Shame, Health and Lived Experience Workshop

Organised by the Centre for Subjectivity Research and the Shame and Medicine Project

Online and at the University of Copenhagen

April 28-29, 2022, CET time zone





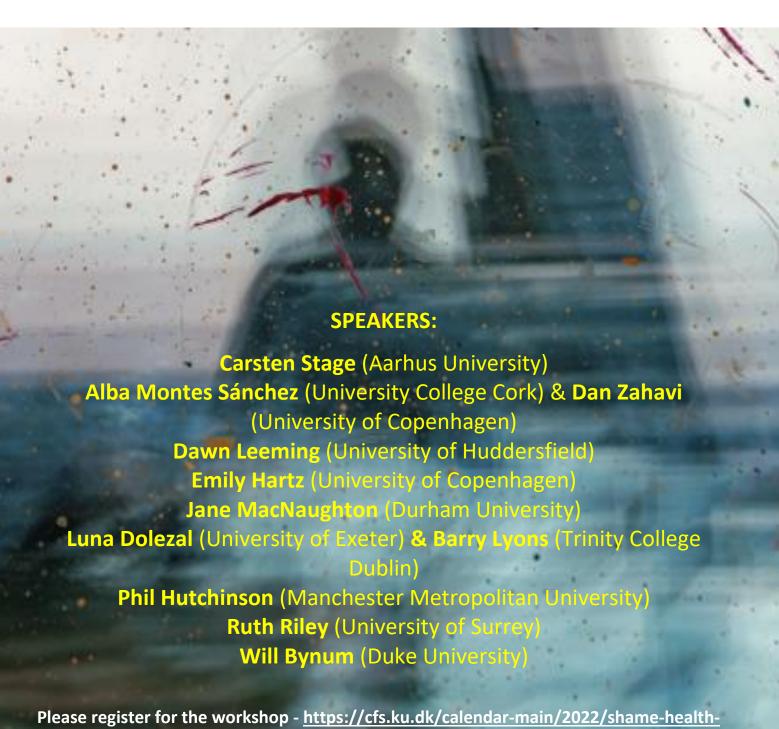
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This workshop is funded by the Wellcome Trust funded Shame and Medicine Project [217879/Z/19/Z] and the Center for Subjectivity Research, University of Copenhagen.

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Online and at the University of Copenhagen (South Campus, auditorium 22.0.11)

CET time zone

THURSDAY 28 th APRIL	
09.15 - 09.30	Introduction - Luna Dolezal (University of Exeter)
09.30 – 10.30	Phil Hutchinson (Manchester Metropolitan University) 'Shame's Object(s): Interactionally Respecifying Stigma.'
10.30 – 11.00	BREAK
11.00 – 12.00	Carsten Stage (Aarhus University) 'Shame and Chronic illness – Exploring the Affective Complexities of Illness- related Shame through Participatory Research on Social Media.'
12.00 – 13.00	LUNCH
13.00 – 14.00	Will Bynum (Duke University) - online 'Learning Medicine in the 'Shadow of Shame': A Qualitative Exploration of Shame Experienced across the Continuum of Medical Education.'
14.00 – 14.15	BREAK
14.15 – 15.15	Dawn Leeming (University of Huddersfield) 'Researching a Taboo.'
15.15 – 15.30	BREAK
15.30 – 16.30	Ruth Riley (University of Surrey) 'Shame Associated with the Stigma of Mental III Health and Culture of Invulnerability in Doctors.'

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FRIDAY 29 th APRIL	
09.30 – 10.30	Alba Montes Sánchez (University College Cork) and Dan Zahavi (University of Copenhagen) 'The Nature and Appropriateness of Survivor Shame.'
10.30 – 11.00	BREAK
11.00 – 12.00	Jane MacNaughton (Durham University) 'Shame in Women's Reproductive Health.'
12.00 – 13.00	LUNCH
13.00 – 14.00	Emily Hartz (University of Copenhagen) 'Eldercare and the Lived Experience of Shame and Boredom.'
14.00 – 14.30	BREAK
14.30 – 15.30	Luna Dolezal (University of Exeter) and Barry Lyons (Trinity College Dublin) 'Unsettling Consent?: Considering the Phenomenology of Shame in Clinical Encounters.'
15.30	END

SPEAKER BIOS and ABSTRACTS

PHIL HUTCHINSON (MANCHESTER METROPOLITAN UNIVERSITY)

Phil Hutchinson is currently Senior Lecturer in Applied Philosophical Psychology in the Department of Psychology at Manchester Metropolitan University, UK. He has worked on Shame, Emotions, Wittgenstein, Ethnomethodology, the Placebo Response and E-cognition. Phil is currently working on a number of projects: One on Wittgenstein and Ethnomethodology, which seeks to remap the relationship by looking at how Wittgenstein and Garfinkel respecify both phenomenology and Gestalt Psychology grammatically (W) and interactionally (EM). A second project on Stigma which seeks to advocate a return to interactional analyses of stigma. And a third project, in collaboration with Doug Hardman, on method in Psychological research.

'Shame's Object(s): Interactionally Respecifying Stigma'

In 2012, I began work on bringing my philosophical work (e.g. Hutchinson, 2008) on shame to bear on the shame as experienced by some people living with HIV and how this affects them, their medical care and public health policy on HIV. As I began this project, it became clear that shame was discussed little, if at all, in the literature on the psycho-social factors impacting HIV treatment, public health policy and a life lived with the virus. Instead, the dialogue about psycho-social determinants, barriers to good treatment and the experience of living with the virus was dominated by reflections on stigma, and had been since the early days of the epidemic in the 1980s. In a couple of papers (Hutchinson and Dhairyawan, 2017a, 2017b), the HIV consultant Rageshri Dhairyawan and I made the point that studying stigma without also studying the emotional response to stigma was a little like investigating danger in the absence of any discussion of the fear experienced in response the perception of danger; our point was that there is an internal relationship between an emotion, like shame, and it's object, like... But here I hit a problem, because after Ragreshri and I made this point and I turned my attention to stigma taken as shame's object, I found that notwithstanding the huge amount of literature on stigma, much of which depicts stigma as an attribute or mark, stigma is a category term which brings together a range of interactional phenomena, such as discreditation, degradation and discrimination. In this talk I lay out a programme for the interactional study of the phenomena which are brought together by the category of stigma. In doing so, I also talk a little about some assumptions about stigma that pervade not only the academic literature but also stigma activism.

References

Hutchinson, P. (2008) Shame and Philosophy: An Investigation in the Philosophy of Emotions and Ethics. Basingstoke: Palgrave Macmillan. Hutchinson, P. and Dhairyawan, R. (2017a) 'Shame, Stigma, HIV: Philosophical Reflections.' *Med Humanit*, 43(4) pp. 225–230. Hutchinson, P. and Dhairyawan, R. (2017b) 'Shame and HIV: Strategies for addressing the negative impact shame has on public health and diagnosis and treatment of HIV.' *Bioethics*, 32(1) pp. 68–76.

CARSTEN STAGE (AARHUS UNIVERSITY)

Carsten Stage is Professor of Culture and Media at the School of Communication and Culture, Aarhus University, Denmark. His research deals with illness narratives, affect, social media and participation. Recent monographs include: Quantified Storytelling (Palgrave, 2020, co-author), The Language of Illness and Death on Social Media (Emerald, 2018, co-author), Networked Cancer (Palgrave/Springer, 2017).

'Shame and Chronic illness – Exploring the Affective Complexities of Illness-related Shame through Participatory Research on Social Media.'

The presentation explores the complex roles shame plays in the lives of people with one or more chronic conditions. This is achieved through a participatory research process in which approximately 200 individuals with chronic conditions voluntarily shared their experiences of shame on or through the social media profiles of a Danish peerled patient community called 'Chronic Influencers'. The crowdsourced material shows that 7 out of 10 experience shame in relation to their illness on a daily or weekly basis. Other central key findings are that shame among the participants seems to stick to 'energetic failures' of the slow or tired body in various social situations; shame is predominantly produced in the intimate sphere and in relation to friends, partners and children; and shame can be politicized, 'rescripted' and displaced as culturally produced, collectively experienced and politically contestable when it is shared through voluntary storytelling among peers. The presentation furthermore discusses how different approaches to shame – linked to notions of the derogatory gaze, impeded positive interest and responsibilization – are useful for understanding shame experiences related to chronic illness.

WILL BYNUM (DUKE UNIVERSITY)

Will Bynum is currently an Associate Professor of Family Medicine in the Duke University School of Medicine. Prior to arriving at Duke in October 2017, he served for seven years on Active Duty in the US Air Force. Will's military service included four years of faculty duties in the NCC Family Medicine Residency Program and a deployment to East Africa as the senior medical director of a special operations command. Will currently serves as the Duke Family Medicine Residency Program Director and Faculty Advisor to the Duke School of Medicine Student Wellness Committee. Will's primary academic interest centers on the role of in the medical learning experience. He is conducting this program of research through a PhD in Health Professions Education at Maastricht University in the Netherlands.

'Learning Medicine in the 'Shadow of Shame': A Qualitative Exploration of Shame Experienced across the Continuum of Medical Education.'

While shame is a powerful, ubiquitous human emotion. The psychology literature is rife with research linking shame to various manifestations of impaired well-being, including depression, burnout, anxiety, diminished empathy, and suicidality, all of which presently vex the medical education community. Further, the hierarchical, high-stakes, and academically intense nature of medical training increase the likelihood for failure (perceived or real) and challenging emotions such as shame. Yet despite these associations and potential for distress—and the ubiquitous nature of shame as a normal human emotion, little is known about the role it plays across the continuum of medical education. This gap is problematic as shame that is unrecognized or propagated—intentionally or otherwise—may have significant negative effects on individual trainees, on patients, and within clinical learning environments. In this presentation, I will provide an overview of our program of qualitative research that attempts to address this gap by asking: how is shame in medical trainees experienced across the continuum of medical education? To answer our research question, we utilized hermeneutic phenomenology, a qualitative approach from the interpretivist paradigm that seeks to convey the nature and meaning of a phenomenon and the contextual factors that shape it. We conducted three separate studies: one each in medical residents, medical students, and pre-medical students from teaching institutions in the United States. In each study, we used an elicitation technique and a semistructured interview to deeply explore participants' lived experiences with shame in medical training. We analyzed the data according to Ajjawi and Higgs's six steps of hermeneutic analysis. Our analysis yielded rich, deep insights into the nature and meaning of shame across the medical education continuum. I will discuss key findings—or "essences" of shame in medical trainees—from across our data set, including: 1) the nature and meaning of the events that triggered and factors that contributed to shame, 2) the destabilizing nature of shame, and 3) the central—and potentially overlooked—role of shame and self-concept trajectories in the professional identity formation of doctors. Within this discussion, I will highlight key elements of shame that link these key findings, including the role of performance-based self-esteem, the impact of underrepresentation, and the presence of ideological influences embedded within the structure of medical education. I will conclude with a broader discussion about the implications of these findings at the individual, institutional, and ideological levels in medical education. In this discussion, I will propose specific ways to advance emotionally resilient learning within shame sensitive learning environments and maximally inclusive institutional cultures and structures.

DAWN LEEMING (UNIVERSITY OF HUDDERSFIELD)

Dawn Leeming is Director of Graduate Education for the School of Human and Health Sciences at Huddersfield University, UK. Previously she was a clinical psychologist and lecturer in psychology. She has a long-standing interest in the management of shame and stigma, with a particular focus on infant feeding and use of mental health services.

'Researching a Taboo.'

Shame is a tricky experience to research as it is difficult for participants to acknowledge and speak about shame and difficult for researchers to witness the shame of others. Shame might be re-experienced through painful disclosure of hidden episodes still considered taboo. Alternatively, if we conclude that others were wrong to have shamed us, shame itself can feel shameful. It is thus one of the most private and hidden emotions, despite being an experience of our position in relation to others. Therefore, understanding how shame can shape experiences of healthcare requires empirical research methods which can attend sensitively to shame as both an experiential and relational phenomenon, though one that is not easily articulated. Drawing particularly on research in two areas (accessing mental health services and receiving breastfeeding support) I reflect on the value of varied methods (qualitative questionnaires, interviews, audio-diaries, secondary data analysis, observation) for exploring shame and related self-conscious emotions, whilst considering ethical and methodological issues and the agendas that researchers and participants may bring. I argue for the importance of not only exploring experiences labelled as 'shame', but also using less direct methods to investigate the subtle ways in which the avoidance of shame can shape healthcare interactions.

RUTH RILEY (UNIVERSITY OF SURREY)

Ruth Riley is Senior Lecturer in Health Sciences at the University of Surrey. She is an applied qualitative researcher and medical sociologist. Her research employs inter-disciplinary approaches to investigate the sources of stress/distress experienced by healthcare professionals and approaches to improving access to support.

'Shame Associated with the Stigma of Mental III Health and Culture of Invulnerability in Doctors.'

Shame associated with the stigma of mental ill health and culture of invulnerability is pervasive within medical culture and is enmeshed in the medical identity. This paper draws on a body of primary research which explores the lived experience of different doctors living and working with mental ill health and/or symptoms related to occupational distress. Specifically, for the Shame, Health & Lived Experience Workshop, we report findings related to shame and the stigma of mental illness and/or occupational distress from a corpus of rich qualitative interview data derived from two in-depth studies exploring the experiences of General Practitioners (n=47) and junior doctors (n=36) working in the National Health Service (NHS) in the United Kingdom. Both studies identify shame as a crosscutting theme across participant characteristics, specialities and settings. Shame is divisive, isolating, prevents or delays doctors from help-seeking, sustains a culture of invulnerability and co-creates a professional identity which often dissociates, disembodies and alienates doctors from their emotions. This workshop will explore shame in this context and invite audience members to discuss potential approaches to addressing a historical and problematic phenomenon within medicine.

ALBA MONTES SÁNCHEZ (UNIVERSITY COLLEGE CORK) & DAN ZAHAVI (UNIVERSITY OF COPENHAGEN)

Alba Montes Sánchez is Marie Skłodowska-Curie Postdoctoral Fellow at the Philosophy Department of University College Cork, Ireland. Her main area of research is the philosophy of emotions (especially shame, pride, envy and guilt) and their moral psychology, at the intersection of philosophy of mind and phenomenology.

Dan Zahavi is Professor of Philosophy and director of the Center for Subjectivity Research at the University of Copenhagen. Zahavi's primary research area is phenomenology and philosophy of mind, and their intersection with empirical disciplines such as psychiatry and psychology.

'The Nature and Appropriateness of Survivor Shame.'

Survivor shame is common among genocide survivors and victims of abuse. For researchers who consider shame a moral emotion, this is puzzling: having been a target of violence is not a moral flaw. And yet, at least since Primo Levi's Auschwitz testimonies, an influential tradition has been defending the moral significance of survivor shame. On the one hand, then, survivor shame seems to be irrational and unjustified. On the other, some survivors themselves vindicate its moral value. Here we argue that to understand this apparent contradiction, we need to distinguish, first, among different varieties of shame and their temporality. Many accounts have conflated shame, shaming and humiliation, and have failed to differentiate the emotions felt during the traumatising events from survivor emotions. Secondly, we need to distinguish between different kinds of emotional appropriateness, specifically fittingness, moral appropriateness and prudential appropriateness. Survivor shame, we argue, is not an episodic emotion, but a multi-track emotional process with various elements unfolding over time. Not all these elements are equally appropriate along all dimensions, and while prudentially it is certainly good to reduce survivors' suffering, this might be better achieved by validating the appropriateness and rationality of some elements of survivor shame.

JANE MACNAUGHTON (DURHAM UNIVERSITY)

Jane Macnaughton is Professor of Medical Humanities at Durham University in the UK and Deputy Vice Provost for Research. Until 2021 she was Director of the University's Institute for Medical Humanities. She is clinically qualified has until recently been regularly clinically active as an Honorary Consultant in Obstetrics and Gynaecology at the University Hospital of North Durham.

'Shame in Women's Reproductive Health.'

The awareness of being seen and judged pervades so much of women's* experience but comes into acute focus in the context of reproductive health. Women's bodies in this context become a locus of shame whether relating to sexual activity or lack of it, being pregnant or not achieving pregnancy, and the perception of the 'appropriateness' of sexual activity as we age. In my talk I will draw upon experience as a clinician working in cervical screening and as an academic interested in the menopause to examine shame in this context. I will explore the origins of shame in both contexts exploring how societal views about women and sexual activity make women turn in upon themselves in negative ways with often devastating consequences. I will examine the misogyny that surrounds the clinical approach to women's health, drawing particular examples from historical work on the menopause. Feminist condemnation of this misogyny and its consequences has had positive results but also negative outcomes for women who feel uncomfortable accessing clinical services. I will reflect upon this context as a distinctive locus of shame for women which men escape for practical and historical reasons.

EMILY HARTZ (UNIVERSITY OF COPENHAGEN)

Emily Hartz works on issues related to the intersubjective constitution of the self. Her work is highly interdisciplinary and she has approached this issue from the vantage point of German idealism, phenomenology of plurality, philosophy of law, gerontology and neuropsychology. Emily holds an Ma in philosophy from Copenhagen University, a PhD in philosophy from the Danish School of Education and is currently finalising an Ma in psychology from Copenhagen University.

'Eldercare and the Lived Experience of Shame and Boredom.'

This talk will focus on whether and how shame structures the lived experience of being old and being dependent on eldercare. To discuss this issue, I draw on examples from existential group-therapeutic work in a nursing home in Copenhagen. Rather than grief and loss, the most prevailing issue for the participants in the group turned out to be boredom. An existential feeling that seemed to prevail in spite of – sometimes even as a result of – the caregivers' sincere efforts to engage the elders in different activities. To understand the phenomenology of boredom in general and of old age in particular I turn to Simone de Beauvoir's work on the existential structuring of old age. On this basis I argue that boredom and shame are intrinsically linked in the experience of being old and of being dependent on eldercare. Finally, I discuss how one might work therapeutically with shame and boredom in a concrete setting.

LUNA DOLEZAL (UNIVERSITY OF EXETER) & BARRY LYONS (TRINITY COLLEGE DUBLIN)

Luna Dolezal is Associate Professor in Philosophy and Medical Humanities at the University of Exeter where she leads the *Shame and Medicine* Project, funded by the Wellcome Trust, and the *Scenes of Shame and Stigma in COVID-19* project, funded by the UK's Arts and Humanities Research Council. She is author of *The Body and Shame: Phenomenology, Feminism and the Socially Shaped Body* (Lexington Books, 2015) and co-editor of the books *Body/Self/Other: The Phenomenology of Social Encounters* (SUNY Press, 2017) and *New Feminist Perspectives on Embodiment* (Palgrave, 2018).

Barry Lyons is a paediatric anaesthesiologist at Children's Health Ireland, lecturer in Medical Ethics & Law at Trinity College Dublin, and Director of Patient Safety at the College of Anaesthesiologists of Ireland. He has particular interest in the tensions between law, regulation and medicine, and in emotional and psychological aspects of clinical practice. He is a core collaborator on the Wellcome funded Shame and Medicine Project.

'Unsettling Consent?: Considering the Phenomenology of Shame in Clinical Encounters.'

Consent is a critical element of the patient – physician relationship. The traditional model of consent holds that its validity is dependent on the appropriate choices being offered, the requisite information being provided, the absence of coercion, and on the mental capacity of the actor to give consent. This prevailing conception of consent presumes an unfettered capacity amongst adults, and unless this presumption is rebutted through an assessment of some cognitive impairment or neuropsychiatric illness, it confers upon an individual the right to consent to, or refuse, any medical intervention regardless of the consequences. While emotions (particularly anger and grief) have long been recognised as impacting upon an individual's choices and actions, it is only recently that researchers have specifically investigated the relationship between informed consent and emotion (e.g., Supady et al, 2011). Following that preliminary report, questions remain around how (or which) emotions might hamper the full processing and assessment of information or values, or influence the understanding of short-term and long-term consequences, or impact upon the determination of free will. This paper proposes that in certain circumstances negative self-conscious emotions, in particular shame, are likely to influence patient decision-making with respect to informed consent. Shame is a powerful emotion that signals to a subject that their identity may be tarnished, and their social bonds threatened. It is often an intensely negative and threatening experience, avoided at all costs. Through articulating the phenomenology of shame our aim is to explore the extent to which the cognitive, emotional, social and embodied components of shame may come together to compromise one's ability to make rational, informed choices in clinical encounters.