

Medical Humanities at WISER
CHCI report 2015-2016

Catherine E Burns

Herewith a short report which allows you to see recent significant developments in Medical Humanities at WiSER: publications, presentations, collaborations and ongoing research.

The academics and assistants and graduate students currently involved in CHCI WISER work are:

Catherine Burns
Victoria Hume
Jonathan Klaaren
June Fabian
Harriet Etheredge
Simonne Horwitz
Sarah Emily Duff
Sarah Nuttall
Renee van der Wiel
Sinethemba Makanya
Carole Cilliers
Shireen Hassim



Above: WiSER Seminar room, University of the Witwatersrand



Left: Dr June Fabian presenting work on kidney care to a SKOK (Centre for Women's & Gender Studies) workshop, University of Bergen, May 2016

Please also visit the new [Medical & Health Humanities Africa network](#) site and join our mailing list

Activities accomplished with CHCI support

- *New memorandum of understanding between Medical Humanities at WiSER and Wits Donald Gordon Medical Centre (WDGMC)*



In 2015 a new MOU was signed which encompasses four major projects to be undertaken in collaboration between the two institutions.

1. PATIENT CARE

The project was initiated in 2014 thanks to feedback from patients to hospital management regarding the “deficits” in their care. In summary patients felt that a “silo-system” existed with each silo comprising doctors, nurses, patients and their families. These silos functioned independently of one another, with little or no communication between them. As a result, patients and their families felt desperate and alienated, in a system where health care professionals were perceived as inaccessible and uncompassionate. The project is led by Dr Harriet Etheredge, a bioethicist and health communications expert.

Phase 1 (2014-15)

The research explored the perceptions that patients had of the care they received in the oncology ward at Wits Donald Gordon Medical Centre. The project was run by a post-graduate student in Health Communication, Harriet Etheredge. Harriet was supported by both WDGMC and WiSER with regard to conceptualisation of the study and its design. She has received academic input, supervision and support from a multidisciplinary team. After presenting her preliminary findings to a working group in the hospital that comprised senior management, clinicians and nurses, the project has now been extended into its second phase.

Phase 2 (2015-16)

This second phase is currently underway, and involves nursing focus groups. A large proportion of the patient feedback focused on nursing practice. The focus groups will explore nurses’ perspectives

with regard to their caring in the oncology ward. The nurses in oncology have previously expressed that they have felt emotionally overwhelmed and inadequately trained to cope with caring for terminal patients and the stress of negotiating patients and families with, what they have called “unavailable” doctors. In addition, very few have been trained at a post graduate level in oncology with respect to the highly specialised component of the medical nursing practice which involves, for example, the administration of cytotoxic drugs, the specific requirements for nursing neutropenic patients. This makes them feel inadequate and disempowered.

2. TRANSPLANT:

The project was initiated in January 2014 and initially comprised multidisciplinary meetings attended by various colleagues in the social and health sciences faculties at Wits. This facilitated some exciting interdisciplinary dialogue from which various projects have arisen, one of which is the “History of Organ Transplantation in Johannesburg, South Africa”. The year 2016 will commemorate the 50th Anniversary of Solid Organ Transplantation in South Africa.

- **Oral history**

Dr Simonne Horwitz, a medical historian based at the University of Saskatchewan, is currently compiling oral histories of transplantation from healthcare professionals and patients across South Africa.

Additional information and resources are being drawn from the Wits Adler Museum, among others. These histories will be archived with historical records and made accessible online; Dr Horwitz's work will also lead to several publications and ultimately a book, to follow up on her highly regarded 2013 history of Chris Hani Baragwanath Teaching Hospital (*right*).



- **Installation by students from Wits School of Art**

Curatorial students from the Wits School of Art will, as their fourth-year Honours project, create a response to transplantation in South Africa since 1966. The installation will be shown at Point of Order, a public gallery in Braamfontein, and at the Origins Centre, on Wits campus, as well as at one of Johannesburg's teaching hospitals.

Together these projects will form the focus of a series of events in February 2016, based at the Origins Centre and WiSER, including panel discussions focused on the relationship between traditional medicine and transplantation, and a seminar for nursing staff dealing with the complex ethical landscape of transplant in South Africa.

3. KIDNEY CARE:

In this project, we propose to capture the lived experience of patients with a severe chronic, life-threatening illness in the form of chronic kidney disease requiring dialysis treatment; as well as that of healthcare professionals supporting these patients.

Patients receiving chronic dialysis treatment experience an accelerated ageing and often, premature death. Some are ineligible for transplant, or wait indefinitely for a kidney transplant. We hope to

capture and explore the complexities of patients experience as they navigate the biomedical “gift” of life, and what life it is – to be intricately connected to a dialysis machine, the “suspension” of waiting for a transplant and the daily risk of dying, whilst seeing those around them suffer and die. Complementing this perspective will be that of healthcare professionals, under daily pressure to make complex ethical decisions unsupported by official frameworks. This body of work will not only contribute an academic interdisciplinary work, but will also be made available in the public space for patient advocacy groups. One such patient advocacy project is currently underway with Lawyers for Human Rights (LHR). LHR are representing Somalian Refugees’ rights to access chronic dialysis care in South Africa, a right they are currently refused.

[Damien Schumann](#), a photographer with extensive experience in documenting issues relating to health and medicine, is currently photographing and interviewing people living with chronic kidney disease, as well as those who care for them, around South Africa. His work will result in a large-scale exhibition at the Origins Centre, on Wits campus, and an online archive of portraits, which will be an ongoing project beyond the exhibition.

Damien's work at Origins will be shown alongside the student installations described above, and will also provide the focus for February's events.

4. NURSING ETHICS (2016-18)

This project was initiated at the request of nurses at WDGMC. WDGMC offers highly specialised medical care in which biomedicine challenges current practice in numerous ways. For example, artificial life support and the challenges faced with organ transplantation and paediatric oncology in resource-poor settings. Nurses have expressed moral distress, potential conflict with doctors, families and their institution as they try to resolve what “care” really means for them in this setting. Dr Catherine Burns has run a series on the ageing nursing population, generational divisions between nurses and care for patients with Alzheimer's and dementia at the end of their life.

In 2017 (the second phase of this work), Professor Lucy Allais from the Department of Philosophy, Wits will be running workshops for nurses to discuss the ethical issues around biomedicine. The format of the workshops will be 1-2 hour sessions, nurses will provide the material for discussion based upon their experiences in the wards. Professor Lucy Allais will provide a philosophical framework for the nurses to allow them to explore the ethical issues in a structured space. Writing sessions will also be held, and reading packs developed, in conjunction with WiSER, to synthesize content of the workshops into a publishable work.

Outputs

- *enabling research approaches which cannot be undertaken without cross-disciplinary work:* The project will be a collaboration between the fields of nursing and philosophy.
- *Publications:* We hope to publish in the form of journal article/s, and potentially also a longer single work.
- *building a field of knowledge:* Nursing practice in South Africa is an under-researched field – nursing practitioners’ opinions are little known in the wider clinical literature, and yet they are at the front line of care, often spending more time with patients than other clinical colleagues. Their insights into the clinical space will be a very valuable contribution.

- *Workshops:* The project will take the form of a series of workshops with nursing practitioners led by Lucy Allias.
- *contributing to care:* It is hoped that by providing space for discussion of complex issues arising from their work, we will mitigate against some of the ethical conflict which can undermine care.

- **JWTC**

The Johannesburg Workshop in Theory and Criticism is an experiment in global conversation based in the South. Located in Johannesburg, we seek to be a critical node in the re-territorializing of global intellectual production. We are a centre for theoretical work that takes seriously a position in the South while addressing international conversations and problématiques. We take the labour of theory and criticism to be significant political work that is crucial to the experimentation in social forms.



CHCI funding supported one keynote speaker and one graduate student to attend 2015's two-week workshop (*left*). It also supported Catherine Burns' talk on 'Ageing and the City' on the first day.

Behrooz Ghamari spoke on "Foucault, Spirituality, and the Perils of Universal History" – a blog about this talk can be found [here](#).

Sinethemba Makanya is a doctoral student – whose PhD title is 'Ukugual kwabantu: The construction of mental health by traditional healers (in Soweto)'.

- **SILICOSIS**

Since 2014 we have been building a theme from Ageing and the Body, focused on the ageing bodies of miners in South Africa, specifically men who worked in the gold mining industry in and around Johannesburg.

Pathologists and public health people, clinical specialists and basic scientists at WITS along with a team at Sciences Po University in France, led by Paul-Andre Rosenthal and his colleagues. Our WiSER clinical and scientific collaborators are all connected to the Medical School except for the pathologist Julian Mthombeni from UJ (a graduate student at WITS); Keith Breckenridge plays a leading role as well as Achille Mbembe, with assistance from Kalema Masua, a WiSER PhD student.

A small group of WITS based people are now working with colleagues at **Sciences Po** in Paris on and around the theme of “Silicosis” and on French – SA collaborations around this. This year 3 key members of their team came to WiSER for a week to examine archival materials and meet with pathologists, scientists, legal professionals and activists – and to write up a grant for further collaborations based on the question of Age and Silicosis – past present and future.

[See the Sciences Po site](#)

This was an auspicious time to meet, a month after the historic SA Judgement in the silicosis class action handed down 13 May 2016, “**Bongani Nkala and 55 Others v Harmony Gold Mining Company Ltd and 31 Others**”, with the civil society groups and trade union representative TAC, Sonke Gender Justice and SECTION27 deeply involved in the action.