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Dr. Lisa Altshuler; Adina Kalet, MD, MPH; Anais Leroy; Penelope Lusk; Dr. Verna Monson. “The Aesthetics of Reflection: Conceptualizing Exemplary Medical Professional Identity through Writing.”

Altshuler, Kalet; New York University School of Medicine.

Leroy; Bowdoin College.

Lusk; NYUoM; Graduate Student, Columbia University.

Monson; Private consultant.

How can we understand structured, reflective writing as an aesthetic undertaking in medical education? At our medical school we evaluate medical professional identity (MPI) through the Professional Identity Essay (PIE), a nine-question structured reflective writing measure based on Kegan’s stage theory of identity development. Conceptualizing the qualities of a mature MPI is critical to supporting professional development.

We are using the PIE to understand the MPI of faculty identified as professional exemplars by students and peers. We invited 32 faculty to participate in the study; 20 completed the PIE to date. PIE scoring focuses on response structure—how and why respondents justify responses—, not content—what and how respondents write. PIE content offers an aesthetic, linguistic field to explore the meaning of physician professionalism.

Faculty respond intensely. Strikingly, one wrote: “I came to the profession from the side of truth rather than love...I was changed by my experiences...where I saw the brokenness of so many lives, and found in spite of myself that I had to think about my patients as not so different than me. I was helped along in this by my study of literature--the world’s great repository of empathy.” Beautifully: “[Medicine] demands self-sacrifice. And I say this in a completely uncomplaining way...As much as this profession takes from me, it is dwarfed by what I have received in return. It makes me exactly who I am today.”

The structured PIE yields stage scores to enrich our understanding of medical professional identity development. But it may also demonstrate a richly descriptive, phenomenological understanding of what it means to be a physician. In attending to the words of physicians as an artistic undertaking, we may be able to utilize the PIE as a uniquely mixed-methods measure that supports professional development and aesthetic appreciation simultaneously in medical education.

Bio:

[150 Words Max.]

Dr. Niro Amin. “Doctor distress: voicing the tipping point.”

GP, Doctoral student in Medical Humanities; Birkbeck, University of London.

This paper examines the meta-narrative of physician distress as a possible precursor to physician suicide. Statistics report that four hundred and thirty health professionals in England took their own lives between 2011 and 2015 (Gerada, 2018) whilst female doctors are four times more likely to end their lives than the general population¹ yet the subject matter remains a taboo. Instead popular fiction has become a mode of communicating stories from the frontline of medicine as experienced by junior doctors.

Adam Kay’s darkly comic novel ‘This is Going to Hurt: Secret Diaries of a Junior Doctor (2017),² is polemic in its entirety about the hospital system but attempts to balance the tragedy with humour. Rachel Clarke’s book ‘Your life in my hands: a junior doctor’s story (2017),³ highlights the political

drama of the junior doctor's strike amongst the pain of patient stories including her own grandfather, a retired doctor who dies whilst an inpatient.

Adam Kay's novel concludes with the death of a patient under his care and the trauma of the case leads to Kay leaving medicine whereas Rachel Clarke experiences similar loss of confidence when she is faced with disciplinary action by her Trust but she chooses to continue practising as a doctor. This paper questions if Kay's and Clarke's written narratives can offer insights into the hidden narrative of doctor distress and what lessons can be learnt about the junior doctor's unmet needs.

References

¹ Professor Clare Gerada, Director of Practitioner Health Programme in London, speaking on the Victoria Derbyshire programme BBC One aired 3 September 2018

² Adam Kay 'This is going to hurt: secret diaries of a junior doctor' Picador 2017

³ Rachel Clarke 'Your life in my hands: a junior doctor's story' Metro Books 2017

Bio:

[150 Words Max.]

Dr Claire Anscombe. "Creatively Constrained Negotiating Disability in Visual Art Production."

History and Philosophy of Art; University of Kent.

Traditional accounts of creativity have framed constraints as negatively affecting the creative process, however there is growing evidence to suggest that certain kinds of constraints may actually enhance creativity.¹ For instance, Stokes has argued that self-imposed constraints can enhance creativity in the production of visual artworks.² However, in this paper, the artists that I examine have each faced externally imposed constraints due to their physical disabilities. For instance, Henri Matisse was left unable to stand and paint after surgery for intestinal cancer, but found that he could produce works using scissors and paper; Helene Schjerfbeck suffered from chronic physical pain, was isolated, and sometimes only able to work for one or two hours of the day, but produced over 1000 works; and Donald Rodney, who suffered from sickle cell anaemia, utilized advancing technology to produce his socio-political work.³ These artists have been recognized for having produced some of the most original and challenging work of the 20th and 21st centuries, yet they have each faced externally imposed constraints, as a result of their physical disabilities, in producing their work.

*In order to explain how these artists have so successfully negotiated the constraining effects of their disabilities, I utilize Gaut's proposal that creativity is an agential disposition, which entails a spontaneous aspect whereby: "If someone is creative in producing some item, she cannot know in advance of being creative precisely both the end at which she is aiming and the means to achieve it."⁴ Accordingly, I highlight that such artists, due to the often changing constraints of physical disabilities, frequently have to innovate new, unforeseen ways with which to achieve their artistic goals, as in the case of Matisse's substantially altered practice where he moved from painting to cutting techniques, and that these external constraints, which traditionally have been far from the central concerns of Fine Art, may even become the content of the work itself. For example, Rodney's work *Psalms*, consists of an autonomous wheelchair that wanders through a gallery. The work functioned to represent the artist in absentia but additionally demonstrated how moving in a wheelchair transforms the simple act of navigating through the world into a complex series of problems to solve.⁵ While these physical constraints may have devastatingly negative effects on other aspects of a disabled individual's life, these examples show that in producing art, agents are able to take control and not only manage these constraints, but produce something of value in virtue of having negotiated these constraints. This accomplishment can, I establish, enhance a disabled individual's*

sense of agency and wellbeing. Additionally, a further value that is generated by directly addressing these external constraints is that such artists have offered audiences sensory insights into what life with particular physical disabilities is like, thus conveying the physical effects of their condition more directly to an audience that may otherwise struggle to comprehend what it is like to navigate the world with such constraints.

Keywords: *creativity, constraint, agency, disability, artists*

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Bio:

[150 Words Max.]

Nicholas Bellacicco. "The Pedagogy of Clinical Empathy: Formation of the Physician."

3rd-Year Medical Student; Lake Erie College of Osteopathic Medicine (USA)

Clinical empathy is a lively topic of discussion in the contemporary medical literature. Research indicates that empathetic physicians receive higher patient satisfaction ratings, as well as improved patient health outcomes, compared to non-empathetic clinicians. Consequently, clinical empathy appears to be instrumental in providing quality patient care. If empathy is essential for improving healthcare outcomes, should not medical students learn to be more empathetic? To address this question, we first explore the distinction between clinical sympathy and empathy. Then, two essays from the medical literature are used to compare the empathetic with the non-empathetic physician. Next, we examine the pedagogical issues involved in teaching empathy to premedical and medical students, as well as to residents. Finally, we conclude by discussing the imperative for training clinicians to deliver quality empathetic healthcare.

Bio:

[150 Words Max.]

Deshae Jenkins, Kate Gaines, Kelvin Chang. "Opacity as Resistance: Mobilizing Opacity as a Response to the Demand for Transparency."

MA Candidates in Narrative Medicine; Columbia University

As students in the graduate program in Narrative Medicine at Columbia University, we are often asked to consider the power of stories or, what we might call, narratives. Narratives are stories that give meaning to experience; as forms of speaking, writing and knowing, they are the primary means by which we make sense of who we are. Although narratives give rise to conceptions of self, narratives are, by nature, culturally-shaped and decipherable. As sources of consolatory and explanatory power, individuals and communities mobilize narrative forms to create meaning in the face of oppression and suffering. Nevertheless, narratives are not inherently just and also have the power to produce and reinforce oppression and suffering.

While we acknowledge the power of stories or narratives to provide healing and empower individuals, we also maintain that stories may be dangerous. Though we often discuss how to make sense of the stories we hear and how those stories ought to be represented to others, we fail to question the demand for stories and the potential harm of sharing. That is to say, we have explored the power of narratives, but have ignored the adverse consequences of sharing one's story. This issue becomes increasingly important given the growing demand for stories, as individuals are asked to recall traumatic or adverse experiences in academic spaces and, more specifically, to gain admission to academic institutions, fellowships and other educational honors. While such stories are often used as tools to assign value and attribute reality to an individual's lived experiences, the demand for stories is ultimately linked to a request for transparency and visibility. Given the risk of transparency and the demand to make oneself visible, it follows that some stories may not be ethical to demand.

In this paper, we offer opacity as resistance as a solution to the overwhelming demand for stories. Opacity, as an alternative to transparency, represents an effort to envision alternatives to the demand to be "visible" but also "transparent". Using Judith Butler's language of opacity and Rachel Hall's theory on the aesthetics of transparency, we argue that opacity as resistance may be operationalized as a refusal of visibility or transparency. Using a narrative framework and an anecdotal experience to explore these ideas, we hope to shed light on the right to remain opaque and suggest opacity as a crucial mode of resistance when the demand to be transparent may potentially cause physical, emotional, mental or psychological harm.

Bio:

[150 Words Max.]

Maria Micaela Coppola. "Down the Rabbit Hole: Tales of Nonsense and Wonder from the Land of Dementia."

Associate Professor; Department of Psychology and Cognitive Science, University of Trento (Italy)

Alice's Adventures in Wonderland will provide the milestones in a quest for sense in seemingly nonsensical stories about Alzheimer's disease. In particular, two stages of Lewis Carroll's story – "Down the Rabbit Hole" and "A Mad Tea-Party" – will constitute the narrative and aesthetic framework for a journey in search of meaning in tales that account for dementia sufferers' progressive cognitive deterioration, from the point of view of onlookers: Toni Harrison's play Black Daisies for the Bride (1993) and John Bayley's biography of Iris Murdoch, Iris: A Memoir (1998), and their filmic versions (respectively directed by Peter Symes, 1993, and Richard Eyre, 2001).

For those who observe a patient suffering from dementia the functioning of the affected brain eludes common sense and understanding. The dementia sufferer enters into a land of wonder, that is, at once astonishing, puzzling and terrific, beyond the onlookers' cognitive, linguistic and behavioural frames of reference. We could say that the possibility of understanding and accounting for the

Alzheimer brain is hampered by tangles of nonsense. The onlooker-patient relationship is also nonsensical when Alzheimer's disease is involved: trying to make sense of the patient's train of thought, striving to access his/her incomprehensible brain world, searching for new channels of communication when common language fails, or attempting to empathise with someone who can be equally unemotional and overemotional appear to be senseless actions.

Still, in stories of dementia we can find witnesses who, like Alice in the first chapter of her adventures, try to follow the rabbit/patient down his/her puzzling, unintelligible – in a word, wonder-full – land. In order to make sense of it, they have to search for new ways of communicating and understanding mental illness. Like Alice with the Mad Hatter, they have to learn the patient's language of nonsense, through which meaning can be conveyed via rhythm, intention, or form, and not by means of well-located words, logical contents or interconnected sentences. An empathetic, albeit feeble, connection can be established, in which the onlookers put themselves in the patient's shoes and tell his/her tales of nonsense and wonder.

These dementia stories can be used as a means for observing illness from an aesthetic perspective: following the patient 'down the rabbit hole' – i.e. bearing witness to mental illness and learning the language of nonsense – can contribute to exploring new modes of communication, to questioning the limits of our ordinary brain world, and to defining new forms of social and cultural cure.

Bio:

[150 Words Max.]

Dr. Lottie Corr. "A picture of health: a literature review examining the integration of Graphic Medicine within medical education."

Clinical Teaching Fellow; NHS Lanarkshire

Visual aids, such as diagrams, mind maps or flow charts, are well established implements in medical education; however, the utilisation of visual narrative remains in its early development¹. Despite recent proliferation of healthcare related graphic texts, the stereotyped history of comics as a form of mediocre childhood literacy dominated by superheroes has discouraged educators from utilising this rich field². It is therefore imperative to reflect on current research in order to best evaluate the value of integrating graphic medicine within medical education.

This presentation will first examine the skills and attributes that medical students can develop from incorporating graphic medicine into medical curriculum. Graphic healthcare narratives can cultivate empathy by relating theoretical knowledge to the human experience and highlighting that healthcare requires more than simply "treating a body", which is particularly relevant in the current climate of compassion fatigue^{3,4}. Engagement with graphic medicine can help build on essential clinician capabilities such as observation skills, attention to non-verbal cues and diagnostic reasoning^{5,6}. Educational programmes that promote student creation of comics are also emerging, and these have the potential to further communication skills by using a medium that conveys complex subjects with limited words⁷. They also encourage creativity and are an opportunity for students to engage without necessity for distinguished technical skill⁷.

Reflective practice, both as students and in further professional endeavours, is an integral feature of healthcare. Despite rising encouragement for formal introspection in various written formats in medical school, there is a stark lack of visual methodology⁷. Experiences during important training landmarks such as the formation of professional identity can be recognised and reflected upon by both reading and creating graphic texts⁸. In a profession blemished by stoicism, burnout and mental health struggles, graphic medicine can also provide a constructive avenue to permit students to

perceive and express worries; ultimately alleviating stress and isolation in a difficult and demanding career⁷.

Finally, it is recognised that the use of visual arts in medical education can enrich student understanding of both patient and practitioner perspectives; however, there is sparse utilisation of graphic narratives at present⁸. Squier argues convincingly that comics, with a distinct combination of words and visuals, have significant potential to effectively communicate the complex impacts of health pathology and adversity, and these elements will therefore be explored⁹. The use of metaphor to describe symptoms is common among patients, and graphic medicine allows for literal depictions of these metaphors⁵. These representations can thus question the implicit accuracy of medical terms that describe subjective experiences, and the ramifications of this will be examined⁶. Additionally, the combination of often universal and relatable images with autobiographical narrative is crucial in creating understanding of the wider socio-political context with which illness is inevitably correlated⁷.

In summary, this presentation will investigate the current attitudes and barriers towards the inclusion of graphic medicine within medical education, as well as outline clear attributes that this compelling discipline has to offer.

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Bio:

[150 Words Max.]

Matthew Crippen; Sarah Hammad. “Aesthetics, Health and the Loss and Emergence of Self.”

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 - Berlin School of Mind and Brain, Humboldt University of Berlin
- Hammad: PhD student at Essex University

Pragmatic aesthetics—especially Dewey’s and to some extent Shusterman’s—converge with ideas from art therapy. By comparison, however, pragmatic aesthetics entails more nuanced conceptions of self and its relation to illness and health. Specifically, we assert that pragmatic aesthetics converges with psychological work on flow, not to mention Eastern meditative traditions. If followed through, these standpoints suggest that self-awareness involves a kind of illness and that this in turn can lead to aesthetic experience— and in most cases, healthy functioning—in which sense of self is lost.

Art therapy, according to standard definitions, involves increasing self-awareness by making and reflecting on art, and also helps patients cope with stress and traumatic experiences. Somewhat

against this, pragmatic and existential thinkers have argued that heightened self-awareness follows from dis-ease, whether in the form of psychological unease or outright illness. Simultaneously, however, obstacles and tensions that motivate self-awareness also supply resistance that can funnel life into aesthetic form, understood as a generally healthy phase during which self melts into world, as in the case of flow states. This outlook accordingly agrees with many therapeutic approaches in emphasizing the self. Yet it departs by suggesting—along almost Buddhist lines—that we lose our sense of self during healthy periods, even while the movement towards wellbeing involves its emergence.

The dis-ease of a civil rights activist, to consider an example, leads her to act in but also against a sick world. This shapes the direction of her life, giving it purpose and form. She cultivates a disposition by developing habits, for habits are dispositions towards and demands for certain activities, and they constitute the self. Dewey, essentially repeating the ancients, insist that neither self nor character would exist without continued operation of habits in our activities. Habits even underlie will, for they are inclinations to chase after and want certain things. Yet participation is not surrender. The woman resists habits or cultural worlds, and resisting customs promotes individuality in mind. It gives the woman something against which to define herself. Thereby she not only becomes an integrated self, but also an individuated one. However, during powerful phases, say, of a protest that is both beautiful and ugly—but unequivocally aesthetic in Dewey’s sense of the term—she nearly loses herself in her world and tasks.

This kind of somaesthetic thinking is worth considering in the context of the experience of art and aesthetics, which has been shown to lower stress related hormones, affect brain functioning and generally cultivate healthful consequences. It is worth considering because it offers ways of elaborating on how art and aesthetic experience can cultivate a more integrated self, while also expanding our contact with the world. It thereby emphasizes how aesthetic experience is crucial to self-growth, enrichment and the search for meaning. Yet it adds that at its height—and this is a point that can be neurobiologically explored—aesthetic experience also entails loss of self.

Bio:

[150 Words Max.]

Dr. Virginia Dakari. “Toward an aesthetic of the unrepresentable: Cancer-related performance as sublime art and an exercise in empathy.”

- Adjunct Lecturer, Department of English Language and Literature, National and Kapodistrian University of Athens;
- Postdoctoral Researcher, School of English, Aristotle University of Thessaloniki.

Where does pleasure reside in theatrical performances that address gruesome illness experiences, such as cancer? Using this question as a take-off point, this paper seeks to delineate the aesthetic of the unrepresentable in contemporary cancer-related performance. The idea of the unrepresentable in performance refers to an art event whose explorations exceed containment in given formal aesthetic frameworks. Employing a Kantian philosophical lens, Jean-Francois Lyotard associates the unrepresentable in postmodern art as an essentially sublime experience, which does not please the spectator by way of its beauty of form, but rather gratifies the spectator’s effort to come to terms with the symbolic terror such a spectacle evokes.

Juxtaposing the above aesthetic tenets with American critic Susan Sontag’s argument against the possibility of extracting any valuable aesthetic outcome from the experience of cancer, expressed in

*her treatise, *Illness as Metaphor*, this paper aims—through an examination of exemplary performance pieces—to question the latter long-held assumption that has extensively affected criticism regarding the diseased body in performance and explore its multiple merits at the crossroads of arts and medicine.*

More specifically, questions taken up by performance theoreticians include the aesthetics of the representation of illness and pain, the nature of artistic intent and the way it affects interpretation, whether or not the intensity of emotional involvement with staged suffering compromises the objectivity of interpretation, and the relation between art and the artist's and the audience's emotions. For medical humanists, discussion focuses on the ethical and social implications of the representation of illness experiences, medical practitioners' share in shaping those experiences, and how implementing these staged narratives promotes ethical medical education and nurtures empathetic medical practice.

Cancer-related performance lends itself to a constellation of not only aesthetic but also ethical considerations. Where is the line to be drawn between sharing an illness experience and running the risk of too much exposure of raw details? Would that render the experience of viewing emotionally elevating or emotionally threatening to the audience? In what ways can medical practitioners harness the experience of attending these performances into their work with patients and help decrease harmful emotional detachment in clinical settings? In all, how do cancer-related staged narratives impart individual and communal change and advance wellbeing even within illness?

*The present discussion, ultimately, suggests a postcritical, relational approach to cancer-related performances. By injecting analysis with aspects of the affective, the aesthetic of the unrepresentable expands on Rita Felski's call for "blending analysis and attachment, criticism and love" (*Uses of Literature*, 22). In its interface with the domain of medical and health humanities, it also indicates a rich pedagogical agenda and a rigorous exercise in empathy.*

Bold, recalcitrant, and fluid, cancer-related art articulates a new aesthetic idiom and the emergence of an "emancipated community," in Jacques Rancière's terms—an engaged community of spectators as partakers, interpreters, and advocates of the healing power of performance.

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Bio:

[150 Words Max.]

Dr. Sandra Danilovic. "Game Design Therapoetics: Cathartic Making for Self and Society."

Assistant Professor; Wilfrid Laurier University, Canada

The game jam is a subset of maker cultures—a contemporary phenomenon whereby independent game designers coalesce in a physical space to prototype digital games over the course of a

weekend, inspired by a theme. Against this cultural backdrop, this phenomenological account describes one particular game jam during which a group of game designers harnessed gamemaking as a novel cathartic tool. They rendered their autopathographies—autobiographical narratives of illness and disability—into computer games. The lived experiences informing their design processes include bipolar disorder, anxiety, depression, post-traumatic stress disorder, attention/deficit hyperactivity disorder, colour blindness, grief, shyness, bullying trauma, and insomnia.

As the principal investigator, I organized this Autopathographical Game Jam as an ethics-approved, qualitative study informed by grounded theory and arts-based methods—a maker space involving 13 recruited participants (10 male, 3 female game designers) making autopathographical games. Informed by semi-structured interviews and design drawings/doodles, I argue that participants mobilized a four-dimensional therapeutic making process, which comprise my analytic framework of the Tetrad of Therapoiesis. This tetrad consists of four dimensions of what I call—sociopoiesis, autopoiesis, fabulopoiesis, and logopoiesis—, which together configure the game jam as a healing maker space. Sociopoiesis is a poetics of community—a collective making of sharing illness narratives similar to a therapy support group. The intimate social encounters of sociopoiesis structured the game jam experience as a divine form of being-with others. Autopoiesis is a poetics of self—a contemplative self-making that regenerates selfhood. In autopoiesis, the designer and their fictional characters co-construct each other in the process of creation. Fabulopoiesis is a poetics of narrative—a metaphorical making through the game’s playable story. Mapping structural similarities between their first-person experiences and the digital game through analogical reasoning galvanized the imagination and cultivated self-understanding. Participants fabulized themselves, reimagining their illness narratives through game characters such as a spirit guide inducing sleep, a detective seeking to understand psychological trauma, and an ADHD diagnostic test qua playable musical instrument. Logopoiesis is a poetics of mathematics—a calculated-making that quantifies the self through programming and notation. Participants used logopoiesis as an emotional coping technique and distancing device for imparting self-clarity and self-assurance. The gestaltic alternation among these four dimensions of therapeutic making allowed participants to shift among the relational locus of sociopoiesis, the subjective locus of autopoiesis, the interpretative locus of fabulopoiesis, and the analytical locus of logopoiesis, which together engendered well-being.

Media discourse often frames video games through the lens of moral panic, vilifying them as morally-bankrupt escapism that contribute to aggressive social behaviours and addictions. This theorization shatters cultural stereotypes of video games by offering a counterintuitive telos of game-making as a transformative personal and social praxis. The tensions of the Autopathographical Game Jam are cogently revealed in the game designer’s impulse for selfexperimentation in actively and unflinchingly confronting lived experiences with illness and trauma. Contrary to popular myth, the Autopathographical Game Jam is a personally-fraught and transgressive maker space that counteracts the cultural trope of ‘safe spaces’ as risk-free zones of identity construction.

Pin-chia Feng. “Against Apathy: Empathetic Storytelling and Narrative Medicine in Final Exam.”

Professor, Department of Foreign Languages and Literatures; National Chiao Tung University, Taiwan

In the final chapter of Final Exam: A Surgeon’s Reflections on Mortality (2007), Pauline W. Chen recalls how she begins to write after her eighty-third organ procurement. Before her encounter with the body of the thirty-five-year-old Asian American woman, Chen in her transplant fellowship regularly “harvested” organs from brain-dead patients and felt assured about her own “immortality” after operating on more than sixty donors (197). The color and shape of the young woman’s breast unexpectedly invoked in Chen a sense of affiliation— “It was as if I were standing naked after a

shower, looking into mirror," as Chen puts it (200). In her "confused, sleep-deprived state" Chen felt that she was pulling apart her own flesh and that the woman was alive (201). The uncanny and unexpected moment of identification of Chen with the anonymous donor offers a literary, and most intimate, representation of confronting mortality for medical practitioners. The profound exhaustion resulted from "sleep deprivation, overwork, and an unbearable, unspeakable grief" Chen experienced after the operation further illustrate the intensity of the psychological impact (202). In fact, Chen's memoir provides numerous cases in which she feels helpless and depressed when faced with the deaths of her patients. Chen, like many medical professionals, started her medical career with the goal of helping people, only came to realize that "[d]eath, more than life, would become the constant in our lives" (6). Chen's affective identification with the Asian American donor seemingly affirms the importance of distancing the self, of separating "the emotional self" from "the scientific self" in practicing medicine (8). However, in her introduction Chen comments on the inadequacy of the "lessons of denial and depersonalization" at medical school in preparing physicians to care for the dying patients and their families, which for Chen is the true "final exam" for doctors (xiii). By punctuating her first-person narratives with supportive documents from sociology, medical history and anthropology, Chen adopts a hybrid form to challenge the enforced separation of the emotional and the scientific. Chen also infuses an element of ethnicity into her memoir by constantly alluding to the influence of her Taiwanese American family and cultural background on her medical career. This paper will analyze the multiple layers of life writing in Final Exam, especially how in the mode of empathetic storytelling Pauline Chen affectively represents her *bildung* as a surgeon and an advocate for reforms in medical education to practice her ethnically informed version of narrative medicine.

Bio:

[150 Words Max.]:

Kathleen Frazier. "Sleep and Trauma: Using Graphic Medicine and Narrative Medicine Toward Trauma Informed Recovery from Disordered Sleep."

Columbia University in the City of New York MS Candidate in Narrative Medicine

Sleep & Trauma is the capstone for my MS Narrative Medicine Program at Columbia University. It will be a graphic medicine narrative, an anthology of comics, about the debilitating effects of trauma on sleep and thereby on every aspect of one's life. Sleep deprivation adversely affects our physical and mental health, our safety, and productivity. Disordered sleep as an effect of trauma is underrecognized and under-researched. Sleep & Trauma will include varied participants' experiences and share potential strategies for advocacy and service delivery, both key components in influencing change. Why a graphic medicine narrative about sleep and trauma? In the last decade, the field of graphic medicine has been highlighting the role that comics can play in the study and delivery of healthcare. Graphic narratives are becoming more prominent as medical education texts. Narrative medicine includes the intersection between art, health and social justice. Might a graphic illness narrative use the art of comics to place long overdue attention on the link between trauma and disordered sleep? Might it raise awareness and empower marginalized voices who may struggle to be acknowledged in healthcare settings? Both trauma and disordered sleep are less visible health concerns and frequently go undiagnosed by clinicians.

Attentive listening and narrative humility are essential in witnessing stories in narrative medicine. Central questions for consideration here are: how to ethically represent another's story? What methodology would best serve participants – perhaps oral history interviews? Who will create the graphics? Might they originate from reflective writing/drawing during interviews? Recovery from my

own experience of twenty years of sleepwalking, night terrors, and insomnia as symptoms of intergenerational trauma includes the use of theater, writing, and art, and continues to be a revelatory and transformative experience. How might contributors to Sleep and Trauma benefit from being witnessed and from creating art?

Bio: Kathleen Frazier is a candidate in the Narrative Medicine MS Program at Columbia University in the City of New York. She is an actress, writer, artist, and sleep activist. As a sleep activist, she advocates for healthy sleep as a basic human right. Kathleen is on the vanguard of raising awareness about the inextricable link between trauma and disordered sleep. Her memoir, *Sleepwalker: The Mysterious Makings and Recovery of a Somnambulist* won the 2017 Independent Publishers Book Award for Best First Book Nonfiction. She blogs for *Psychology Today* and lectures widely on the topic of sleep and trauma. For her spring 2020 capstone, Kathleen is creating an outline and first draft of a graphic medicine narrative, an anthology of stories, about the debilitating effects of trauma on sleep. The narrative will share potential strategies for advocacy and service delivery, both key components in establishing a discipline-wide profile to influence change.

Dana Gage MD MS. “Can the techniques of narrative medicine help?”

NYS Department of Corrections and Community Supervision

A Middle-aged woman meets with her orthopedist to discuss the results of her latest MRI. She has had pain in her low back radiating to her right leg. They have built a rapport and he did not hesitate when she called, to schedule it. He trusted her judgement. She trusted his expertise. During the MRI there was a prolonged pause. That pause was further elaborated when the patient, also a physician, heard the final words from her orthopedist: "You also have two large pelvic masses. They are suspicious for malignancy. You need to take care of them before we worry about your back." The middle-aged woman physician arranges to see an oncologist and a surgeon, both strangers to her. Her disease is a stranger as well. How might she build, or help to build enough rapport with these strangers who will try to cure her? How can she help them want to do their very best? Can the techniques of Narrative Medicine help?

Bio:

Dr. Aleksandra Glos. “The art of mind-changing – solidarity in dementia care.”

University of Krakow

Many studies, across various disciplines, have confirmed that artistic and cultural programs can significantly improve the experience of persons with dementia. While drawing on this data, this paper will take a different angle. It will ask what lessons art practiced in the context of dementia care can teach us, as thinkers, carers, policymakers, friends and all those with the interests of people with dementia at heart. I will then argue that these lessons are three-fold: firstly, they teach a strikingly actual lesson on the contemporary theories of rationality; secondly, and most importantly, they are a valuable lesson about what we owe each other, about the meaning of solidarity, citizenship and the fundamental features of a decent society, and thirdly, they give an unusual insight into the theory of art and its meaning in the constitution of solidarity. All of these arguments amount to the conclusion that social practices of solidarity can be salutary both to persons with dementia, and also to the paradoxes of contemporary healthcare and some of the maladies of today's society. Fulfillment of the duties of solidarity (for example, by introducing participatory art programs in dementia care settings)

does not require high financial expenses. It does, however, require a lot of moral imagination, which this paper advocates for.

Bio:

[150 Words Max.]:

Sheila Grandison. “Group viewing of modern and contemporary art objects in the education of mental healthcare professionals: an NHS-Tate training initiative.”

East London NHS Foundation Trust and City, University of London.

The public galleries of Tate offer a unique social space for collective and participatory learning. Numerous, but often short-term, projects have looked at implementing a creative, arts-based component into the practice of healthcare professionals¹, with clinicians reporting a link between creative practice and more compassionate, emotionally responsive care. How?

A long-term East London NHS partnership with Tate has delivered highly participatory training workshops in front of artworks at Tate Modern and Tate Britain with adult users of mental health services, ward-based nursing staff, specialist psychiatric registrars and consultant psychiatrists, with the aim of developing skills within everyday practice for relating to and engaging with adults with a range of communication difficulties in more creative ways.

Significant in the changing landscape of museums and galleries since the 1990s is the role of adult group visits. This presentation seeks to explore the wide-ranging engagement of new adult audiences within museum and gallery contexts where being in a group is central. In an increasingly individualised world, museum and gallery visitors report the value of looking at art objects as a group activity. What is it about group viewing that is so powerful? How can the group observational and conversational dynamic be captured in ways that inform both reception theory and the delivery of healthcare? What happens in the group?

As part of the partnership’s on-going research into conversations in the gallery, some of the processes at work when voices come together and are held in dialogue about contemporary art will be explored through a sample of NHS-Tate workshops delivered in the period 2012-2019, including: Drawn to Dialogue,² and the related day-long event entitled ‘What Made Sense?’ with adults with a range of communication difficulties, and Space! 2016, with members of the Royal College of Psychiatrists. The presentation will end with an in-depth case study from the Creative Approaches to Compassionate Care series of workshops for nurse development, based on the exhibition of work by the contemporary artist Jesse Darling: ‘The Ballad of St Jerome’ at Tate Britain, 2018-2019, when the three words resilience, vulnerability and control were used as prompts for engaging with the artworks. Engagement in this context shows how the group, and the space we offer, can create change in language, attitude and thinking with the work of artists as the bridge.

References

¹ All Party Parliamentary Group (APPG) (2017) Policy Briefing: The Role of Arts and Cultural Organisations in Health and Wellbeing’.

² Fuirer, M, Grandison, S. (2012) ‘Drawn to Dialogue: Nouns and Verbs’. Engage, 30, Special Issue: Arts and Healthcare, Summer, pp. 86-98

Bio: Sheila Grandison is an art psychotherapist (Goldsmiths) and group-analytic group supervisor (IGA). She is currently Training & Development Lead for Arts Therapies, East

London NHS Foundation Trust, and Visiting Lecturer, School of Health Sciences, City University of London.

Dr. Julia Hitchcock. “Effectiveness of using art and design in Health Applications to improve Hypertension and Diabetes Health Literacy in India.”

Associate Professor of Art; Baylor University

Integrating artistic research with scientific exploration and scientific analysis provides a scaffolding for expanding visual nomenclature and formation of new experiential global health learning. Metaphor and analogy are critical components of health research and share important artistic research in under explored areas of “research connectivity.”

- *human communication: increase understanding by reducing the complexity of healthcare information making usable the complexity of scientific information in objective measurements*
- *behavior modification and behavioral characteristics: develops a linkage between personal health assessment, scientific knowledge pertaining to the human body and wellbeing, opening up new applications and realms of mediated experience relying on science and cultural investigation*
- *amplification of negotiating discourses: place, language, culture, environment and health technology interface and how this shapes the way scientists conceptualize, undertake and interpret their research*

Health gaming app animated educational videos on hypertension and diabetes are used for data collection through explicit query and patient observation in the D J Hali Slums and rural communities in Bangalore, India (2017-2019). The apps facilitate replication- health workers can educate communities in more efficient and engaging methods. The user interface places the targeted communities in a social space, sharing in the embodied experience and creating virtual witnessing –i.e. production in a user’s mind of an image of narrative scenes where context is more easily understood. This process of group witnessing is increasingly relevant in communities where societal norms are controversial, gender prohibitive or scientifically misinformed. It demonstrates that when vital health information is effectively replicated by animation screening it allows for a much wider social engagement in the understanding of preventative healthcare practice.

Data collection for socio demographics and pre and post-test questions animation are built into the app structure. Data tracks changes in understanding and modification in personal healthcare. Data is the evidence of a residue of artistic engagement not in its purest art form but data is evidence that art exports knowledge into unlikely spaces and disciplines.

Bio:

[150 Words Max.]:

Ji-Ching Hsiung. “Arrowsmith and the Arts as Social Practices.”

Assistant Professor; Chung Jen Catholic Junior College of Nursing

Published in 1925, Sinclair Lewis’s Arrowsmith is the first American novel that concerns a medical researcher. The author declares in the preface that the book is a fictitious tale whose bacteriological and medical components came predominantly from a real medical doctor named Paul H. DeKruif. Lewis is inviting his reader to imagine the world he projects in his work of fiction, a world both distinct from and related to the actual world. One consensus view on the work in question is that

through his way of writing, a combination of realism and satire, Lewis rails at unscrupulous things about American society in general and the medical profession in particular. As Nicholas Wolterstorff indicates in his Art Rethought, "Emotional engagement on the part of the reader with events and characters in the projected world of the novel, and moral judgement on them, are crucial components in how novels can and do serve the cause of social justice" (213). Using Wolterstorff's concept of the arts as social practices, this paper argues that Lewis and Dr. DeKruif turned real life events into an absorbing novel with a view to eliciting emotional and moral responses to the fictional characters and, on the strength of transference, empathy with fresh-and blood victims of amoral behaviour in the actual medical world. Martin Arrowsmith, the protagonist of the novel, aspires to be a phlegmatic scientist like his mentor Max Gottlieb. However, as the book progresses he moves toward the sentimental side and relents in the end, hoping to save more lives. Coined by C. P. Snow, the phrase "two cultures" denotes that there have long existed a science side and a humanities side in high culture in the West. The novel seems to embody an attempt to eliminate the tension between the two cultures, especially medicine and literature, and works of the arts are evidently not useless in the projected world.

Bio:

[150 Words Max.]:

Eugenia S. Kim. "Lithium Hindsight 360: Narrative, Empathy and Somatic Movement in a Virtual Reality Environment."

PhD Candidate; City University of Hong Kong

The word "mental illness" often brings to mind a condition that takes place internally in the mind. Yet the reality is that mental illnesses are often accompanied by physical symptoms. Depending on the specific condition, a patient may feel symptoms in their bodies or show them through their body language. This is in contrast with symptoms that are experienced as modifications in vision and hearing. One such condition is bipolar disorder as patients may or may not experience aural and visual hallucinations. Lithium Hindsight 360 (LH360) is a VR experience prototype that uses contemporary and somatic movement to describe a non-hallucinating patient's experience with bipolar disorder. It is meant to show other patients a potential way for them to share their own experiences with illness through motion capture of body language and reactions. The choreographic process draws upon the Life Art Process, Authentic Movement and Contact Improvisation to structure a movement narrative. This narrative is then mapped to 3D animation in an immersive environment. The overall goal is to provide an anonymised non-confrontational environment where patients can share their stories with family and friends. Two issues of importance are whether empathy is achievable through this technology and the balance between truth and dramatisation in storytelling. At this point in time the author concludes that for bipolar disorder, only a deep sympathy can achieve as each patient has a unique experience. From an aesthetic perspective, this means that an illness experience may not look or feel very sophisticated. This raises a necessary conversation about the sensationalised portrayal of mental illness in the arts and media. While a patient's experience sometimes coincides with the expectations of the general public, the truth may be more subtle than expected.

Bio:

[150 Words Max.]:

Stephen R. Latham, JD, PhD. "What is a beautiful death, and does morality demand one?"

Director, Yale Interdisciplinary Center for Bioethics; Yale University

*This paper will use Nicolai Hartmann's theory of high and strong values—a theory that has entered the mainstream of analytic aesthetics via the aesthetic writings of Aurel Kolnai, among others—to try to define some characteristics of a beautiful death, and to explain (using some well-known facts about how and where people in contemporary developed nations die) why it is difficult to achieve a beautiful death in the current context of intensive medicalization of the dying process. Along the way the paper will consider the application of other ideas well-known conceptions of beauty—Dewey's, Santayana's, Moore's, Sartwell's, and Nehamas's—to the idea of a beautiful death; though these applications will be fairly brief, and more suggestive than thorough. The final portion of the paper will build on work by Sophie-Grace Chappell and other contemporary ethicists to try to establish at least a prima facie duty of caregivers to help their loved ones achieve a beautiful death. The idea of an aesthetically beautiful death has emerged in several different periods in the West. The beauty of the physical corpse is important in Homer; both sublimity and beauty were celebrated in the early Christian ideal of martyrdom; the beauty of the deathbed scene was a powerful motivator to American Puritans; the beauty of Romantic suicide swept Western Europe as an ideal after the publication of Goethe's *The Sorrows of Young Werther*. This paper argues for a revived appreciation for the potential of death to exhibit aesthetic beauty, and argues further that an ideal of beauty is both better justified than, and would serve the dying and their families better than, the contemporary ideals of battle and war that seem to characterize medicalized death.*

Bio:

[150 Words Max.]:

Lynn Sara Lawrence, MS, MSW. “While Strolling Through Vuillard’s Garden at Vaucresson I Stumbled Upon A Family Secret.”

Narrative Medicine Program, Columbia University

This paper describes the unfolding of a co-construction between viewing Vuillard’s Gardens at Vaucresson and the author’s internal experience of a family secret hidden in plain sight provoked by the painting. An initial mood of feeling beckoned into this lush, quiet morning was dispelled by a reading of the adjacent plaque identifying a figure in the foreground that she had missed. Her mood abruptly changed. The author felt like a voyeur. The theme of camouflage in art and the author’s biography had co-mingled. It was not until writing this event that the trauma was “represented” in a multi-faceted way. The author’s point of view shifted, enlarged. Now inside the frame, she was the hidden figure obscured in the background. Time conflated and the artwork from long ago became the present moment.

This paper will demonstrate that art because it is so evocative, and yet so undemanding, has the power to evoke memory, a useful tool in working with all populations, and that writing gives shape to what was previously not metabolized. Principles paramount to narrative medicine are discussed, primarily intersubjectivity, co-construction, temporality, representation and writing as discovery.

No painting is complete without the viewer’s reaction to it. Tracing the long arc of the “Beholder’s Share” with a close reading of the Garden at Vaucresson enables the author to not only to uncover a secret in her own life, but in the painter’s life as well, as their biographies intersect around what is hidden.

Narrative medicine pays close attention to close reading of texts. Dimensions of time and mood are critical. Ironically although the author is a psychotherapist, it was two art historians George Kubler

and Frank Ankersmit that gave her the needed insight to begin to decode the mystery of why the hidden Lucy made her feel so unsettled. This is tantamount to understanding Kubler's analogy between stars and works of art, both being portions of an "arrested happening". This is the link between the present in the past and the past in the present. Ankersmit's instruction to pay attention to one's mood when viewing a painting proved instrumental in helping her retrace the signposts leading to the "do not see this" of the past.

In addition the work of Daniel Stern, specifically "The Present Moment" focuses on the moment of "now" and with it the co-construction that occurs between two people, even if one is in a painting, and the other the viewer.

Bio:

[150 Words Max.]:

Viktoría Lloyd-Barlow. "Autoethnography of an Inarticulate Subject:¹ Transgressing the Neurotypical Narrative."

PhD Candidate; University of Kent, School of English

This paper challenges the current dichotomization of autism and narrative, approaching the subject in two stages. Firstly, the work deconstructs the medical and cultural processes that have augmented the problematisation of ASC and literature. An inability to engage with narrative discourse (or creative storytelling) is central diagnostic criterion for autism; a perceived impairment in understanding or generating fiction, therefore, is a fundamental indicator of neurological difference. The restricted social-emotional, cognitive, and linguistic knowledge and abilities common to autism have been diagnostically linked with an impaired ability to share understandings of events and experiences through narrative.² Studies have also reported an atypical inability to reference mental states in narrative³ thus linking theory of mind impairments to narrative incompetence.⁴

The imposed medical model of autism is literal and incompatible with creative narrative; '[Imaginative creativity and metaphor are] ... considered outside the scope of any individual with autism.'⁵ The positioning of autistic comprehension as fixedly literal rejects the autistic's ability to engage intelligently with central aspects of successful fiction, such as metaphor and analogy. Yet storytelling benefits the universal human need to foster social understanding and interaction. Writers typically agree that narrative promotes and teaches empathy, thereby alleviating issues associated with Theory of Mind impairments; 'The purpose of story – of every story – is to help us interpret, and anticipate, the actions of ourselves and of others.'⁶

Neurotypical people in social situations tend to respond intuitively, while for the autistic person, interaction with others is more likely to be consciously enacted on the basis of previous experience and intellectual knowledge. Well-crafted narratives are typically a more reliable resource in this context than social experience, as the second part of the paper demonstrates. Literary works are evidenced individually as textual provision for the atypical framing of normative behaviours. The autistic navigating the atypical world exists, foremost, creatively; he must constantly frame and interpret his experience. Atypical social interaction requires applied, rather than instinctive, context and this lends itself to literature as a framework of translation. The utility of narrative is demonstrated in this paper through close readings; both classical literature and the speaker's own PhD fiction are used as functional models for social translation. Work from the latter is also used to confirm the suitability of literary narrative for an autistic protagonist. Fictional autistic experience, such as overwhelming sensory issues, are authentically expressed within passages of this first person, linear text. These examples adhere to the thesis that is not the narrative structure itself which

prohibits atypical engagement; such exclusion is not constructed in language or form but is a medical and cultural process.

References

¹ 'Inarticulateness ... originates with restricted language skills but is generally overlaid by other factors including a lack of self-esteem, learned habits of compliance, social isolation or loneliness, and the experience of oppression.' Booth & Booth, 2010

² Bruner & Feldman. 1993; Capps et al.; Loveland et al; Loveland & Tunali, 1993.

³ Baron-Cohen, Leslie & Frith, 1985; Tager-Flusberg, 1992.

⁴ Losh & Capps, 240.

⁵ Murray, Stuart. Representing Autism Culture, Narrative, Fascination. (Liverpool: Liverpool University Press, 2008). Ebook. P16.

⁶ Cron, Lisa. Story Genius. (New York: Crown Publishing Group, 2016). P16.

Bio:

[150 Words Max.]:

Prof Ian Sabroe and Dr. Chris Millard. "Clinical experience and things not said, as revealed by study of narrative."

Prof. Sabroe: Professor of Inflammation Biology; University of Sheffield

Dr. Millard: Lecturer in the History of Medicine and Medical Humanities; University of Sheffield.

Clinical practitioners engage in a career that is associated with high levels of burnout, stress, and psychiatric morbidity. A fixed notion of clinical identity engenders behaviours that resist an open discussion of psychological stress. Medical learning teaches specific patterns of information gathering and sharing, such as the clinical history, and through established patterns of behaviours drives a social structure and specific clinical identity. Clinicians rarely realise the extent to which their identity is shaped from early experiences by powerful stereotypes, and by cornerstones of medical education that frame understanding of illness and clinical identity, such as the simple but powerful tool of the clinical history.

The study of narratives written by clinicians is revealing, both for what is said and what is not said. Such narratives often use case stories to illustrate key points, presented in a structure akin to that of a clinical history used in medical information collecting. Narratives typically describe a deep conflict with a lawless, uncertain and unpredictable world in which the practitioner lacks sufficient tools to meet need, and where financial and organisational factors further compound a perceived ability to deliver care. Compelled by altruistic philosophical models, conflict between ideals and practicalities becomes evident. Nowhere is this more obvious than in the discussion, or lack of discussion, of physician failures. Such failures include the inevitability of error and the nature of human fallibility, and perceived personal failures such as insufficient resilience or problems with mental health.

Examining what is said and not said in clinical stories written over the last century, work presented here will examine the interactions between altruism, error, and cultural stereotypes of medical practice that generate particular problems around the handling of medical mistakes and perceptions of personal weakness or illness.

Bio:

[150 Words Max.]:

Elizabeth Mitchell, MD. "Will Reflective Writing Reflect Burnout During Residency."

Associate Professor of Emergency Medicine; Boston University School of Medicine, Boston Medical Center

Residency training is a grueling process, which can lead to feelings of burn out. Many medical students enter into residency with a sense of optimistic anticipation and enthusiasm about their career and clinical education. Hopefully, they also feel a strong sense of empathy and a desire to help others. For many residents the intense training, long hours, difficult cases, sleep deficit, and other stressors, may lead to depression, loss of empathy, personal and professional relationship conflicts, and loss of career satisfaction. These feelings may be demonstrated in their writing.

Hypothesis: Using a writing prompt repeated throughout residency, we will demonstrate shared changes of physician burn out that may occur in Emergency Medicine resident trainees.

We will ask residents to respond in a timed session, with written text, to two open prompts at the start of each residency year, beginning with internship and ending at the start of their 4th, and final year of training. The selected prompts are:

- 1. Being a doctor is*
- 2. I see my career choice now as*

After the writing period residents may share with their class what they have written. This will be on a purely voluntary basis. We will keep each returned response anonymous but will retain the ability to track respondents to follow the progression of changes that may occur in residents through their writing. We will perform qualitative analysis of the written text coding for common themes. This approach is different from current quantitative surveys to assess burnout in that it may provide themes to better address symptoms of burn out as well as pinpointing areas in training where these changes occur. This will allow for early and more focused intervention.

Bio:

[150 Words Max.]:

Dr. Ivan Nenchev and Benjamin Wilck. “Linguistic and Philosophical Problems with Psychiatric Metaphor Comprehension Tests.”

Dr. Nenchev: Assistant Professor; University of Medicine Berlin

Wilck: Doctoral Candidate; Humboldt-Universität zu Berlin

Our paper exposes inconsistencies in recent psychiatric literature on figurative speech comprehension, focusing on metaphor comprehension. Both psychiatric diagnostics and research employ figurative speech comprehension tests to determine the test person’s ability to understand figurative speech. The inability to understand figurative speech, which commonly counts as a symptom of schizophrenia, is called “concretism”. We argue that the psychiatric metaphor comprehension tests used in psychiatry to determine metaphor miscomprehension are committed to linguistically and philosophically contestable background assumptions. Especially paraphrase tests imply a sharp distinction between literal and metaphorical meaning and, in particular, the view that metaphor comprehension consists in the ability to paraphrase metaphors. Moreover, they presuppose that healthy people effortlessly and intuitively understand metaphors, which implies that failing paraphrase tests indicates mental disorder. Against this we argue that while metaphor miscomprehension might well indicate mental disorder, failing paraphrase tests does not demonstrate metaphor miscomprehension, after all. By identifying linguistic and philosophical difficulties with the underlying understanding of metaphor in the reviewed psychiatric literature

(altogether 295 studies), we suggest to revise the testing procedures currently in use. The main claims of our paper are the following:

- i. *The psychiatric tests for concretism currently in use fail by relying on linguistically contestable background assumptions.*
- ii. *Many of the psychiatric metaphor (or, more generally, figurative speech) comprehension tests currently in use are even inconsistent with their own linguistic background assumptions.*
- iii. *Especially the psychiatric metaphor paraphrase tests, which constitute the dominant variant of psychiatric figurative speech comprehension tests, fail to show what they are supposed to show. That is to say, psychiatric metaphor paraphrase tests are not sufficient to detect concretism in the proband.*
- iv. *Insofar as the correlation between schizophrenia and concretism is established on the basis of metaphor paraphrase testing procedures, the commonly held view that concretism is a symptom of schizophrenia is not justified (even though it might well be true).*
- v. *There is a philosophical way to save psychiatric metaphor paraphrase tests from being abandoned. By appealing to contemporary philosophical research on metaphor, we suggest a modified psychiatric metaphor paraphrase test for concretism, which does not fall victim to the same linguistically contestable background assumptions as the standard paraphrase tests.*

Besides providing a showcase for the application of philosophy of language in clinical research and diagnostics, the present research project contributes to a better understanding of the linguistic features of schizophrenic patients.

Bio:

[150 Words Max.]

Nealie Tan Ngo. “The Body Issue: What Global and Historical Perspectives of the Ideal Female Body Can Teach Us About Our Own Present-day Bodies.”

Second-year medical student; Yale University

Poor body image is currently a worldwide public health crisis disproportionately influencing women and girls, and its effects are reaching children as young as primary school. This issue is compounded with the rise in social media and the Westernization of beauty ideals around the world. However, poor body image is more sinister than just not feeling happy with the way one looks: physical bodies are social bodies, and beauty is linked to our perceptions of health, wealth, power, and overall success, which affect women’s overall views of their capabilities, strengths, and worth. Therefore, we must re-evaluate how we see, treat, and think of our bodies. History can be used as a tool to help expose ideals of women’s beauty as arbitrary, and this suggests fluidity and subjectivity of the very notion of perfection.

The Body Issue: What Global and Historical Perspectives of the Ideal Female Body Can Teach Us About Our Own Present-day Bodies is a graphic novel that explores the cultural and social factors influencing female body image and aims to be an entertaining, educational tool for teaching history and medicine. Drawing from historical and contemporary sources, such as advertisements, magazines, and body satisfaction surveys, as well as personal experience, the author tries to understand the overemphasis on women’s physical appearance. The graphic novel narrates the stories of four different historical societies: Tang Dynasty China, the Efik people, Victorian England,

and Sparta, comparing and contrasting them to each other and modern American day society. Education about this history and its influence on women's and girls' identities, self-conception, and health can promote open conversation and, perhaps, change for the better how parents talk to their children about their bodies. The graphic novel aims to help readers understand how social and cultural factors can impact body image and recognize that even throughout history, no one perfect female body exists. Finally, the graphic novel also invites readers to consider bodies as a means to individuality instead of assimilation, and decide for themselves the terms on which they'd like to think about their own bodies in diverse social, cultural, and ever-changing environments.

The author wrote and illustrated this graphic novel for her senior project at Yale University, where she graduated in 2018 with a B.A. in the History of Science, Medicine, and Public Health. The novel received the Yale Martin Klein and George Rosen Prize (awarded to the most outstanding senior essay in history of science/medicine) and has been featured in the 2019 University of Toledo's Health Science Campus Artist Showcase and on the Yale Medical Historical Library's Instagram. Certain portions of it will also be published in an upcoming edition of the AMA Journal of Ethics.

Bio:

[150 Word Max.]

Tom Grey; Prof Desmond O'Neill; Dr. Hilary Moss. "Aesthetics and healthcare spaces: from theory to pragmatics."

Grey: Research Fellow; Trinity College Dublin

Prof. O'Neill: Consultant physician in geriatric and stroke medicine and Professor in Medical Gerontology; Tallaght University Hospital and Trinity College Dublin

Dr. Moss: Course Director, MA Music Therapy; Irish World Academy of Music and Dance, University of Limerick

Hospitals are often aesthetically deprived environments (Moss and O'Neill, 2014). Few hospitals give attention to aesthetics and beauty within hospital spaces (Caspari et al., 2011) but evidence is growing of the benefits of the arts on health, well-being and recovery. It is arguable that everyday aesthetics are more important than high art. This symposium will present an overview and two original research projects at a Dublin teaching hospital, the first focusing on dementia friendly hospital design and the second reporting on research as to the role of the arts in hospital spaces and as a vehicle for service user narrative. The presenters will reflect on practical and academic experience in the field of aesthetics and hospital, and in particular focus on the importance of teasing out the aesthetic, leisure and cultural preferences of patients, visitors and staff, as well as curatorship (Moss and O'Neill, 2019). The elements of design will focus on the synergies and tensions between form following function and frozen music (Grey et al., 2017) and outline the engagement of clinicians and architects in promoting clinicians for design (Anderson et al., 2018).

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Bio:

[150 Words Max.]

Marianne R. Petit. “Sharing Secrets: Our Hysterectomies.”

Associate Arts Professor; NYU

It began with a simultaneous post to Instagram and Facebook. In 2017, I underwent a total abdominal hysterectomy, and upon waking up from surgery I felt surprisingly well. While I am typically rather private, I decided to be open about this. I had access to good health insurance, excellent medical care, and the support of three work communities—privileges many women don’t have. I felt no reason to remain silent other than a sense of shame brought on by a cultural stigma that I wouldn’t have had my appendix been removed instead. And so, in an uncharacteristically public political act, I posted an image of myself from the hospital on social media. The outpouring of support was overwhelming, but even more surprising, 17 women I knew reached out to tell me that they had been through the same thing, some only weeks earlier.

I was stunned and began to reflect on the discomfort and silence that surrounds hysterectomy when according to the Centers for Disease Control, hysterectomy is the second most frequently performed surgical procedure for U.S. women of reproductive age. Approximately 20 million American women have had a hysterectomy, and approximately 600,000 procedures are performed each year. Still, no one likes to talk about it.

I believe strongly in the creative expression of individual stories and see personal narrative as a platform for generating empathy and compassion. The sharing of our stories can be deeply uncomfortable, but the courage of one’s truth can also give us the capacity to hold another person’s story while safely reflecting on our own.

As a result, I created an anthology entitled “Our Hysterectomies” (2018), an eBook containing the illustrated first-person accounts of 16 women who have had hysterectomies, oophorectomies, myomectomies, and more. The downloadable book also contains animation, as well as printable DIY papercraft. Developed with an intention to increase awareness and support women’s access to healthcare services, the book was first made available as part of a fundraising campaign wherein all donations went directly to Planned Parenthood and all supporters received a copy of the eBook, regardless of donation amount. The book, as of September 1 2019, is now available to all as a free download.

This 20-minute presentation will present the creation of the project, discuss participant experience, review the range of storytelling, and outline next steps.

Bio:

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Dr. Rebeca Pardo Sainz. “Illness visual narratives: aesthetics and ethical questions.”

Faculty of Communication of the Universitat Internacional de Catalunya (International University of Catalunya)

The ongoing research project (2019-2021) “Visibilizing pain: illness visual narratives and storytelling transmedia” analyzes how illness visual narratives have changed its aesthetics and modes of

representation during the last 40 years, especially since the appearance of digital photography and the Internet.

Classic visual representations of illness were authored by professionals of medicine or journalism and showed the worst face of illness, the most dramatic cases and the hardest institutions as mental asylums. Those images were frequently published to denounce some critical situations that contributed to change as it happened in Italy with Depardon the antipsychiatry movement. Nevertheless, they also contributed to create the stigmatizing iconography that represent some illnesses and patients as dangerous, antisocial, violent, isolated and de-humanized.

In this context, the emergence of Internet and social media has empowered caregivers and patients giving them access to their own public representation. Their Self-referential images are especially important as they are trying to fight for awareness and social changes sharing their daily life not only as patients but also as social beings. These photographs are mainly shared in Social Media, but they are also present in Photojournalism, art and even in advertising. The family and domestic images contribute to improve empathy with patients and caregivers as they connect with spectators by what Marianne Hirsch call "Affiliative look".

It can be said that self-referential photographs and visual arts, autobiographic documentaries and graphic medicine are configuring new practices and representations in which there is room for tenderness, joy and humor along with pain and drama. This constitutes a new visual movement ranging from popular media to fine art or mass media that is changing the international iconography of illness based on the aesthetics of everyday life and contribute also to the creation of a new kind of communities online that favor encounters and exchanges between peers without prejudices.

These daily images can be understood as more honest with the patient's and caregiver's reality since they come from a greater number of diseases, illnesses and even (dis)abilities, from different countries, cultures and religions. These new practices are democratizing the representation of pain and medical/health questions contributing to the illness and medical narratives, the medical humanities and the health communication with new approaches to education, information, expression and healthcare.

On the one hand, self-referential images are humanizing and contributing to normalize the public image of certain groups and diseases/illnesses that have traditionally been represented linked to social isolation, violence and marginality. On the other hand, the new representations of illness, for example those that follow the tendencies of fashion selfies, also raise interesting ethical questions because of the connections established between some controversial contemporary beauty canons and illnesses/diseases.

This paper proposes the analysis of the illness visual narratives aesthetics, which vary depending on the type of illness or patient portrayed, and the main changes in their representation during the last 40 years outlining the main ethical dilemmas that the encounter between aesthetics and illness/disease representation poses in medical humanities and health communication.

Bio:

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Margarita Saona. "Vital Signs: The Literary Genres of Infirmity."

Professor of Latin American Literature; University of Illinois at Chicago

Confronted with a terminal diagnoses, a chronic illness, or a near-fatal experience, many patients take to the written word, creating texts in a variety of genres: journals, poetry, blogs, or memoirs, each genre offering specific ways in which to process the physical and emotional demands of a gravely sick body. The rhetorical and aesthetic resources offered by these genres provide patients with a deeper understanding of their condition. While some genres serve as an appropriate medium for discussing symptoms and treatments, others are more likely to provide a space for the writer to elaborate on the sudden awareness of their own mortality, and others still offer a way to playfully explore the illness metaphors so common in both ordinary speech and medical discourses.

Some patients write because they want to share their experience with others. Some write to keep their loved ones informed of their situation. Some write because writing gives them ways to assert their agency in moments in which they feel disempowered by physical impairments. Some try to reexamine words made strange by the medical context.

I will examine works by Susan Gubar, Barbara K. Lipska, Gillian Schirrefs, S.L. Wisenberg, and Lila Zemborain, to discuss the way patients suffering from heart disease, multiple sclerosis, or different forms of cancer use essays, memoirs, and poetry to help them cope with the ontological distress of illness through language. My purpose is to investigate the rhetorical and aesthetic strategies they employ to communicate experiences that alienate them not only from others but also from their previous “normal” selves.

*In her autobiographical essay about writing fiction as a patient, Gillian Schirrefs explains, “As I write, I become not the object of a medical procedure but a subject equipped to interrogate such experiences by means of storytelling.” In her case, for example, fiction writing does not necessarily deal with her illness as a theme in the story, but issues of objectification surface as a result of her experience with the medical establishment. In Lila Zemborain’s poems in *Matrix Lux*, on the other hand, the incantation of words, the echoes of syllables decomposed, seem to want to exorcise malignant cells out of the body. Susan Gubar’s *Memoir of a Debunked Woman* elegantly discusses cancer metaphors while simultaneously exposing her own excruciating suffering.*

*Language and its literary forms provide a variety of ways for some patients to cope with pain and existential fear. A growing number of critical studies try to understand the way literature relates to our experience of maladies, from Susan Sontag’s classic *Illness as Metaphor* to Thomas Courser’s *Body Language: Narrating Illness and Disability*. I hope my work will contribute to an understanding of why and how patients use language to cope with their disease.*

Bio:

[150 Words Max.]

Ezra Schwartz. “The Early Medical Encounter.”

"M.D.,C.M. Candidate and M.S., Narrative Medicine; McGill University, Faculty of Medicine Columbia University in the City of New York

For better or worse, today’s access to—and saturation of—information shapes both private and professional behavior. If the pressure of patient flow limits a doctor’s visit to fifteen minutes, and the amount of time the average visitor to the Louvre spends with a work of art is ten seconds (including the time taken to read the label),¹ then the importance and influence of the early encounter is increasing. This research paper is dedicated to the first moment of the intersubjective encounter (with art or otherwise), that defined by the unconscious assessment a priori to conscious

interpretation, and its authority in the clinical encounter between doctor and patient. It is thus a valuable target for medical education.

*Simplified, the dynamics between observer and artwork occur in two stages. First, the observer's senses are attacked, indeed overwhelmed, by the work. Our adaptive unconscious uses reflexive techniques (e.g. thin-slicing as explained by Malcolm Gladwell in *Blink: The Power of Thinking Without Thinking*) to triage and resolve this information to a more manageable load. Because pattern collection, discovery, and comparison are under unconscious control, the question arises concerning accountability for snap judgments based on thin-slicing. However, if the conscious self studies the patterns that thin-slicing utilizes and our immediate reaction given these patterns, then the conscious self can predict—or at least become more accountable—for these judgments. In other words, the adaptive unconscious operates behind a locked door; by studying the door enough, peeking through the keyhole and cracks between door and the doorframe, one can still learn (a surprising) amount about the room behind.*

*Second, uncomfortable as the victim of a sensory attack, the observer responds by dominating the artwork through the act of interpretation. The influential—and politically reprehensible—20th century philosopher Martin Heidegger thoroughly explores this retaliation in his essay *The Question Concerning Technology*. Writings from the great thinkers Walter Benjamin, Gaston Bachelard, and Susan Sontag accentuate Heidegger's philosophical exploration and viewed together draw the conclusion that the observer's intellect and desire to interpret (both under conscious control) dissolve the uncertainty of the encounter by categorizing it into a comfortable system. Once we become attuned to this conscious power reversal, we can restrain the unconscious desire prompting the reversal and so maintain space in the intersubjective encounter.*

As visual art is a strong vehicle to discuss the theory behind the dynamics of the early encounter, it is also the appropriate method by which to coach medical students through the early medical encounter. Medical schools across the continent (most notably Columbia Vagelos College of Physicians and Surgeons, Weill Cornell Medical School, and the Humanities and Arts Club of McGill Medical School) have adopted close observation of visual art into their medical curricula and/or extracurricular activities to gain skills relevant to the clinical encounter.

References

¹ Findlay, Michael. *Seeing Slowly Looking at Modern Art*. Prestel, 2017. 81.

Bio:

[150 Words Max.]

Gillian Shirreffs. "Imagination and Storytelling: Tools to Help Navigate Life with Multiple Sclerosis."

PhD Student; University of Glasgow

*In this presentation I will examine the ways in which I have used imagination and storytelling to navigate twelve years of chronic illness, from multiple sclerosis diagnosis in 2007 to the third year of a PhD in creative writing. I will discuss my doctoral project in which I consider the relationship between object and illness by means of a novel, Brodie, and a collection of essays and images entitled, Subject-Verb-Object. The novel is narrated by an object (a copy of *The Prime of Miss Jean Brodie*) and spans 30 years. It begins with the eponymous narrator being given to Violet Munro as a gift for her sixteenth birthday and tells the interwoven stories of six women. I will explore the ways in which the novel seeks to function as a metaphor for the experience of life with multiple sclerosis. Brodie's experiences mirror something of my own: of the period of unwelcome intervention,*

confinement and oddness an MS relapse will inevitably bring. Hungry for information, Brodie is able to see, hear, smell, intuit and can communicate with other objects. The narrator is, however, limited in that she/he (Brodie has no fixed gender) cannot move unaided. This existence may be marked by limitation and a lack of control, but it is full and vital thanks to Brodie's imagination and keen interest in the lives and stories of others. In this presentation I will also discuss the way my doctoral project imagines into life three medical objects – a hypodermic needle, a medical plinth, and an MRI scanner – telling their stories as a means to interrogate the relationship between medical subject and medical object.

Bio:

[150 Words Max.]

Viswanath Swamy. "Portrait Photography – A Rehabilitative Tool."

MSc Candidate, Narrative Medicine; Columbia University in the City of New York

Medicine is an increasingly image-driven field. Conventional forms of images have been used for diagnostic, teaching, and progress purposes, such as those acquired from radiology or pathology. Although images have taken a foundational use by physicians, the potential use of imagery for patients as a means for medical therapy has largely been unexplored. At the Maison des Femmes in Saint-Denis, France, portrait photography is a supplemental activity that is offered for women recovering from rape or forced genital mutilation to assist them in reclaiming their bodies and identities. A portrait photographer captures the women's countenances and bodies over a period of time, allowing the women to directly engage in their recovery process. A central question, therefore, is whether the act of being photographed or the engagement with photographic images can act as a tool for listening and bear witness to a patient in various clinical settings. In other terms, can engagement with photography enhance mental and physiological rehabilitation beyond traditional medicine for patients recovering from life debilitating illnesses, sustained trauma, mental illness, or physical disabilities? This presentation intends to examine the use of portrait photography as a complementary tool for healing in clinical settings. In particular, this presentation will postulate if patients who engage with portraits of themselves over a longitudinal time-frame can enhance the rate and outcomes of recovery by increasing levels of self-awareness, body reclamation, personal identity formation, and emotional restitution.

Bio:

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Dr. Avril Tynan. "Layers of Forgetting: Detective Fiction and Dementia."

Turku Institute for Advanced Studies; University of Turku, Finland.

In Hemming Mankell's famous Scandinavian noir series featuring the fictional police inspector Kurt Wallander, the final book Den orolige mannen (2009; The Troubled Man, 2011) narrates a spy scandal set against the backdrop of the protagonist's memory loss, ultimately diagnosed as Alzheimer's disease. The loss of memory becomes intertwined with the unravelling of the mystery, so that the reader is drawn into the confused world of the protagonist and the narrative, forced to question each twist and turn. Although the polar, noir, or detective genre may seem at first incongruous with the representation of dementia – the first aims to uncover "what happened" through the gathering of clues and establishing of facts, while the latter is often considered as a fragmentation of the self, a loss of identity – the two interact in ways that enrich and complicate one

another, and the wide and typically accessible readership of crime fiction harnesses a valuable global vehicle for narrative understanding.

In this paper, I consider how the polar genre may present and enrich the portrayal and understanding of dementia. Detective fiction typically demonstrates a palimpsestic narrative form in which one story lurks beneath another, and the layering of lies, perspectives, and secrets presents a cautious back and forth across time and space, and from one character to another. Claire Gorrara has demonstrated the ways in which the French roman noir genre gains valuable insight through the structure of the palimpsest. The narrative presents the investigation as the superimposed overwriting of “what happened” that must scratch beneath the surface to uncover the truth, so that the text itself is composed of “two narrative sequences that simultaneously pull the reader back in time to reconstruct a missing story of crime and forward in time to follow the processes of the investigation”.¹ As the detective narrative unfolds, it delicately peels back the stories and histories of the mystery to arrive at a conclusive understanding. Alzheimer’s disease, in a similar way, can be perceived as an overlaying of current memories with earlier ones, where memories appear out of sync, or where one memory is “reactivated” (Dillon 2007: 2)² for reasons that appear incomprehensible to the onlooker. The dual sequencing of the detective genre may nourish an imaginative engagement with dementia, and with Alzheimer’s disease in particular, that helps the reader to empathize with the complex vacillations of memory that define instances of age-related memory loss.

I approach this theory from the perspective of narrative theory, suggesting that the empathic challenges faced by readers of dementia narratives may be facilitated through the lens of crime fiction. Rather than simply discussing how the two may interact from the perspective of content, I suggest that the narrative form and structure of detective fiction creates a hermeneutic tool for understanding Alzheimer’s disease. Ultimately, this genre may help us as a society to perceive of dementia as a complex and fragile unravelling – rather than a stripping away – that uncovers a core identity at the centre of personhood.

References

¹ Claire Gorrara, *The Roman Noir in Post-War French Culture: Dark Fictions* (Oxford: Oxford University Press, 2003), p.3

² Sarah Dillon, *The Palimpsest: Literature, Criticism, Theory* (London: Bloomsbury Academic, 2007), p.2

Bio:

[150 Words Max.]

Marjolein Uitham. “Illustrations bear comfort and relief.”

Master Art Education; Hanze University of Applied Sciences Groningen

Abstract

Purpose: *to examine what would be the advantage of using illustrations in the preparation of children before undergoing medical treatment and examine which criteria an illustration should have to be able to support the information provided.*

Methods: *Both literature study and field research has been carried out. In this study 22 children received a preparation for surgical treatment using illustrations. They received a questionnaire before and after the information provided. A survey was conducted among the pedagogical staff, nursing staff and the parents of the children in hospital.*

Results: *It has been found that especially young children indicate that they understand the illustrations better than the photos used in the same preparation. Older children indicated a preference for preparation with photos. An explanation for this could be that older children are further*

in their cognitive development, making them more skilled in logical reasoning. They are better able to handle abstract concepts such as heaven and death.

Conclusions: *It can be concluded with caution that the drawings and instructional illustrations used in the preparation have clearly visualized the information about the surgical treatment.*

Summary

Children have the right to know what will happen to them during a medical treatment. They have the right to information. It is the medical professional's responsibility to help them understand the information. This research project shows that the information that children receive about their medical treatment is not always understood. This information does connect with the cognitive development of the child, despite the use of photos and demonstration material. Illustrations can help their ability to understand. What is the advantage of using illustrations in the preparation of children before undergoing medical treatment? The objective of such an illustration when providing verbal or written information has been examined. In addition, it has been researched which criteria an illustration should have to be able to support the information provided. This study will contribute to the design guidelines for illustrations that can be used in the education of children. The used methodology consisted both literature study and field research. It has been found that an instructional illustration designed for understanding the insertion of a gastrointestinal tube is especially useful in the emergence room (ER). In such a situation there is little time for an extensive preparation for this insertion.

Bio:

[150 Words Max.]

James B. Wendt , MD. "The use of the role of Narrative in Hearing What the Patient Is Trying To Really Say."

Bronx VA Hospital and Clinics: Staff Physician, Adjunct Instructor Columbia University Physicians and Surgeons

James Wood in How Fiction Works speaks of two primary narrative styles: Direct Voice and Indirect Free Voice. David Simel, MD, Duke University Professor of Medicine and the lead editor for JAMA the Rational Clinic Examination, writes listening is not just about letting a patient talk and 'shutting up,' it is about "figuring out what it is the patient is actually telling us, without us assuming that we know what they mean." And just as James Woods shows us that authors of fiction weave between the voice of their character, their own literary voice and style, and what Woods calls the language of the world, patients, too, tell their stories using the language of society and, increasingly, the internet as well as others languages like that of their family and surrounding environment. When telling our stories, it is not inherently disingenuous or untrue to use these other languages, but what if by clarifying and identifying these various elements, we might better understand "what the patient is telling us" and also, co-construct a narrative that becomes closer to their unique voice, stripped of what it is we know or that which the patient has been told he or she must accept as truth?

I would propose to study the way patients tell their stories. Whose voices are they using? How might we as physicians and other health care providers learn from direct and free indirect voice to enable us to better allow for us to "figure out what it is the patient is actually telling us?" And moreover, can we help patients better express their unique voice uncluttered of the cloaks and disguises and masks, they have been taught they must wear? Might this lead to better approaches to individualizing care? How would this be measured?

Bio:

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