Writing Henry: The moralities of representation

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Abstract: Extreme human suffering and death has the potential to bring about a paralysing discomfiture, not merely about situations witnessed, but how they should be represented. Should it be enough to tell the story, free from the trappings of disciplinary theories, of one man’s attempt to live his death according to his own moral framework, and hope that there are enough people who will take the time to contemplate it? The story below is Henry’s story. It does not seek to arouse moral sentiment by the exposition of one man’s suffering. Nor does it attempt to valorise the man, or romanticise the abject poverty in which he lived. Rather it seeks to represent a life lived - to the death - on its own terms and according to its own morality.

While drawn to the life-force of this man, and the brutality of his circumstances, my personal, moral and emotional responses conflict with my academic and social position. This demands a level of conscious intersubjectivity and critical self-reflection which, I argue, is a necessary part of the process that is too often glossed as fieldwork experiences or ‘data’ but in fact represents part of our lifeworld.

Keywords: Critical self-reflection, reflexivity, intersubjectivity, HIV/AIDS, South Africa, representation, bearing witness, social suffering

‘Ek eet baie, ek slaap baie, én soen baie baie’ (I eat a lot, I sleep a lot, and kiss lots and lots)
‘Henry’

This is the longest complete sentence that Henry spoke to me in the six weeks prior to his death, and is the only form of verbal self-representation he made to me throughout our interactions. Without wishing to overanalyse it, it is telling that he made the statement in response to my questions about the availability of food with which to take his antiretroviral medication. As I sat on an upturned crate by his bedside, I was caught off guard by this vibrant individual who, despite the fact that he was emaciated and lying on a bare mattress in a dark shack, was still living his life to the full. It was apparent from the start that Henry had never been and would not, in its final chapter, become a passive observer of his life. The twinkle in his eye as he uttered the last four words left me in no doubt that he was flirting with me. Outrageously! It was wonderful. The transcript of our conversation cannot do full justice to my reaction - ‘Interviewer: [Laughs]’. Henry’s partner, Winnie, and the home-based care worker present were visibly embarrassed, rushing to interject and redirect the conversation to ensure that for the rest of the interview Henry was effectively prevented from making any real contribution and things could be kept on a more ‘appropriate’ footing. Sadly, the ‘appropriate’ conversation was the all too familiar macro-narrative of hardship, poverty, AIDS and death – a story told by millions throughout Southern Africa and beyond. In the circumstances, Henry’s failed attempts to shift the narrative of his life from a medical to a human sphere, seemed far more remarkable.

From the outset my visit to Henry’s home was a challenge, the first of many that he would present me with. As we headed back to the clinic that first day Jill, one of the Home based carers, said to me ‘OK, so now we know you will visit people in their homes.’ Only some months later was I told there had been substantial doubt that I – a white, middle-class, female researcher – would really be willing to visit some of the most destitute areas on the edges of a deprived informal settlement. Henry’s home, known to the whole clinic as one of the most problematic environments, had been chosen as some kind of induction for me.

Over the next six weeks as I was drawn into meetings with Henry, his partner, extended family and medical team, my role as a white, middle-class, female researcher became increasingly irrelevant as I was forced to interact as a fellow human being. The effect was profoundly unsettling. Although I had been in similar situations previously, this time, for all I had learned (and taught) as an anthropologist about the clinical gaze and the need to bear witness to those whose lives we seek to understand, I was completely unprepared for the raw, visceral reaction I experienced.

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While attempting to conceal my reaction from Henry and his family, privately I found myself at sea and unable to deal with the turbulent emotions that arose. In the months after his death I could not begin to write without becoming overwhelmed. How could I possibly do justice to the man, his memory, or our encounter? The genuine voice of suffering would be trivialised by the translation of Henry's experience into the language of science and technical expertise (Arendt, 1968). Given that his voice had not been heard during his treatment, writing such a paper would compound that injustice. A rational vocabulary would contribute to a 'symbolic violence' (Bourdieu 1999). 'Giving voice' or 'bearing witness' would simply become a means of arousing moral sentiment to create a 'compassionate moment' (Fassin, 2008), or worse, an exotization of African AIDS – something I have always fought to avoid. As part of a multi-disciplinary team conducting ethnographic research such issues, while regularly discussed, are seldom resolved to everyone's satisfaction. The ethics, morals and politics of representation are such that there can be no definitive answer.

Objective measurements cannot convey the distress of poverty and social degradation in lived experience (Kleinman & Kleinman 1997). Jackson (2010) contends that we ‘do violence to the complexity of lived experience when we make analytical cuts between emotion and thought, or emotion, the senses, thought, and action’ and indeed field experiences can be highly emotional, often unpredictable, sometimes distressing. For that reason, our multidisciplinary team has chosen to tell two stories. One (under review elsewhere) is an academic assessment of the myriad state, social and community structures and services that failed to save Henry’s life. To some extent this has rendered Henry’s presence invisible so he has become almost secondary to the process. The second story, this paper, is situated in the gulf between that battery of agencies and the lived reality of individuals who access those agencies’ services.

The guiding framework for this piece is one of ‘radical empiricism’ (Jackson, 1989), which can be understood in two separate senses (Davies, 2010). Firstly, that the relationships between things (person-to-person, person-methodology, person-environment) are matters for empirical study. Secondly, radical empiricism takes as critical those periods during fieldwork ‘when we are not applying a self-contained method (defined as a method productive of formal interview, statistical, or inventory data)’ (Davis, 2010:23). Rather, it occupies the spaces between things in relationship, and between each separate use of a self-contained method. Crucially, this recognises the use of both approaches (traditional and radical empiricist) in any ‘season of research’ (Davis, 2010:23). This piece is drawn then, from extensive field notes, recorded interviews and participant observation. It also draws on my own ‘non-cognitive modes of learning – the bodily, emotional, or imagined modes of learning which can provide entrées into knowing’ Luhrmann (2010).

There is much that could be said about the social order of Henry’s life – the structural violence which formed its backdrop; hierarchical structures and racial organization which predominate; moral economies which confound; historical inequities which persist. All of this has been done elsewhere. Insofar as his story is one of hardship, pain and eventual death, Henry is all too familiar, so much so that he disappears into the local, national and eventually international statistics about deaths from AIDS. Perhaps there is a paragraph somewhere that speaks of virological failure on first round ARV treatment, or the impact of abject poverty, maybe even the social barriers to accessing and adhering to medication; Henry will be one of the millions represented there; lost in what Rapport (2003) would consider ‘reductive essentialisms’.

This paper is not about how Henry’s death is represented, but about his life and how that is represented. While referencing the evil of totalitarianism, Arendt (1994) argues for the development of a style of writing that allows debate on the issue that ‘solves no problems and assuages no suffering’. Such writing will ensure that we be challenged and perplexed by the ‘difficulty of understanding how our world could be made so inhuman that we might be drawn to engage with the political project of building more humane forms of society’ (Wilkinson, 2006). I do not wish to equate or compare Henry’s experience to the suffering of anyone else, nor to suggest that the care he was given should in any way be considered totalitarian or inhuman. However, sometimes, as Das (1997) observes, pain and suffering ‘may also be experiences that are actively created and distributed by the social order itself’. The complexity of writing about his life and these circumstances calls for a style of writing which will neither turn its face from, nor swallow in, his suffering. I present a short biographical narrative representing the individual life wherein we will hopefully find ‘the data with which to overcome the reductive essentialisms of gender, class, nationalisms, race, ethnicity, religion, age, epoch, locality and so on, regarded as imperative statuses’ (Rapport, 2003:16). It considers Henry’s ‘self-conscious, life-project’ and asks whether it provided ‘a route to a dignified and accomplished life’ (2003:14) or can be seen to have increased his control over his life course (2003:21).

I do this through the multiple lenses of those who knew him - as a fun-loving partner and lover (partner); a doting father (youngest child); a
misguided innocent (absent adult children); a hapless victim (home-based carers); a non-compliant patient (medical team). To these I add my own representation, and Henry’s representation of himself to me. It is undoubtedly the case that none of these is entirely accurate, and several are disputed, but all may be moral insofar as they are principled and decent, or have at their heart ‘that which is at stake for individuals and collectivities’ – ‘what really matters’ (Kleinman, 2006). What really mattered to those around him, his family, loved ones and medical team, was keeping Henry alive. What really mattered to Henry was to be allowed to live what was left of his life as he chose.

For much of our interaction Henry was silent – either by choice, necessity or imposition. Such silences are deeply contextualised and defy simplistic interpretation but any confusion arising therefrom is, Loeb (2006) argues, a direct result of its connection to power as currency for its exercise. At times Henry’s silences were what made people listen. The silences are deliberately echoed in this account. Any attempt on my part to ‘give voice’ to them, or to resolve some of the paradoxes and present a nicely rounded conclusion would, I believe, be unforgivably crass. In the final analysis Henry’s story is cut short, deliberately and brutally.

Henry:
Although he said little during our interactions, Henry was quite capable of making his views apparent. I watched in many family meetings with his medical team while people spoke about him, around him and at him, while Henry was effectively rendered mute, giving little indication that he was aware of the efforts being made on his behalf. When he did speak his voice was unclear and sometimes unintelligible. With the benefit of voice recordings we can rewind continuously to decipher what was being said, but even that is not always clear. In general, decisions were made about his medical care with minimal involvement from him aside from a random grunt or muttered ‘Ja’, when elicited. However, on rare occasions he made it very clear that he was listening, and as those around failed to pay attention to his wishes he chose to register his objection in ways that were increasingly distressing and uncomfortable. When his partner Winnie tearfully objected in ways that were increasingly distressing and uncomfortable, Henry’s representation of himself to me. It is

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the prospects of either partner finding work were, at best, remote. In any event, no employer would take on anyone so visibly debilitated by illness. Eventually, nine months before our first meeting, Henry tested HIV-positive at the local clinic and was referred for treatment.

When we met, the couple’s only income was a monthly child benefit of R230 (approx. €23) for their 8-year old daughter, Henrietta (the only child they had together). They had built themselves a shack on a piece of land which they were renting for R200 (€20) per month. Winnie’s face lit up with pride as she described to me how they built their home together against all the odds. With no access to water or electricity, this shack sat in a cluster of 5 or 6 others, about a mile from the main informal settlement of the area. Scraps of furniture, discarded from other homes, were arranged in two dark rooms – a single bed, a broken dresser, a chair, some plastic shelves, some crates, an assortment of battered tin plates and pots. When rent wasn’t paid the landlord came and removed anything of worth from their shack, so there was no question of them having a radio or mobile phone, or anything of apparent value. Neighbours helped out as much as possible, but support from friends and family was erratic. At the back of the shack, out of sight of the road, was a dumping ground where the landlord illegally dumped the contents of factories he was contracted to clear – empty industrial drums; chemicals; resin.

**Intervention:**

Two days after our first meeting Henry arrived at the clinic three hours late for his scheduled appointment. I had offered transport for the three mile trip but what was needed was manpower to carry Henry to the car, which could not get closer than 100m to his home because of the soft sand. The almost entirely female burden of caring has unexpected consequences. *****

Henry arrives into the crowded clinic’s waiting area with a small entourage - the two home-based care staff are joined by Winnie, and two of Henry’s adult daughters. The medical team are delighted to see the daughters because this family needs an urgent intervention. Henry sits erect in the wheelchair but looks unbearably weak. His hands fall loosely into his lap and he stares straight ahead. He has the most incredible blue eyes, which, given the fact that his cheeks have sunken back into his face, seem to take over his entire face. He is dressed in grey trousers, a blue shirt and, despite the heat, a black zip-up sweater and heavy work-boots with no laces. His grey hair peeps out from beneath a grey knit peaked cap.

In stark contrast to their skeletal father and his partner, Henry’s daughters are both overweight, cheerful girls. In a stuffy, over-crowded office Henry, his daughters, Winnie, myself and June, the ARV counsellor, listen attentively as the senior clinic nurse, Sr. Charlene, explains that Henry is seriously ill and something urgent needs to be done. Winnie cannot cope because she is HIV-positive and unwell herself, and because of their living conditions. No mention is made of Winnie’s alleged drinking problem, although in private conversations with me this point is constantly revisited. There is no appetite on anyone’s part to meet Winnie’s repeated requests that they be provided with the support they need to remain in their own home while they continue treatment. There is obvious tension between Winnie and the girls but everyone seems to have decided to co-operate in Henry’s best interests. Sr. Charlene is brutally direct – unless these medicines work, Henry will die. They need someone to take responsibility to help. Henry is bent forward in the wheelchair seemingly ignoring proceedings. Tracy, his youngest daughter has said her father can come to live with her, but there is not enough space for Winnie. Although there has been some resistance to this in the past, Winnie now agrees that it is probably best that Henry go to his daughter while she returns to her father’s home. It is emphasized to both Henry and Winnie that this is a temporary measure and once Henry is ‘back on his feet’ they will be together again. No mention is made of their 8 year-old daughter and who she will stay with. The meeting is emotional and once or twice threatens to break into recriminations between the daughters and Winnie. Finally, Sr. Charlene asks Henry if he will agree to this course of action and he mumbles ‘Ja’, but it is difficult to say how much he is really taking in.

Once this has been decided, I listen as June counsels Henry’s daughters about the affect and effect of the ARV medications, while Henry and Winnie return to the waiting area. Tracy and her sister are told that these are 2nd line drugs; that there are no 3rd line drugs; this is their father’s last chance; the tablets must be taken at the right time; the combination must be taken together; if one tablet is left out of the combination the therapy becomes ineffective; diet is important; Henry must eat fresh fruit and vegetables, etc. The instructions come thick and fast as the two girls listen, wide-eyed, and have no questions to ask. I am a bit doubtful whether Tracy can comfortably accommodate her father because she has now said quietly on a couple of occasions ‘I must just make space for him’. She also lives in a shack, albeit one with electricity and access to water.

Outside in the waiting area Henry is ponderously eating some kind of stew from a plastic
tub, staring ahead stoically. When he has had enough he puts the tub on the table beside him and Winnie hands him a peeled mango, and a paper towel to absorb some of the excess juice that spills down his chin as he tries to eat it.

We are called to an office for Henry to be weighed. There is not enough space to close the door behind the wheelchair and I hold it steady as Henry is lifted onto the scales by Sr. Charlene and Winnie. Immediately he stands up and his trousers although belted tightly, fall down around his calves, exposing the underpants which hang loosely on protruding hip-bones. Although he is a tall man, over 6 ft., he weighs only 40kg (approx 6 stone). I try to shield him from view of the waiting area as Winnie and Sr. Charlene struggle to keep him standing upright and pull up his trousers in a confined space. Unable to help himself, Henry leans forward onto their backs as they stoop to help him.

Long periods of waiting characterise any visit to the antiretroviral therapy (ART) clinic. In the wide corridor that serves as a waiting room, a row of patients fan themselves desultorily against the stifling mid-morning heat, as they wait to be called for obs, counselling, pill counts, consultations. The corridor is a thoroughfare used by other staff and patients, most of whom hurry by, lest there be some suspicion that they might also be waiting to see the ‘HIV-doctor’.

Tracy and Henry are called away to a treatment cubicle and Tracy returns to ask me to join them. I am gradually being drawn deeper and deeper into the intimacy of Henry’s life. Tracy continually glances towards me, apparently overwhelmed as Sr. Charlene explains to her how to attach a condom/catheter to her father. In her face I see a sudden realisation of the enormity of the task she has taken on and I can think of nothing to say that might offer any consolation. Sr. Charlene gently puts a hand to her arm and says, ‘dis nie jou Pa nie nou, dis jou paciente’ [this is not your father now, this is your patient], but Tracy does not look reassured. A second nurse shows Tracy how to wash her father/patient, how to rub cream into pressure spots, and how to dress the pressure sores that have begun to appear on the base of his spine and his buttocks. Everything is done with the utmost professionalism and care, but throughout the process Henry lies, almost naked, with his face to the wall apparently sleeping and I find myself hoping that he is unaware of what is happening and thus spared any embarrassment. His bundle of clothes is placed on a work surface beside me and the flies continue to hover over, and settle on, his jersey. Once Tracy has been instructed on Henry’s proper care, she is given a bag full of dressings, creams, gloves, etc. and we return to the waiting room.

And so the day proceeds. At this stage Henry and his family have been at the clinic for three hours. The heat is oppressive but although the emergency doors have been opened no air circulates and Henry is becoming confused, irritable and belligerent. It takes a further four hours for us to complete the doctor’s consultation, fill Henry’s prescription at the hospital pharmacy and return to the doctor’s office so Tracy can be fully briefed about the medication. I count 14 different types of medication. Every morning Henry must take 19 tablets (7 ARVs and 12 for other conditions) and every evening he must take 7 (3 ARVs and 4 for other conditions). Finally the doctor is satisfied that the family is sufficiently prepared and they head home. Tracy’s preparation for the transition from daughter to carer is deemed complete.

Shifting the lens:
As the family left that day, I was called back by the doctor who commented ‘You look like you need some counselling yourself’. Immediately I realised that the day’s trauma had etched itself on my face and I had failed utterly in my attempts to remain distant. Distraught and frustrated with myself, my tears seemed futile and completely self-indulgent. On one level I was distressed by Henry’s condition and circumstances, the seemingly forced compliance and a sense that Henry’s care was to some extent being imposed on his children who were not only acting from a sense of duty more than compassion, but seemed ill-equipped to cope with the level of care needed. But my distress was further compounded by my inability to intervene and speak for Henry in a situation where his voice was drowned by the voices of reason from those who sought to help but left him bereft of any agency. I felt my professional role as researcher, which might have indicated some level of empowerment, prevented any intercession. Jackson (2010:47) contends that ‘to participate in the lives of others, in another society, is to discover the crossing-points where one’s own experience connects with theirs – the points at which sameness subsumes difference.’ This was my crossing-point with Henry. Having witnessed others, including my own father, make the painful but informed decision to refuse potentially life-saving and/or life-enhancing medication, I was privately of the view that there were other options available to Henry which no-one seemed willing to offer – the support required to stay in his own home as he wished and undergo treatment, or the option of palliative care in his own home with his partner. From this point on my role became increasingly complicated. As I fought to maintain ‘professional distance’, I was increasingly drawn (by family and the medical team) into an intervention with which neither I nor Henry...
agreed.

A week later I discovered that Henry did not in fact move to Tracy’s house as planned; I was asked by the home-based carers to collect him from his home and bring him to the clinic. On later enquiry I was told that the previous week when driven to Tracy’s house he had sat in the car and screamed, refusing to get out. I arrived at Henry’s shack and was met by his 8-year old daughter, Henrietta, who led me into the dark room where Henry lay on the bed. Winnie was not at home.

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As I explain why I’m here, Henry says something to Henrietta and she takes a small bucket from under the bed and holds it so he can pee into it. Although she seems to take on the role of carer with great ease, the shock of seeing an 8-year old acting outside of the normal role of a child; holding her father’s penis to guide a stream of urine into a bucket, spurs me into action. I cannot remain the passive observer in these circumstances. I am forced to engage fully as a fellow human being. We set about trying to dress Henry in a pair of tracksuit pants that I take from the washing line. I have done this before for sleepy children or for loved ones for whom I have been caregiver, but there is something incongruous about sharing such an intimacy with a virtual stranger. Now I am engaged in the physical act of supporting Henry, touching his emaciated body; feeling the coolness of his skin against mine, his jutting bones; leaning forward to allow him to rest his weight over my shoulder; shifting his weight onto my back so I can manipulate the trousers over his protruding hips. The sudden catharsis I experience from stepping out of the restrictive role of observer is brought crashing to a halt as I realise that without help we cannot get Henry to the car outside. Henrietta has already realised the problem and suggests we go to Tracy’s house for help. This will mean leaving Henry alone and I am faced with the very real dilemma that caregivers in such situations experience every day. You do what you can... what you believe to be the right thing... under the circumstances.

Almost four hours after I got the original call, with the help of Tracy and Noel (Henry’s son), we arrive at the clinic. Winnie arrives unexpectedly and as we settle down to wait the strong smell of woodsmoke that was present in the shack lingers in my clothes and the heat and smell are cloying in my nose and throat. This time when we are called into the counsellor’s office Henry attempts to stand his ground.

June:  
Henry, wat het jy vir my beloewe?

[Henry, what did you promise me?]

Henry:  
Niks nie. [Nothing]

June:  
Het jy niks beloewe nie? Jy het vir my gesê jy gaan by jou dogter gaan bly?

[Did you not promise anything? You told me you would go to stay with your daughter.]

Henry:  
Nee man! [No man.]

June:  
Huh?

Henry:  
Nee, ek wil nie daar gaan nie.

[No, I don’t want to go there.]

Winnie:  
Hy sé ‘die dokter se gat’, hy gaan nergens, hy gaan na sy huis toe. [He says ‘the doctor’s arse’ he’s not going anywhere, he’s going to his house...]

he says he never said that [i.e. he would go to Tracy’s].

Henry:  
Hmm... ek is nie gelukkig daar nie

[I am not happy there.]

Eventually he is told that he must now go to Tracy’s house because Winnie cannot cope. ‘Winnie doesn’t want you any more, do you know that?’ June tells him. ‘Winnie doesn’t want you. She said she has no time for a sick man.’ The words strike me as unnecessarily brutal but Winnie sits impassively. Nor does Henry react to this news.

Tracy explains what they have been doing up to now to try to ensure that Henry has taken his meds. Her husband goes over to Henry and Winnie’s home at 7 in the morning on the way to work and makes sure he has his first dose of ARVs. At 9 a.m. Tracy goes over to give Henry his other medication (non ARV related) and to treat any pressure sores and put in the catheter. Her father is not co-operative, she explains. He hides the tablets in his cheeks and under his tongue and spits them out; she finds them under the bed; he removes the catheter immediately Tracy leaves.

The doctor again stresses the importance of Henry moving in with Tracy. She explains that he doesn’t have any more chances. If he will not move in with Tracy then the only alternative is for him to be sent to the hospice and his family may not see him for up to six months (the cost of transport is prohibitive). She asks Henry if this is what he wants and he says it is not. Her tone is urgent, but kind, throughout and she includes me in her gaze as she says ‘I know you’re tired, Henry, but there are people here in this room who will help you if you will let them help you’. She tries to encourage him to make the effort for the sake of the other people in his life. Eventually Henry is cajoled into saying that he will go to Tracy’s house.

On the drive home Henry lies sideways on the back seat with his head in Noel’s lap. I am pre-occupied - conscious of the fact that Henry may again be unco-operative when we get to Tracy’s house. How will I react? I decide that if Henry refuses to get out of the car I’ll tell him that I can’t take him to his own home; he’ll have to get someone else to take
him. I am conflicted here because I feel that would be patronising and disrespectful to his wishes. Surely that should be his choice. As it turns out, my concerns are unnecessary. We pull up outside Tracy’s house and there is no protest from Henry as Noel lifts him onto his back and carries him through to Tracy’s room. A small entourage of children assembles to greet us and escort us into the room. There Noel turns with his back to the bed and sits down, placing Henry gently on the bed where he falls backwards so that his frail body bounces slightly with the pressure. He laughs. There is no sign of any distress on his part with being at his daughter’s house, or of Winnie’s absence. I notice that his handshake is surprisingly firm as I wish him well and say goodbye.

Some two weeks later, and six thousand miles away I receive a text message:

Sorry to say our friend died this morning in hospital. RIP

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Notes:

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2 It should be pointed out that while I might generally consider myself to be middle class, it has been argued that for those living in reduced circumstances such as we encounter here, my status would be seen as considerably higher.

3 This work arises from a 30 month ethnographic study conducted in the West Coast Region of South Africa’s Western Cape Province – ‘Understanding barriers to access and adherence to antiretroviral treatment in the Western Cape’. The study was funded by a Global Health Research Award (GHRA) from the Health Research Board and Irish Aid, with additional support from the Combat Diseases of Poverty Consortium (CDPC). I am grateful also for the support of the staff at the School of Public Health at University of the Western Cape (UWC) where I was based while in South Africa.