoing. Clinical success is measured in relation to survival rates and this raises interesting questions about the costs of survival, about the limits of medical interventions and about informed consent.

Room 144 - STS & Medicine

Inside and Outside the Black Box: Evaluating Pharmaceutical Institutional Performance

John Abraham

(King's College London)

In the aftermath of the 2020 Cumberlege Inquiry into alleged pharmaceutical injuries in the UK, pharmaceutical safety remains a salient issue. Can pharmaceutical sociology help? This paper addresses the troubling question of how we can evaluate the performance of secretive pharmaceutical companies and government drug regulatory agencies in protecting the public from unsafe drugs. More controversially, and going beyond Cumberlege, can we relate such performance to wider politico-sociological phenomena such as capitalism, neo-liberalism, technocracy, and democracy? To answer these questions, while also addressing the obstacles of secrecy involved, this paper argues for an ambitious comprehensive drug case study approach in which the entire sample of pharmaceuticals are subject to in-depth study (inside the black box of pharmaceutical companies and regulatory agencies). The sample is determined by a relevant quantitative performance indicator (output data visible outside the back box), such as number of drugs that have been withdrawn from the market on safety grounds. Performance can be evaluated cross-sectionally both by reference to international comparisons and over time. The paper explains why case-study analysis is essential to interpret quantitative drug safety withdrawal data because a drug could be withdrawn from the market because of protective post-market regulation or because of unprotective pre-market development/regulation allowing an unsafe drug on to the market in the first place. Simultaneous temporal and spatial analysis then shows how some countries have more public-protective social systems than others, and how political changes (e.g. neo-liberal reforms or greater demoncracy) over time undermine or enhance those social systems.