NELSON MANDELA
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PROFESSORIAL INAUGURAL LECTURE

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Topic:

Stigma Syndemics & Symbolic (isms) in the context of HIV: Ways of Knowing in Health Care

Faculty of Health Sciences

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NELSON MANDELA UNIVERSITY

Inaugural Lecture of

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Summary

The negating effect of stigma on health outcomes has been widely established. Described as a hidden burden of disease, stigma significantly influences the inequities in health. The seminal work of Sociologist, Erving Goffman's initially published in 1963 continue to underpin our current understanding of stigma as socially influenced through the symbolic interactions of everyday experiences that influences behaviour.

Within the context of HIV, stigma remains a barrier in ending the epidemic and is associated with diminished health outcomes, health seeking patterns and poor quality of life. The significant advances in HIV treatment, has increased the life expectancy of people living with HIV, and has shifted the management of HIV as a manageable chronic illness. However the negative stigma outcomes experienced by people living with HIV remains. Moreover, the interactions of other syndemics (that is the co-existence of another disease/s, or social factors) further contributes to the stigma experienced by people living with HIV. This may refer to the co-existence of TB, depressive or other mental health disorder, younger woman, pregnancy, and occupations or work type industry, such as mini-bus taxi drivers, sex workers to name a few syndemics.

Central to the health are the values and attributes of caring, towards the restorative process for sustained health and improved wellbeing. To enable care, there is a need for health care professionals to know how to care. Patterns of Knowing or Ways of Knowing developed by nurse theorist Barbra Carper (1975, 1978) and extended by Chinn and Kramer (2008) has become widely applied in nursing and health professions education and training. Ways of knowing acknowledges five inter related facets (empirical, ethical, personal, aesthetic and emancipatory) inherent in the provision of holistic care.

The lecture will reflect on the syndemics associated with HIV related stigma, and the symbolic interactions with health care; in the provision of health care and in education and training of health care professionals. This will be framed against ways of knowing, how health care professionals know how to care, the inherent and learnt symbolic meanings in how care is provided, and its potential to demystify and eliminate the perpetuated HIV related stigma.

Key words: HIV related stigma, ways of knowing, behavioural interactions health professional care

Acknowledgement and Appreciation

It is incredibly humbling to share this space with so many prolific scholars whose work continue to shape nursing and health sciences scholarship. This achievement is through the acknowledgment of peers in the discipline and my colleagues at Nelson Mandela University, who have reviewed the body of work I have co-created with students and colleagues and determined it to being significant to meet this milestone. Thank You!

I recognise the responsibility that comes with this position and will endeavour to continue to enhance Nursing and Health Sciences scholarship.

I have been and continue to be surrounded by many individuals whose perspectives and experiences have intersected with mine. I am grateful for everyone who have been and continue to join me in this journey of learning and discovery.

I recognise the collective celebration of achievement this is for my:

- Family and in particular my husband (Neil), daughter (Alexandra), parents (Raymond and Rosemary Kisten),
- Friends and colleagues and for the Nursing Profession

I also Acknowledge and Thank

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Author Note

This document presents the summarised points reflected in the full lecture and not a verbatim of the speech/lecture. Work within the area of Ways of Knowing how to care in Stigma Curriculum Creation is under review for a publication (submission December 2021) and hence the lecture notes provides a summary in respect of copyright agreements with the publisher.

Positioning of Self to Research

Research Paradigms – the lens with which we view the world how we see our reality

Two moments in my journey has framed my way of *understanding* and *knowing*

The first moment was through my involvement as a research assistant for more than seven years under the leadership of the late Emeritus Professor Leana R Uys. It was within the remote health districts of KwaZulu-Natal, in particular the uThukela health district, among the beauty of the majestic and unending rolling landscape of the Drakensburg mountain range. The research we were conducting measured HIV progression among pregnant and non-pregnant women. It was prolonged engagement of over 18 months of data gathering, of mapping the experiences of women accessing care that I was confronted by the shame, fear, and isolation and denied care women living with HIV experienced every day.

Further to this, my involvement in a five year study measuring HIV related stigma over time that was conducted in South Africa, Lesotho, Eswatini, Malawi and Tanzania further framed and deepened my understanding of the multifaceted psycho-socio-ecological lens of HIV related stigma, the vulnerabilities of women in particular, and role of health care systems in negating care.

The second moment came through unlearning and relearning that I experienced within my PhD research study. Under the guidance of my study promotor, Professor Ntombifikile Mtshali, the education framing of understanding in regards to how actions, knowledge and clinical practice is informed through experience, reflection and the process of co-constructing learning was shaped. A very iterative process and a paradigm shift from the positivist, linear and structured manner in which I was accustomed to relating to the nature of HIV; to a more in-depth and layered way of understanding the meaning attached to a person's experience with living with HIV.

It is in this framing that I share my reflections for this evening's lecture which I have entitled:

"Stigma, Syndemics & Symbolic (isms) in the context of HIV: Ways of Knowing in Health Care"

The lecture will discuss

- The interconnectedness of Stigma to HIV, other stigmatised facets and influence on behaviour
- How one comes to know how to care, the inherent knowledge that influences how we care and
- Framing future research in terms of how responsibilities of nursing and health professions education and training in terms of stigma consciousness in knowing how to care

Reflection of the burden of HIV in South Africa

Against the global experiences in the past year and a half, over the COVID 19 pandemic, we as a country know all too well the experiences of another pandemic, HIV. A global pandemic that has contributed to almost 36 million HIV related deaths since the start of the epidemic some four decades ago. The UNAIDS (2020) report indicate that there are currently 1.7 million new HIV infections and 27.5 million people accessing Anti-Retroviral Therapy. Within the national landscape, reflected in Statistics South Africa's 2021 annual mid-year report, there are an estimated 8.2 million (3.7%) people are living with HIV, of which 19.5% are adults between the age 15-49. Moreover, in terms of HIV and AIDS related death, there was an estimated 274 000HIV related deaths reported in 2007 with a noted increase to 79 000 in 2020**,** and a notable increase to about 85 000 HIV and AIDS related death is reported for 2021 (exact HIV and AIDS related rates are 2007: 274 501, 2020: 79 420 and 2021: 85 154, Source: StatsSA, 2021). Despite efforts to mitigate the effects of COVID 19, there was a decline in the annual number of clients remaining on ART by approximately 4% (StatsSA, 2021).

As part of the Joint United Nations Programme on HIV/AIDS (UNAIDS) 90-90-90 strategy towards eliminating HIV by 2020, as per 2019 South African estimates, 92% of all people living were aware of their status, 70% were on ART and 64% had viral load suppression (UNAIDS, 2020). Women in particular are more vulnerable or at higher risk of HIV infection and in 2020 in sub-Saharan Africa, six in every seven new infection were among girls aged 15-19 years and an approximate 4200 young women aged 15-24 years are infected with HIV every week, that HIV in per week.

Over the years there has been considerable efforts and advancements in the care and treatment related to HIV. This has contributed significantly to the increased life expectancy of People

Living with HIV (PLHIV) and HIV being transformed to a manageable chronic illness. As such, an increase in co-occurring illnesses that may be more predisposed to HIV or related to the continuum of lifestyle and ageing such as NCDs mental health disorders, Tuberculosis to name a few, which further confound the burden of HIV.

The Syndemic Nature of HIV

Research over time has enabled us to better understand the dynamics of HIV not only from a biological perspective, but also from a sociological, psychological, cultural/spiritual and economical perspective.

The interrelated effects of HIV on the psychosocial facets of a persons' functioning has been extensively researched. And has allowed us as health care providers of care for PLWHIV to better understand the nature of HIV in terms of : self-efficacy, Quality of Life (QoL), QoL (work-life); resilience, spiritual wellbeing; symptom management; coping strategies, and psychological distress to name a few. It is also this understanding that helps us to understand and engage better in not only the drivers of HIV, but towards a model of care and engagement of self as health care practitioners in respects to care that encompasses the holistic inter-relationships within the nature of HIV related care.

It is within this understanding that psycho-social models have framed our understanding of how predicting behaviour or behaviour intentions that drive HIV infections. Some of which are the Health Belief Model, Theory of Reason Action or Theory of Planned Behaviour, or Social Cognitive Theories. As a nurse researcher, the work of Mead and Symbolic Interactionism resonates within the paradigm of how I have viewed HIV related care and in particular the nature of stigma and its intersections, inter-relationships and the syndemic nature of stigma with HIV. Symbolic Interactionism approaches offer a perspective or worldview in framing how HIV related stigma is negotiated, resisted and apportioned in everyday life; the destructive effects of practices which denigrate the positionality of an individual in the context of health and interfacing on health seeking behaviours.

Stigma Process

Of all of the aforementioned intersecting elements that fuel HIV, stigma remains the greatest barrier to reducing and eliminating HIV. This is supported through a growing body of literature supports stigma and discrimination as fundamental causes of health disparities. Stigma and

discrimination experienced by women living with HIV experienced in health care influence the health care decisions, access and health seeking behaviour and utilisation of women living with HIV. Thus, understanding how stigma and discrimination manifest and function in health care encounters is important to better understand health disparities for women living with HIV, especially younger women. Stigma significantly influences the inequities in health.

Described as a hidden burden of disease, the negating effect of stigma on diminished health outcomes, health seeking patterns and quality of life among PLWHIV has been widely established. Stigma is associated with hesitancy for HIV testing, disclosure of status to family, friends and health care providers, ART non adherence or reluctantly to commence treatment, and depression and anxiety and related mental health problems.

For adolescents or younger adults living with HIV, the greatest barrier of stigma is transitioning of care, and adolescent friendly approaches to facilitate this transition, recognising that very often the adolescent may have become recently aware of their HIV status through a primary caregiver or parent. The internal processing of the new diagnosis, against the manner in which the adolescent is received within their health service, may often be the driver for loss of continuity of ART for the adolescent. Understanding the role of stigma is critical for healthcare providers in changing this narrative.

Stigma is socially influenced, and a manifestation of a process wherein an individual is considered as having an attribute or trait or belonging to an entity (community, occupation, area of living) that is considered undesirable. HIV related stigma among urban and rural settings, are also influenced by cultural norms, beliefs and values related to HIV. It is influenced and perpetuated through power, as those that determine the discrediting trait, create systems of power that label, stero-type and separate, the process of othering, creating the 'us' and 'them', the 'isms' and the phobias'. It is within this interaction, that the grounding to create inequities is created, as very often the separating, exclusion, othering – results in the social exclusion, but also access to the resources that was part of the social connection (Holzemer, Relf, 2021).

The social isolation of the person experiencing the stigma, usually self isolates from any form of interactions where further forms or level of or intensity of stigma may be received. And usually negative manifestations of blaming, shame and social judgement and devalued self – identity.

Stigma process encompasses categories, drivers are individual level – fear of contagion, knowledge, or prejudicial attitude towards PLHIV or key population groups. Facilitators – structural or societal that influence stigma, the presence or absence of protective systems. Stigma Outcome- consequences of stigma (Perceived, anticipated, internal and experienced or external stigma). Syndemically layered/intersecting stigma - is the co-occurrence of stigma related to HIV status, gender, profession, poverty or sexual orientation. Measuring stigma among PLWHIV identify that internalised and perceived stigma being the most frequently occurring type of stigma experienced or reported, and most strongly correlated or associated with intention for testing, health seeking behaviour and attrition in terms of ART care.

This is an important consideration, for health care providers. The characteristics of this form of stigma, indicates to the subtleness in which internalised feelings of fear of receiving or anticipating negative experiences from others, self-blame and shame fuels health decision making. In understanding HIV related stigma and the multiple dimensions of stigma related to HIV, it has enabled interventions aimed at reducing HIV related stigma. A limitation though has been that often the interventions do not reflect the multidimensional or the syndemic nature of the HIV and the multiple stigmatised facets of the individual living with HIV.

Relevance to health care and knowing how to care

Against this understanding of the intricacies of HIV and stigma, requires reflections of this through and educational lens. Critical to nursing and health sciences research and scholarship; in an effort to close off gaps or find solutions through research, is the significance to nursing practice. Here we often reflect on the findings of research in respect to the contribution to the existing knowledge, or the contributions to our practice and to the scholarship of teaching and learning. In a similar manner, how does our cumulative understanding, sequencing, factorising and theorising of the syndemic nature of HIV and stigma influence how we care?

To frame this, I reflect on the patterns or way of knowing, proposed by a nurse theorist Barbra Carper and whose work has been applied and utilised in various health professions.

How do we come to know how to care?
What frames how health care in regard to HIV and stigma is provided?
What the inherent and learnt symbolic meanings in how care is provided
and its potential to demystify and eliminate HIV?

Central to the health are the values and attributes of caring, towards the restorative process for sustained health and improved wellbeing. Carper's Ways of Knowing and later extended by Chinn and Kramer, acknowledges five inter related facets (empirical, ethical, personal, aesthetic and emancipatory) inherent in the provision of holistic, patient centred care.

While developed in the discipline of nursing, it's utility in the past decade as become more within medical education and health professions education. Understanding each person as being uniquely individual, the therapeutic role of self to form authentic connections and ethical decision making underpins the essences of knowing how to care.

Empirical knowing expresses the element of evidence informed practice, and shapes how we come to know how to care, through the use of previous scientific informed knowledge systems, the use of theories of caring, behaviour models and reasoned action to name but a few. These empirical knowing or knowledge facets, enables our caring to being aligned to knowledge that is reliable, verified and contextually implemented. Ethical knowing as the name indicate underscores the values, moral and ethical principles that informs our framing of caring in the context of HIV, the ethical framing from a utilitarian or deontological framing that has the potential to further perpetuate or diminish implicit stigma characteristics in how we care. Aesthetic knowing is achieved through empathy, dynamic adaptation and understanding of the components as a whole while appreciating the individual drivers of care that requires application of knowing how to reflect tailored care interventions in caring. Emancipatory knowing as a construct of knowing reflects the consciousness towards citizenship, social accountability, justice and a grounding in being critically reflective of the societal, cultural and political landscape that intersects with health and the nature of caring with a mindfulness of stigma.

Expanding the constructs of Caper's Way of Knowing to intervening with HIV related care offers a framework to engage with inter-relatedness and symbolic interactions of conditions that enables the experience and process of stigma. The model allows us a framework to guide our agency as health care professionals in how we engage with stigma as a construct, discipline in our curriculum. These are discussed in terms of:

- Stigma consciousness within how we facilitate learning of diseases that are highly stigmatised

- Rejection Sensitivity
- Role of generational stigma
- Stigma screening to inform clinical care and in health assessment
- Integration of HIV and psychosocial determinants on curriculum

Concluding comments

The multifaceted dynamics of stigma on ending the HIV epidemic requires a holistic overview of how we care, the role is also on nursing and health professions education in the manner in which curriculums are crafted. Consciousness of how we use self in relation to student and in relation to caring for individuals living with HIV. The work continues, however we are better informed on how to create sustainable and appropriate solutions.

References

(this list reflects the research that underpins the discussion points inherent in the lecture)

Adamu, A.; Mchunu G.**;** Naidoo. J. R. (2020). Predictive influence of coping style on stress and resilience among women living with HIV in Niger State, Nigeria. *African Journal for Physical Activity and Health Sciences (AJPHES).* 26(1): 99-112.

Chinn, P. and Kramer, M.K. (2011). Integrated Theory and Knowledge Development in Nursing.

Carper BA. (1999). Fundamental patterns of knowing in nursing. Perspectives on philosophy of science in nursing: an historical and contemporary anthology. Philadelphia: Lippincott

Dlamini, P., Wantland, D., Makoae, L., Chirwa, M., Kohi, T., Greeff, M., Naidoo, J., Mullan, J., Uys, L.R. and Holzemer, W.L. (2009). The impact of perceived HIV stigma on reasons for missing ARV medication among persons living with HIV infection in five Africa countries. *AIDS Patient Care and STDs*. 23(5): 377-387.

Feyissa, G.T., Lockwood, C., Woldie, M, and Munn, Z. (2019). Reducing HIV related stigma and discrimination in healthcare settings: A systematic review of quantitative evidence. https://doi.org/10.1371/journal.pone.0211298

Greeff, M., Uys, L.R., Holzemer, W.L., Makoae, L.N., Dlamini, P.S., Kohi, T.W., Chirwa, M.L., Naidoo, J**.**, & Phetlhu, D.R. (2008). Experiences of HIV/AIDS stigma of PLWA and nurses from five African Countries. *African Journal of AIDS Research.* 10(1): 78-108.

Gaede BM, Majeke, SJ, Modeste, RRM, Naidoo, JR, Titus, MJ, Uys LR. Social support and health behaviour in women living with HIV in KwaZulu-Natal. *SAHARA: Journal of Social Aspects of HIV/AIDS* 3(1): 362-368.

Holzemer, W.L., Uys, L., Makoae, L., Stewart, A., Phetlhu, R., Dlamini, P.S., Greedd, M., Kohi, T.C., Chirwa, M., Cuca, Y and Naidoo, J.R., (2007). A Conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing.* 58(6):541-551.

Hutchinson, P and Dhairyawan, R. (2017). Shame, Stigma, HIV: philosophical reflections. *Medical Humanities*. 43 (4).

Link, BG, Wells, J, Phelan, JC, and Yang, L. (2015). Understanding the importance of Symbolic Interaction Stigma: "How Expectations about the reactions of others add to the Burden of mental illness stigma. *Psychiatric Rehabilitation Journal*. 38 (2): 117-124.

Mead, GH (1934). Mind, Self and Society. Chicago: University of Chicago Press

Stangl, A.L., Earnshaw, V.A., Logie, C.H…(2019). The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. BMC Medicine. https://doi.org/10.1186/s12916-019-1271-3

Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoae, L., Dlamini, P., Phetlhu, R.D., Chirwa, M., & Kohi, T. Urban and rural differences in HIV/AIDS stigma in five African Countries. *African Journal of AIDS Research.* 6(1): 17-23.

Naidoo. J.R. & Mtshali N.G. (2017). Sisonke- together we can": Conceptualisations of a critically reflective communities of practice nurses caring for women living with HIV. *Africa Journal of Nursing and Midwifery.* 19(3):#1410 *https://doi.org/10.25159/2520-5293/1410*

Naidoo, J.R., Ngcobo, S., Ncama, B.P. & Brysiewicz, P. (2017). Experiences of nurse graduates of an integrated HIV curriculum from a selected University in South Africa. *Africa Journal of Nursing and Midwifery*. 19(2):#1228 https://doi.org/10.25159/2520-5293/1228

Naidoo. J.R. & Mtshali N.G. (2017). Sisonke- together we can": Conceptualisations of a critically reflective communities of practice nurses caring for women living with HIV. *Africa Journal of Nursing and Midwifery.* 19(3):#1410 *https://doi.org/10.25159/2520- 5293/1410*

Tyler, I and Slater, T. (2018). Rethinking the sociology of stigma. *The Sociological Review*. 66 (4). https://doi.org/10.1177/0038026118777425

Relf, M.V.,Holzemer, W.L., Holt, L. Nyblade, L., Caiola, (2021). A Review of the State of the Science of HIV and Stigma: Context, Conceptualization, Measurement, Interventions, Gaps, and Future Priorities. Journal of the Association of Nurses in AIDS Care. http://dx.doi.org/10.1097/JNC.0000000000000237

Stangl, A.L., Earnshaw, V.A., Logie, C.H…(2019). The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. BMC Medicine. https://doi.org/10.1186/s12916-019-1271-3

Stockton, M.A., Giger, K., and Nyblade, L. (2018). A scoping review of the role of HIV related stigma and discrimination in non-communicable diseases care. PLOS One

Uys, L.R.; Holzemer, W.L.; Chirwa, M.L.; Dlamini, P.; Greeff, M.; Kohi, T.W.; Makoae, L.N.; Stewart, A.L.; Mullan, J.; Phetlhu, R.D.; Wantland, D.; Cuca, Y. & Naidoo, J. (2009). The development and validation of the HIV/AIDS Stigma Instrument – Nurse (HASI- N). *AIDS Care.* 21(2): 150-159.