

WEDNESDAY 13 SEPTEMBER

18:00 -19:00

Jubilee Building Foyer

Poster Presentation

Poster 1

Do they even care? How does racism impact the outcomes for patients with sickle cell disease in the UK and USA?

Edna Adu

(Lancaster University)

This paper provides a comprehensive review of the current literature on the impact of racism on patients with Sickle Cell Disease (SCD) in the UK and USA, including potential mechanisms through which racism contributes to health disparities in this population. SCD is a genetic blood disorder that disproportionately affects individuals of African descent, and has been racialised as a Black disease. Despite medical advancements, individuals with SCD still face significant health disparities including increased mortality and poorer health outcomes compared to patients with hereditary diseases of similar nature that affect other (White) demographics. Racism, a systemic and prevalent social determinant of health has been identified as a critical factor in shaping the experiences and health outcomes of patients with SCD. SCD patients face a multitude of negative consequences resulting from racism, including inadequate research and educational resources, discriminatory treatment in clinical settings and insufficient funding and attention devoted to the disease. My analysis highlights the need for more targeted interventions that address the specific experiences and challenges faced by patients with SCD in navigating healthcare systems that perpetuate racism. This paper will contribute to a better understanding of the intersection between racism and SCD and provides a framework for developing effective strategies that can improve health outcomes and reduce health disparities in this vulnerable population. As such it contributes to the increasing interest in how racism plays a part in creating and perpetuating healthcare inequalities for ethnic minorities.

Poster 2

An exploration of young people's sexual wellbeing: a qualitative evidence synthesis

Raquel Boso Perez, Ruth Lewis, Jennifer Littlejohn, Malachi Willis, Kirstin R. Mitchell

(University of Glasgow)

Our paper reports on a qualitative evidence synthesis exploring young people's lived experiences and subjective perceptions of sexual wellbeing. Sexual wellbeing is facet of a person's overall sense of wellbeing, closely linked to one's physical, sexual, and mental health. Its study can facilitate the exploration of positive, protective, and contradictory aspects of youth sexuality.

In this paper, we understand sexual wellbeing to be a set of positive sexual emotions and cognitions, which include feeling safe, respected, comfortable, autonomous, secure, and able to work through challenges and past traumas. For us, sexual wellbeing is an enduring, yet malleable disposition towards one's sexuality and sex life resulting from the accumulation of (dis)advantageous experiences within socio-structural context. Our definition is one of multiple, in a field that draws on varied approaches to

the conceptualisation and measurement of sexual wellbeing (and where often studies can fail to provide a definition).

We bring studies on youth sexual wellbeing into dialogue to generate distinct analytical insights. We build on the team's prior work theorising sexual wellbeing, using our existing conceptualisation to inform the design of our literature search strategy. Our findings will report qualitative insights into how young people experience sexual wellbeing, further characterising and elaborating on the conceptualisation of sexual wellbeing. This synthesis will be of use to those seeking to bolster young people's sexual health and wellbeing, aiding their ability to centre young people's experiences in their work.

The protocol was prospectively registered in PROPERO (CRD42022315593) and published in a peer-reviewed journal (DOI:10.1177/16094069221123674).

Poster 3

Patient and primary care practitioners' perspectives on consultations for fibromyalgia: a qualitative evidence synthesis

Ailish Byrne, Katherine Jones, Michael Backhouse, Fiona Rose, Emma Moatt, Christina Van Der Feltz Cornelis

(University of York)

Background: Fibromyalgia presents a challenge to both the patients experiencing symptoms and the staff aiming to treat them. This qualitative review aimed to synthesise how patients and practitioners experience primary care consultations, develop a rounded picture of how they perceive each other, the challenges to primary care consultation, and how they might be tackled.

Methods: CINAHL, Embase, CENTRAL and Medline were searched from inception to November 2021. Qualitative studies were included if they explored the perspectives and experiences of either fibromyalgia patients or primary care practitioners. Quantitative data, studies not published in English, not set in primary care, or that did not distinguish the type of patient or clinician were excluded. Included studies were analysed using thematic synthesis and their quality assessed.

Results: 30 studies met the inclusion criteria. Thematic synthesis identified three overarching themes: 1.) life turned upside-down— exploring the chaos experienced by patients as they seek help; 2.) negative cycle – highlighting how patient and practitioner factors can create a detrimental cycle; 3.) breaking the cycle – validating patient-doctor relationships underpinned by clear communication can help break the negative cycle.

Conclusions: Fibromyalgia patients experience uncertainty and chaos that can clash with the attitudes of GPs and the help they can feasibly provide. Difficult consultations in which neither the GP nor patient are satisfied can easily occur. Promoting supportive, reciprocal, and open patient-doctor relationships is essential. Future research is required to further explore GP attitudes and to develop an intervention that could improve consultations, patient outcomes, and GP satisfaction.

Poster 4

Trauma and identity among late diagnosed autistic women with experience of sexual assault

Katrine Callander

(University of Kent)

The rate of sexual trauma in autistic women is a significant public health concern, as it has been evidenced to have frequent and substantial implications for mental health and wellbeing. Aspects of trauma - such as disclosure, societal stigma and cultural stereotypes - influence long-term processes of mental distress and physical health. This presentation will focus on the preliminary pilot data of the primary researcher's PhD, aiming to improve understanding of the intersectionality and inequalities associated with autistic women's sexual assault trauma and disruptive identity impact.

The research explores how autistic women narrate their experiences and impact of sexual assault and how perspectives on trauma change following a late autism diagnosis. It draws on gender and disability studies while being informed by the neurodiversity paradigm of autism.

This allows for intersectional review of concepts surrounding narrative identity construction and disruption, compound injustices, othering and marginalisation. It enables thematic analysis of the interaction between personal narrative and social environment, as it is experienced by the individual post-trauma. Critically, the primary researcher is a late diagnosed autistic woman with experience of sexual trauma. This will enable considerations of participatory research, reflexive auto-ethnography and researcher positionality. The research aims to increase visibility of autistic voices and improve understanding of the impacts of sexual trauma for this marginalised group.

Poster 5

From race matching to selective mixed-race privilege: Taiwanese gay fathers' reproductive navigation through the ovum selection process

Jung Chen

(Department of Sociology, University of Cambridge)

In 2019, Taiwan became the first country in Asia to legalise same-sex marriage. However, the reproductive rights of LGBTQ+ people remain on hold. Neither joint adoption nor assisted reproductive technologies are accessible for non-heterosexual individuals. The only legal and feasible way for gay men to become parents is through transnational third-party reproduction. This paper explores Taiwanese gay men's understanding and strategies for selecting egg providers. The data came from 53 in-depth interviews and participant observations. There were approximately 150 gay father families in Taiwan, and most of their children are mixed-race, which makes them exceptionally 'visible,' since around 95 percent of Taiwan's population is of Han ethnicity, and Westerners account for only 0.1% of the total population. Han-Caucasian-mixed-race children often receive extra attention for their appearances. While Western gay fathers frequently attempted 'racial matching', in terms of choosing the egg provider depending on the racial background of the non-biogenetic father, Taiwanese gay fathers constructed a different route. The findings reveal a dynamic bargaining process for selecting egg providers that is both situated in a transnational context and embedded in the local racial hierarchy, where Han-white-mixed-race people are privileged. This article argues that the emerging 'mixed-race privilege' became predominant among gay men's strategies for navigating their gay father families in Taiwanese society, where not only LGBTQ+ families but also mixed-race people are minorities. This article also proposes a transnational perspective that engages discussions of the biogenetic framework, racial hierarchy, and the reproductive industry on a global-local intersectional scale.

Poster 6

Using CareFlow Vitals in secondary care: more preferred than paper?

Shannon Costello, Alison Bullock, Liam Turner, John Frankish

(Cardiff University)

Introduction: Hospital staff in some Welsh Health Boards use CareFlow Vitals, a software installed on mobile technology and the electronic health record, to record the vital signs of patients in place of using paper-based forms.

Aim: To assess the impact of CareFlow Vitals installed on iPads on patient care management and clinical practice from the perspectives of a range of healthcare staff using the technology.

Methods: A mixed methods study incorporating case study and survey design. Case studies include four wards in Hospital A and three wards in Hospital B within the same Health Board. Observations and semi-structured interviews were conducted at the case study wards. A survey was also distributed to users of CareFlow in the two hospitals.

Preliminary results: Healthcare staff do not unanimously prefer either CareFlow Vitals or pen and paper to record patient observations in practice. CareFlow Vitals is perceived to be more accurate, allows easier detection of errors and is seen as more convenient. Paper-based forms were perceived to be simpler, quicker, and easier. Older participants, and participants with more years of experience preferred paper-based forms. Participants who preferred paper-based forms perceived that CareFlow Vitals has had some negative impact on patient care management whereas participants preferring CareFlow Vitals reported a positive impact on care management.

Conclusion: Healthcare staff using CareFlow Vitals in secondary care in Wales are divided in whether they prefer using CareFlow Vitals or paper-based forms to record patient observations. Both mediums have their perceived advantages and disadvantages compared to the other.

Poster 7

Paradoxes of Neoliberalism: psychiatric service user experiences of disability benefits and mental health recovery in west Scotland; a thematic analysis of semi-structured interviews

Benjamin Gregory

(University of Glasgow)

Personal independence payment (PIP) is a UK disability benefit introduced under austerity. A meta-analysis found welfare cuts in high income countries worsened mental health outcomes. Austerity policies reduced spending on services while social stressors increased. In 2016 Scottish government gained devolved powers, with disability benefit reforms rolled out in 2022. Qualitative research in Scotland indicated a conflict between mental health recovery and benefits. This study aims to explore the experiences of psychiatric service users claiming PIP. A second aim is to compare these experiences with recovery.

By representing a marginalised group in policy reforms, this work aspires to epistemic justice. Data was collected in Glasgow and Lanarkshire for a Masters dissertation. Eight individuals with experience of psychiatric services participated in one-hour semi-structured interviews. A thematic analysis was conducted. My personal experiences of PIP, psychiatric services, and benefits advice guide my interpretations.

The central concept for this analysis is a paradoxical experience between (in)dependence. In PIP independence manifested in financial gain. But depends on a system recognised to work against “us”. The same tension exists in mental health recovery. Independent recovery encompasses growth, productivity, and control. However, recovery required community support. Mental health issues did not easily fit with PIP assessments. Self-presentation in independent recovery conflict with presentations of need in PIP assessments.

These contradictions exemplify paradoxes in Neoliberalism. Widening inequalities increase the need for state support. Still individualism characterises a personal responsibility for socioeconomic position and ill-health. Policies to improve community support and expand benefit provision can reconcile these paradoxes.

Poster 8

“My brain & my heart don't communicate together”: exploring vloggers' use of medical ontologies to share their symptom experiences with postural tachycardia syndrome

Mitchell Hogg, Vincent Deary, Julia Newton, Tim Rapley

(Northumbria University)

Postural Tachycardia Syndrome (PoTS) is an autonomic nervous system condition characterised by heightened heart rate (increase of >30bpm for adults) upon standing. Whilst PoTS is associated with impaired daily functioning, burdensome fatigue and poor quality of life, little research has been undertaken to examine how patients attempt to share their debilitating, daily symptom experiences with

others. The current study therefore employed narrative analysis to explore how people with PoTS communicated understandings of their chronic illness within the re-telling of their own diagnostic stories. A purposeful sample of 20 YouTube vlogs, triangulated alongside semi-structured interviews of 15 people diagnosed with PoTS (Mean Age= 35.3, SD= 12.1), were coded through NVIVO. The conduct of narrative analysis was guided through the adoption of a performative approach (Meraz et al., 2019). Rigour was achieved through reflexive note generation, numerous team analysis discussions and data triangulation. Within their narratives, storytellers constructed and drew upon socio-medical frameworks- those surrounding the autonomic nervous system- to communicate understandings of their PoTS to others and to account for their widespread symptom experiences. Through these models, storytellers depicted experiencing symptoms as a heightened bodily awareness, through the portrayal of their PoTS as a perceived 'disruption' to their body's unconscious pathways. Storytellers employed metaphors and personification to allocate blame towards their bodies for their disrupted daily functioning. The identification of the autonomic nervous system- as a common, patient-derived socio-medical ontology- ultimately serves as an effective explanatory model for researchers to utilise for the development of specific, new patient-acceptable interventions for PoTS.

Poster 9

ERicar: Engaging Roma women in the co-creation of an antenatal care information resource

Mabel Lie, Caroline Claisse

(Newcastle University)

Background - Czech-Slovak Roma women suffer barriers to antenatal care such as stigma in the UK contributing to reduced engagement with health services. There is a scarcity of research and intervention studies with this population. This study aims to co-create an antenatal care community information resource with a group of these women, through understanding their maternity needs to inform design considerations for a prototype of an antenatal care information resource.

Objectives

1. To understand Roma women's needs in pregnancy, childbirth, and maternity services
2. To share publicly available antenatal information resources such as pregnancy apps
3. To co-create a low-resolution paper prototype of an antenatal care information resource that meets their needs

Research activities

1. Eight participatory workshops with 6-8 women leading to the co-creation of an antenatal information resource.
2. Peer research, qualitative analysis, culminating in a community event and webinar for public and professional stakeholders.

Findings

The women's pregnancy journeys covered several topics such as unplanned pregnancies, nausea and vomiting, pregnancy loss and birth trauma. Through all these, the main message they wished to convey was the need for women in the community to overcome the stigma of seeking help for their mental health. Our information resource developed using a co-creative participatory approach will facilitate timely uptake of antenatal and mental health support services. Signposting Roma women to reliable information and healthcare provision will potentially reduce poor maternal and perinatal health outcomes and healthcare costs.

Poster 10

Qualitative study of help-seeking for stroke and heart attack during the Covid pandemic: Communicating findings to diverse audiences.

Carolyn Tarrant, Christina Weis, Joy Spiliopoulos, Agnieszka Ignatowicz, Dan Lasserson

(University of Leicester)

The Covid pandemic is likely to have impacted on access to healthcare in a range of ways including through changes to the availability of services, and influencing patient decision-making. Drawing on concepts of candidacy and illness work, we explored how patients experiencing a non-Covid critical condition accessed help during COVID-19 lockdown periods, and the impact of Covid on their decision-making.

Thirty-one semi-structured interviews were conducted across two English NHS Trusts, with patients (and/or their carers) admitted to hospital due to a stroke, TIA, or heart attack between March 2020 and May 2021. Data were analysed using a modified grounded theory approach, in particular, constant comparison, supported by NVivo.

We found that the ways in which patients experienced and made sense of their symptoms fundamentally shaped their decisions about seeking help through emergency care. The impact of the Covid pandemic on help-seeking depended on individuals' perceptions of their non-Covid symptom severity, and their response to ambiguity. Gender and social capital also impacted on help-seeking. Our findings have implications for policy, including messaging about accessing healthcare during times of crisis. We worked with an illustrator who produced an illustrated sketchnote of the findings; our presentation will highlight this type of output as an accessible and impactful way of communicating complex findings to diverse audiences.

Poster 11

Stigma power and weight-centric health policy: a narrative analysis of comparative policy responses and individual's stories.

Ruth Venn

(University of Portsmouth)

This poster submission, a critical analysis of neoliberal health policy, represents the first-year stage of a PhD research project. 'Stigma power' is the theoretical lens used to understand how weight-centric health policy in the Global North is constructed and how UK policy is experienced by individuals, during times of economic crises. Obesity is widely accepted to be a 'global problem' and is the dominant focus of attention in government health policies. Neoliberal weight-centric health policies position individual's body size as the key determinant of both current, and future, health status. A perceived association with obesity and expensive chronic illness enables governments to frame the consequences of obesity as an economic problem. Consequently the 'overweight' and 'obese' are subjected to portrayal as an 'economic burden', resulting in stigmatisation.

This study extends the argument that obesity policies may intentionally curate, perpetuate and amplify weight-based stigma to distract citizens from an array of socio-economic causes of ill health. 'The associated harms of weight-based stigma and discrimination, are well researched. To explore the less well understood concept of weight-stigma as governmental power tool, this comparative critical policy discourse analysis is triangulated with an examination of individual's narratives. The research aims are to firstly, understand the impact that UK obesity focussed policy has on the health and wellbeing of citizens from differing intersectional positions of inequality. Secondly, to explore how individuals understand weight-centric policy. The objective is to reduce weight-based stigmatisation and improve health outcomes through policy change recommendations.