

## FEATURE

# Life Esidimeni: Applying a Human Rights Lens

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*The Life Esidimeni incident has been the subject of a great deal of discussion in the media and elsewhere – and rightly so. Tragedies such as these need to get as much attention as possible to prevent us from becoming indifferent to the suffering of the poor and keep us focused in our different fields on seeking ways to alleviate preventable suffering in the health system.*

*Applying a human rights lens requires investigating deeply-held assumptions about why certain people end up suffering certain afflictions beyond the presenting issues (Yamin 2015). This calls for an understanding of the role that poverty, gender inequality, social and systemic exclusion, and political failure play in perpetuating human rights violations.*

*Seen in this regard, the Life Esidimeni case presents a series of human rights violations at the heart of which were vulnerable and poorly resourced mental health-care users. The article describes each of the main rights that were violated; due to the interrelated nature of rights, infringing on these rights also violated other underlying rights, such as the right to food and water.*

*The commentary in this article reflects on the arbitration hearings led by Justice Dikgang Moseneke and the judgment he delivered on 19 March 2018. It also draws on information from human rights organisations, such as Section 27, that have been advocating for the rights of mental health-care users.*

## Background to the Life Esidimeni tragedy

In October 2015, the MEC for Health in Gauteng announced the termination of the contract between the Department of Health and Life Esidimeni (Makgoba 2017). Around 2,000 people who were receiving specialised psychiatric treatment were to be moved out of Life Esidimeni to families, NGOs and psychiatric hospitals providing acute care as part of the Gauteng Health Marathon Project.

The MEC said the reasons for the closure of the

facility were, among other things, to save money and implement a de-institutionalisation policy. Whilst this policy was commendable, it required careful implementation and time in which to develop and capacitate community care. Prior to the closure, civil society groups had made several efforts to prevent the Gauteng government from moving patients out of Life Esidimeni, but these were unsuccessful (Section 27 Fact Sheet 2017).

From March to June 2016, mental health-care users were discharged from life Esidimeni in large numbers, in the course of which they were subjected to untenable conditions in ill-equipped

and ill-prepared facilities, leading to the death of 144 patients and to thousands more being exposed to trauma and morbidity. By 2018, the whereabouts of about 44 of them was still unknown (Moseneke 2018).

Subsequently, the Minister of Health requested that the Health Ombud investigate the circumstances surrounding the death of the mentally ill patients. The Ombud wrote a detailed report uncovering a multitude of violations and recommending compensation for families that had lost loved ones and measures to ensure that the surviving patients did not suffer further trauma (Makgoba 2017). One of the recommendations was to establish an alternative dispute-resolution process to determine redress mechanisms and compensation.

This led to arbitration proceedings that included affected families and patients. The proceedings were concluded in February 2018 with a judgment from retired Justice Moseneke. In the judgment, the government was ordered to pay a substantial sum to claimants for the shock and psychological harm the patients experienced, for funeral expenses and for constitutional damages, with the payments to be made not later than three months after the publication of the award.

## **Applying a rights lens**

The corpus of human rights is made up of binding international texts to which South Africa has assented, among them the International Covenant of Economic Social and Cultural Rights (ICESCR) and International Covenant on People with Disabilities (ICPD). It also consists in non-binding interpretive documents such as general comments, technical guidance and treaty-body recommendations, including, for example, the 1991 United Nations Principles for the Protection of Persons with Mental Illness. To domesticate international law, national legislation, such as the Constitution, has been adopted with provisions similar to those in the international documents.

Against this backdrop, a number of rights were violated in the Marathon Health Project, including the right to life, right to the highest attainable



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standard of mental and physical health, right to food and water, and the freedom from torture and cruel, inhuman and degrading treatment.

All these rights are catered for in South Africa's Constitution and, more specifically, its bill of rights. The advancement of human rights and freedoms is one of the tenets of the Constitution. The Constitution is the supreme law and any law inconsistent with it is invalid. It binds all state organs and every official entrusted with public power. South Africa has also enacted laws and policies to cater for persons living with mental health conditions. These include the National Health Act, Mental Health Care Act, and National Mental Health Policy Framework and Strategic Plan.

Accountability is a key human rights principle. The lack of accountability and transparency was a significant factor in the Marathon Health Project. In playing their accountability role, states should respect people's rights by refraining from denying or limiting access to health care. By prematurely terminating the Life Esidimeni contract without providing a reasonable alternative, the state limited mental health-care users' rights. States are also required to protect people's rights by adopting legislation to ensure equal access to health care and prevent third parties from infringing on the rights to health and health care (Durojaye E and Agaba DK 2018).

All public officials who made decisions on the Marathon Health Project were bound to adhere to the Constitution as well as the laws and policies relevant to mental health-care users. By delegating power to NGOs, state organs empowered them with



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public power, which entailed that the NGOs were required to exercise their mandate lawfully and in a reasonable manner. Ultimately, the exposure of mental health-care users to under-resourced NGOs amounted to a failure by the state to play a preventative role – instead, the state facilitated the abuse of users’ rights by third parties contracted by itself.

Duty-bearers should also be answerable to citizens by providing them with timely, accessible and accurate information and encouraging public participation in policy decisions. The Marathon Health Project treated mental health-care users and their families as beneficiaries rather than as active participants in decisions that affected their lives. They were not privy to information about when and where they would be moved; instead, families had to conduct lengthy searches for their loved ones, sometimes finding they had died. Moreover, patients and families were not involved in the decision in the first place to move them from Life Esidimeni, and attempts to contest the move were ignored or met with disdain.

Accountability also entails the efficient, economical, equitable and effective use of resources. The evidence revealed that care at some of the hospitals to which the users were moved cost three times as much as that at Life Esidimeni. While the NGOs, on the other hand, cost less, most of them lacked essential requirements for mental health-care users; at times, funds to the NGOs were paid late, or paid to ones that had closed down. This demonstrated the government’s lack of adequate planning for the move.

## Rights that were violated

### 1. *The right to life*

The right to life is at the basis of all human rights. Article 6 of the International Covenant on Civil and Political Rights (ICCPR) declares every human being’s inherent right to life and provides that no one shall be arbitrarily deprived of his or her life, as does article 11 of South Africa’s Constitution.

In this regard, it has been highlighted already that 144 mental health-care users lost their lives. Both the Ombud’s report and the arbitration hearings revealed that the deaths were not natural but were caused negligently and unlawfully. The government’s defence – that it could not have foreseen that the move would lead to death and suffering – was refuted by reference to the fact that it had been cautioned repeatedly by NGOs and the families of patients that the project had the potential to cause harm and lead to loss of life, warnings the government did not heed.

Furthermore, the NGOs to which patients were moved were not equipped to provide for them. The NGOs were selected on mysterious grounds and all 27 of them operated without valid licences. Conditions at their premises were so bad that they were called ‘death traps’. Patients were transferred, whether in departmental vehicles or vehicles owned by NGOs, without a written plan for the transportation. While in transit, some had their hands or feet, or both, tied up. Others suffered the trauma of being moved from place to place, which forced families in turn to go from place to place looking for them. Patients were often moved without their clinical records or personal belongings.

Mental health-care users also faced a series of challenges after they were moved to the NGOs. These included lack of appropriate caregivers to identify or provide appropriate medicine for them; food of poor quality and insufficient quantity; understaffing or inappropriate staffing; insufficient security; and inadequate blankets and clothes for the cold period. Some NGOs were overcrowded, with unhygienic and ill-maintained facilities (one had a leaking roof

and a door about to fall off its hinges). Some patients reported abuse and mistreatment. Multiple deaths – more than 95 per cent – ensued at these ill-equipped and ill-prepared NGOs.

## **2. The right to dignity**

The preamble of the Universal Declaration of Human Rights recognises ‘the inherent dignity and the equal and inalienable rights of all members of the human family’, and declares that ‘contempt and disregard for human rights have resulted in barbarous acts that have outraged the conscience of mankind’.

Similarly, the South African Constitution enshrines human dignity and the achievement of equality among its fundamental values. Article 10 of the Constitution declares that everyone has inherent dignity and the right to have his or her dignity respected and protected. The right to dignity is especially important in South Africa, as it is vital for a meaningful departure from the oppression of colonialism and apartheid.

However, the Marathon Health Project trampled on the mental health-care users’ dignity by failing to include them and their families in decision-making pertaining to their movement to the NGOs or private hospitals; by transporting them in inhuman conditions; and by exposing them to ill-functioning facilities, leading to the undignified death of some and the untold suffering of others.

The evidence showed that those who searched for their loved ones were confronted with emaciated, dehydrated and ailing patients in dingy, unkempt NGOs – a clear demonstration of undignified treatment. Other families reported that they conducted long searches only to find that loved ones had died. One claimant said the body of a loved one was found decomposing in a hospital mortuary.

## **3. Freedom from cruel, inhuman and degrading treatment**

Freedom from cruel, inhuman and degrading treatment is closely related to the right to dignity.



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Such treatment consists of systematic acts that are not only unkind but hateful and directed at causing bodily and psychological hurt and harassment. Evidence by various expert witnesses during the arbitration proceedings demonstrated that the treatment of the mental health-care users amounted to torture.

One witness said that the way the users were treated was reminiscent of the apartheid regime:

The entire project is a sad reminder of Steve Biko ... who died in detention. On the night before he died he was placed on cell mats on the floor of the Land Rover, semi-comatose, naked and handcuffed, and driven to Pretoria Central Prison. No medical records were sent with him. Neither was he accompanied by any medical personnel during the medical journey (Moseneke 2018).

Another expert observed that

[i]f you take a group that did not know the move was coming, weren't prepared for it and are moved on the back of trucks, tied with sheets without identity documents, without wheelchairs, that amounts to torture. And then they are moved into filthy dangerous environments as if they are not human and you deny them basic food and water you overcrowd them ... All those are features of actively torturing people.



**The right to health and health care is also related to other rights violated in this case, such as the rights to food, life, non-discrimination and human dignity**

#### **4. The right to health**

Ultimately, all the actions above violated the right to health of the mental health-care users. The realisation of the right to health and health care is also closely related to that of the other rights violated in this case, such as the rights to food, life, non-discrimination and human dignity. Article 12 of the ICESCR recognises everyone's right to the highest attainable standard of mental and physical health. Article 16 of the African Charter has the same provision, emphasising moreover that state parties must take the necessary measures to protect the health of their people and ensure they receive medical attention when they are sick.

Section 27 of the South African Constitution recognises everyone's right to health-care services. The state must take reasonable, legislative and other measures within its available resources to progressively realise this right. By failing to take rational and reasonable steps to protect the right to health and health care of the mental health-care users, the state violated the right to health. Furthermore, by transferring them to NGOs that were not in position to ensure adequate food and water, the state violated a series of determinants vital for the realisation of the right to health and health care.

## **Conclusion**

The catastrophe that was Life Esidimeni is a reminder that even though it functions under an elaborate and aspirational constitution, the South African health system still faces a range of challenges that are capable of leading to violations of human rights. The blatant disregard that public health officials showed for mental health-care users despite attempts by various parties to warn them of the irrationality of their actions is symptomatic of the situation on ground, especially where it concerns users who are poor and vulnerable.

A responsive public health system should be able to foresee and prevent the tragedy that happened in the Marathon Health Project. It is hoped that lessons have been learnt and will be put to use in continuous improvement of the health system and in protection of the rights of vulnerable people in their attempts to access health-care services.

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