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1918 · 2018

forward together · saam vorentoe · masiye phambili

The care economy: setting the stage

Leslie Swartz, Stellenbosch University

The care economy

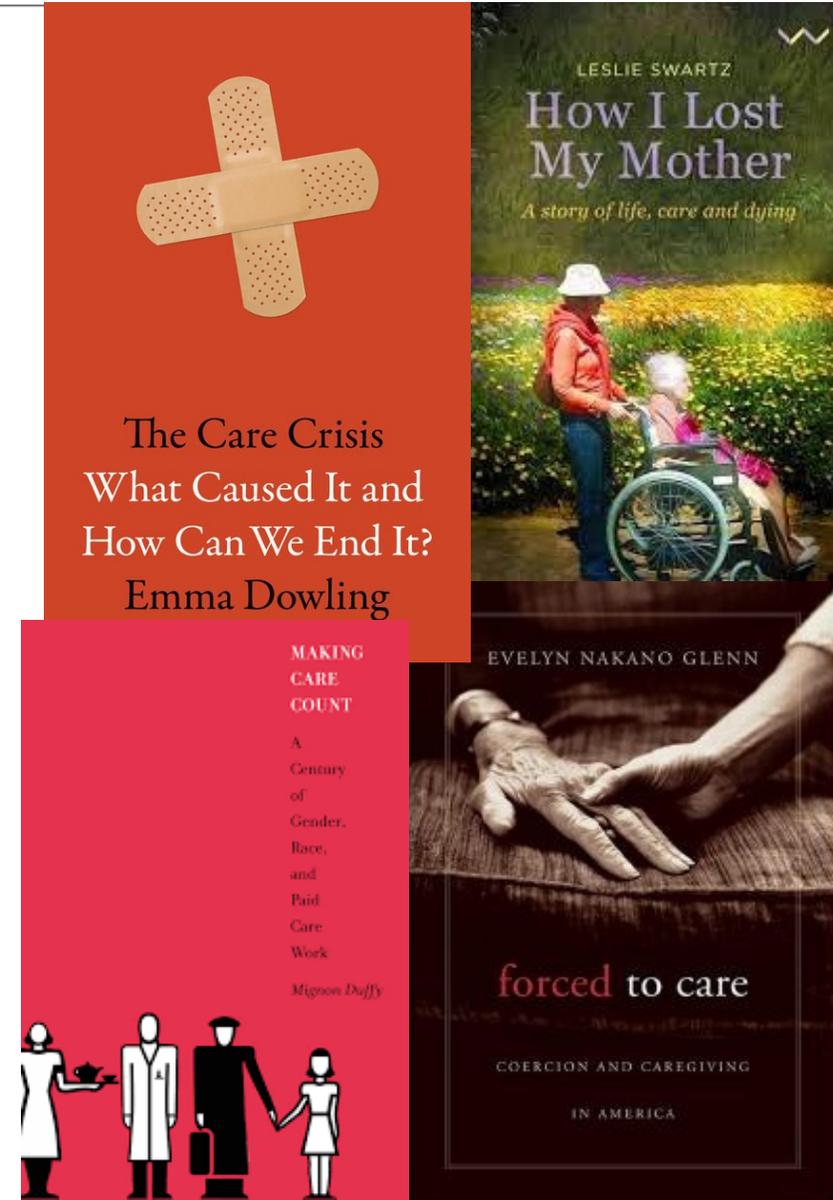


- Care is central to how we live our lives and look after our environment
- Care is raced and gendered
- Care is a huge international industry
- As populations age globally, care becomes more obvious
- Care is often invisibilized – values of ‘independence’ tend to obscure the ubiquity of care
- Costing care is difficult as it is everywhere, often informal, often not thought about
- Care is a key issue for disability – roughly 15% of the world’s population

Care and migration

- As part of what has been termed “the care crisis”, associated partly with changing demographics and ageing in wealthier communities and countries, there has been a growth in the care sector
- Links with more general migration of health workers globally
- Who does caring in wealthier communities and countries?
 - Poorly paid, vulnerable workers
 - Race, gender, class
- Role of remittances in the economies of low- and middle-income countries
- So: disability even in wealthy countries is a key rights and equity issue for less wealthy countries, and is not just a wealthy country issue – and the link is often through care.
- For more on this, please see our previous webinar https://youtu.be/ZF_E3mwLdpE

Swartz



- As with all other issues, COVID-19 highlights and exposing existing social issues and inequalities
- Lockdowns and the pandemic:
 - Decreased access to health care
 - Transport difficulties
 - Accessibility of materials, masks etc
 - Interruptions in life-sustaining care
 - Triage issues – who gets care and on what basis?
 - Long COVID and the future

Ned, L., McKinney, E. L., McKinney, V., & Swartz, L. (2020). COVID-19 pandemic and disability: Essential considerations. *Social and Health Sciences*, 18 (2), 136-148.
https://www.samrc.ac.za/sites/default/files/attachments/2020-12-15/SaHS%20Vol18_No.2.pdf

McKinney, E., McKinney, V., & Swartz, L. (2020). COVID-19, disability, and the context of health care triage in South Africa: Notes in a time of pandemic. *African Journal of Disability*, 9, 9 pages. doi: <https://doi.org/10.4102/ajod.v9i0.766>

Disruption of services and perceived injustice



- *“That’s another thing, nobody is allowed to accompany me [in hospital], you know being disabled or being immuno-compromised or being sickly, you need that support.”*
- *"Like now I do not have a [manual] wheelchair. I use the electric one so now it does not have a battery. I cannot get it [new battery] and so do not have any transport at present and therefore cannot go anywhere [in my wheelchair]."*
- ***“A quad died in hospital because he couldn’t get assistance. The medication was cut off because they couldn’t even assist him until he died. Right of life has just been taken away because he’s not like anybody else,”***

Care, exploitation, intimacy

- Care relationships are often hidden and care devalued
- Essentialist ideas about culture and gender
- Fear of vulnerability
- Genuine intimacy in the context of unequal and exploitative relationships
- A danger: when exploitation is recognised, reciprocity may be lost
- The challenge: How to recognise and value care, create a more equal society in a way which is not exploitative and also values care as part of the intrinsic humanity of us all.



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Mental Health and the Care Economy

Prof Bonga Chiliza
Department of Psychiatry

INSPIRING GREATNESS

Life Healthcare Esidimeni Tragedy

- March 2016: Mental Health Care Users were hastily transferred to NGOs and other psychiatric hospitals in attempt to 'deinstitutionalise' mental healthcare
- Health Ombud, Prof. Malegapuru Makgoba, investigated the deaths of patients & published a report entitled: **'NO GUNS: 94+ SILENT DEATHS AND STILL COUNTING'**
- Following the report, former Deputy Chief Justice Dikgang Moseneke was appointed to arbitrate an **Alternative Dispute Resolution** between government and families of the Life Esidimeni deceased and the survivors.
- In terms of **common law damages**, DCJ Moseneke ordered the state to:
 - Pay claimants for psychological injury and trauma, funeral costs, counselling for families
 - Erect a memorial for the victims of the Life Esidimeni Marathon Project
 - Pay US \$67 000 (R1 million) in constitutional damages to each claimant
- Current proceedings: Life Esidimeni Inquest to ascertain the facts relating the unnatural deaths. Findings from the presiding judge will aid the NPA`s decision to take **criminal prosecutions** forward

Mental Health and the Care Economy

- Prolonged and systemic neglect of mental health care
- Poor investment in mental health services
- Psychosocial disabilities and lost income
- Hospicentric care
- Deinstitutionalisation requires numerous interventions in various sectors
- Delays in the pathway to care
- Hidden care work

COVID-19 Pandemic and Beyond

- COVID-19 Spotlight on Mental Health Care
 - Fight for “our beds”
 - Treatment pathways
 - Distributive justice
- Recovery-oriented mental health services
- Rights based mental health care
 - Moving away from the biomedical model
- Effective participation and inclusion of people with psychosocial and intellectual disabilities
- Lancet Psychiatry Commission on Psychoses in Global Context

The Care Economy

The World Bank



Sameera Altuwaijri.
Global Lead, Population and Development
HNP Global Practice

At the WBG,
we recognize...

- The care economy is a powerful entry point for increasing female employment
- The solutions to reducing labor gender gaps across the world lie in many corners, but a well-functioning care economy is especially crucial.
- Married women spend 14 to 42 percent of their non-leisure time on childcare, compared with 1 to 20 percent for married men. And changing demographics, aging societies, and declining fertility rates also make the burden of elderly care a growing challenge.
- The care economy has intrinsic inequalities; disability and gender are two top ones

COVID-19 + the care economy = business unusual

- Women's jobs are 1.8 times more vulnerable to this crisis than men's jobs. Women make up 39 percent of global employment but account for 54 percent of overall job losses
- The virus is significantly increasing the burden of **unpaid care**, which is disproportionately carried by women
- Disability impacts on women are disproportionately represented in industries that are more affected by COVID-19 than men
- Pandemics can both incite and exacerbate violence against women

COVID-19+the care economy = business unusual (2)

- Women make up large parts of the health workforce, but they may have less decision-making capacity within the sector and less access to protective equipment in times of crisis compared to male health workers.
- New measures are needed to safeguard women's economic opportunities during COVID-19 and ensure that legal gains women have made in the workplace over the last 50 years aren't wiped out
- Most primary caregivers to the ill are women, which further exposes them to the infection. Women, traditionally responsible for caring for children and the elderly, often remain in charge of caring for the ill during the outbreak of a pandemic.
- Women also provide care for the disabled in their households and communities. Women with disabilities themselves carry a double burden

Our response...

- The World Bank Group has stepped up its support to countries as they tackle the unprecedented threats posed by the COVID-19 crisis and is paying special attention to the pandemic's different impact on men and women.
- In our projects, we advise and urge health care leaders to;
 1. Consider the linkages between human capital formulation and inequalities like disability
 2. Adopt an inclusive, human-centered design
 3. Collect disability data: In order to measure and manage outcomes, people with disabilities must be included in studies, clinical trials and data collection
 4. Develop training programs for health care professionals: These programs must be aligned with the specific care needs and rights of persons with disabilities.
- Although social norms strongly highlight the role of women as caregivers, there is scope for policy aimed at increasing the capacity, quality, and availability of childcare and early education as complementary of home-based care and for women who need childcare support.

THE CARE ECONOMY

VIC AND MIKE:
LIVED EXPERIENCES OF DISABILITY
AND CARE ASSISTANCE

Aug 2021

Dr. Vic McKinney

I need personal assistance all the time







- Travelling by plane



- Using passenger assistance unit (PAU) to get to plane door level





- Mike carries Vic to plane seat



- Front row seats are easier because of legroom

Having support has given me opportunities





Vic's Identity in society – father & husband
His disability is secondary



Playtime in the
pool



At the beach





Jamie feeding dad

