ON ABJECTION, FORFEITURE AND THE REMAKING OF SOCIAILITY IN LESISIFO


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Genealogical accounts of the HIV/AIDS epidemic document the historicized swells and riffs of attention associated with particular risky populations or sexual practices, with effective prevention techniques or brands of responsible and caring citizenship, and with the politics of antiretroviral treatment. An unprecedented amount of attention – often underscored by outrage, panic and hopelessness – has centred on the issue of access to antiretroviral treatments in Africa, and on the malaise of public health systems in Africa (Nguyen, 2010). Research writing about the African “treatment decade” between 1995 and 2005 finds antiretroviral treatment as a globally promised restitution nuanced with insurmountable hitches, varying degrees of support and resistance, and lucky breaks on the ground that govern living with or death from AIDS (Robins, 2009).

Patricia Henderson’s book, AIDS, intimacy and care in rural KwaZulu-Natal: A kinship of bones, provides a microcosm of human experience in this recent politicized writing about the advanced epidemic in South Africa. It is located in a poor, rural community between 2003 and 2007, a transitional time for various (stuttering) antiretroviral treatment rollouts. A kinship of bones is a worthy and meticulous ethnographic account of lesisifo – this illness, a local isiZulu term commonly used to refer to AIDS – in Okhahlamba, a sub-district in the northern Drakensberg in KwaZulu-Natal. Henderson, as a white woman and funded anthropologist, lived in this rural community for three years doing fieldwork, and visited regularly thereafter; and this book is a collection of “stories” about people living with HIV and AIDS, and her exchanges with them. In a time of acute illness and chronic poverty, the book offers an experiential account of suffering, death and sorrow; of the intimacies and intricacies of care of the sick within and between households; and of the tenuous hopes of healing provided by traditional and biomedical treatments. These stories are unfolded with an anthropological eye on local (isiZulu) cultural practices and ways-of-being in everyday life.

A kinship of bones includes a (too) brief section entitled “The study in relation to local literature” (pp 26-30), which sells itself somewhat short in terms of examining the
insights that anthropological and ethnographic research about HIV/AIDS in Africa has produced. These insights include “rich descriptions” of the multilayered dynamics of an epidemic within a community, and critical unpacking of static notions of “culture” as local and global understandings of illness and treatment collide (Dilger, 2010). This writing has also pioneered a narrative style of telling stories about sick, dying and healing people, and stories about the research itself, that address participation, reflexivity about otherness, and ethics – for example, in Steinberg’s (2008) Three-letter plague, previously reviewed in PINS (see Wilbraham, 2011). A kinship of bones does bring several fresh lenses to these (mostly) white-authored accounts of black people’s experience of HIV/AIDS. This freshness incorporates finely textured observations of the embodied, affective and financial aspects of illness within dispersed families; theoretical tools to unpack the parameters of “care” and “responsibility” in relationships with the sick; and a principled stance on the ethics of undertaking research with people who are dying or in mourning. These themes are picked up in more detail below.

A kinship of bones begins with the story of Nkosinathi Dladla’s life; his work, girlfriend, home, illness, treatment, death and funeral in 2003 (Chapter 1). Pseudonyms conceal the identities of real people in A kinship of bones as an ethical precaution where AIDS is still a stigmatizing status. Nine years after his death from khesiifo, Nkosinathi’s narrative is both uneasily familiar and uneasily unfamiliar to South African readers as a primal scene - migrant labour to support a distant homestead; silence about a seropositive diagnosis; a return home, sick, emaciated and emasculated; acrimony within a family regarding the costs of treatment and vagaries of care; inaccessible clinics and hospitals, rendered more so by stigma; an “isolated” death and further familial discord around funeral arrangements. Drawing on theoretical notions of abjection and horror (from Kristeva) and pollution (from Douglas), Henderson uses this account of a young man’s illness and death to give substance to theoretical themes in A kinship of bones - the falling away of bodily coherence in the visceral experience of AIDS as polluted flesh falls away and bodily fluids leak from a disintegrating body (p 41); the fracturing of social relations of intimacy within households, and the forfeiture of social standing (as a breadwinning man) as pollution spreads. This is also an exploration of the care of a ravaged body proffered by women, home-based carers and mothers, aunts and sisters, wives and girlfriends; and the withholding of that care, of abhorrence, exhausted resources, distancing and desertion.

Here and in following chapters, A kinship of bones examines three strands of care, grounded in practices that act on and issue from bodies, that reciprocally reconstitute forms of sociality and mutuality – namely, “to touch and be touched, to carry and be carried, and to exchange speech in the context of illness” (p 23). The book takes its name, A kinship of bones, from a young woman dying of AIDS, who thanked her home-based carer for “touching her bones” while nursing her (p 18). An ethics of respectful attention, care and responsibility towards an ailing or vulnerable other – the notion of solicitude (from Levinas), akin to the hackneyed African ubuntu – is founded on the assumption that selfhood is inter-subjective. Thus, the absence of these threads of inter-relationship fabricates suffering as “a form of solitude, of being cut off and shut up within the self” (p 25). This understands the abjection and forfeiture of an AIDS-ravished (or AIDS-affected) body as physical and social suffering, disintegration and death.
These ideas of belongingness and survival are further explored in the lives of young people who have lost one or both parents to Aids – so-called “Aids orphans” (Chapter 3). This chapter centres on notions of domestic mobility in the changeable custodial arrangements and living circumstances of orphans, and tells the stories, as carefully contextualized case studies, of several young people from Okhahlamba. While incorporating aspects of mourning, despair and turmoil in these accounts, Henderson’s descriptions point to resilience, dexterity and agency in orphans’ pursuit of care and relationship within wider networks of kin and community. Elsewhere, drawing on other aspects of this anthropological fieldwork with young people from this district, Henderson (2012) explores ritual (funerals, marriage ceremonies, games or theatre production activities) and metaphor (expressive genres including letter-writing and local repertoires of terms referring to Aids) as ways in which young people experience and express feelings related to separation, disappearance and death; and “re-stitch threads of sociality” and continuity in their lives.

There is much in A kinship of bones’ impressive ethnography and critical argumentation against what is taken-for-granted for psychologists and other social scientists in the Aids-Research-Industry to attend to. For example, Henderson resists the discourses of vulnerability and social pathology that circulate about “Aids orphans”, and which underpin rights-based interventions with parents and forms of family-support (p 84). This does not naively idealize the resilience of orphans (or any poor, black children affected by Aids), but it questions how “care” is framed in relation to young people and opens spaces for fluidity, variability and complexity. Another useful argument is Henderson’s principled upholding of an ethic of solicitude towards her research participants in respectful avoidance of direct, rapid-fire questioning related to illness or death. Such questions are framed in A kinship of bones as insensitive or threatening for the ill and the dying, those who care/d for them, and for a community in which illness and death are multiplying. Against this, Henderson maps the slow unfolding (over a five-year period) of trust, disclosure and care with one Mandla Shabalala, as she, and his home-based carer, “accompany him in his illness” (Chapter 2, p 70). This witnessing presence by an ethnographer suspends quick understandings of suffering, holds back impulses to interview or to intervene, and allows an ill person “time in which to engage in ways that they have chosen” (p 59).

The narrative style of A kinship of bones is established in and with “stories” – with Henderson’s own acknowledgement of her love of “storytelling”, inherited from her deceased parents (p 12). My reservations about this remarkable and personal book gathered quietly around its untheorized take on narrativity – with its stories standing as conduits to authentic experience, emotion, identity and silenced voices. Henderson seeks “in true empirical fashion” to “record what was ‘out there’”, as she encountered it (p 18). Perhaps this naïve realism was inscribed by the abjection of the realities encountered; that lives were bruised and complicated enough without adding layers of narrative de/constructions? Simply put, narrative distinctions have been drawn in qualitative research activity between “story-finding”, excavating research participants’ accounts of their experience, and “story-creating”, cobbling together fragments from various sources and voices to interpretively forge an integrative account (Kvale, 2009). The narration of A kinship of bones draws intuitively and unevenly on these genres. My disquiet surfaced in the last two chapters, where Henderson’s analytical story-creating shrinks, and excerpts of research participants’ discourse expand. These long excerpts (sometimes more than a page long) seem to give participants room to tell their
stories in their own words. There is nothing inherently wrong with this story-finding – it is possibly a prized feature of anthropological or empirical realism. Theoretical themes around “care” and “responsibility” are established previously, and resonate through the last chapters. The stories themselves are riveting to read – for example, a love story between two HIV-positive people (Chapter 4), and a home-based carer and Aids activist’s experience of accompanying illness in her community (Chapter 5). But several qualms lingered about these stories and their story-telling.

For example, the narrative excerpts from the HIV-positive couple – their own words about their courtship, HIV-diagnoses, bouts of illness, marriage and wishes to have a child – were taken from testimonials they presented in various public forums (including churches) to speak out about their HIV-positive status. It is not clear if they were paid a stipend for these storied performances, but they had been persuaded to perform them numerous times by a local NGO to raise Aids awareness among church-goers (p 130). Smith and Watson (2010) conceptualize “coached” or “coerced” narratives in autobiographical moments such as these, where institutional contexts and discursive constraints shape what is (and may be) articulated. Such a theoretical approach to narration might have offered a tool to unpack the contexts of manufacture and performance of these life-stories more critically; and to engage with the Christian religiosity that was complexly entangled here with traditional African cultural beliefs about illness and healing (cf Nguyen, 2010). For example, care and responsibility seem to be uneasily coupled here with confession and self-transformation, with didactic prophecy, and pedagogy.

But my qualms about stories taken as “experience” should not detract from the value of this beautiful, messy-with-life book. I am awed by Henderson’s protracted ethnographic work, and her storytelling, that at once sprawls out into a community and spills inwards, closely grained, looking steadily (and respectfully) at the minutiae of how illness, grief and healing is experienced in mutual, inter-subjective gestures. There is something astute, fierce and intimate that we take away from reading A kinship of bones – like touching and being touched, we see and care about people in a different way.

REFERENCES.


