

## Social and cultural issues in human tissue use in South Africa

Mary Elizabeth-Anne de Haas, BA (Soc Sci) (Social Work), BSocSci (Hons) (Social Anthropology), MSocSci (Social Anthropology), currently Research Fellow, School of Law, UKZN

University of KwaZulu-Natal, Durban

'One frequently encounters references in lay and professional writings of the ever expanding markets for human tissue where the body is reduced to a "source of raw material for saleable products" ... we are witnessing the global expansion of a "human body shop" ...'<sup>1</sup>

### Human bodies in socio-cultural context

How societies treat the bodies of their members, including when they are dead, tells us a great deal about them. Stone Age burials, like those of the Egyptian rulers, show respect for the dead and beliefs in an afterlife. In our contemporary global village the patenting of human tissue, and the public display of preserved corpses, reflect ways in which bodies have become yet another commodity in what prominent psychoanalyst Erich Fromm refers to as our 'technicised' society<sup>1,2</sup> (among other things, Fromm<sup>2</sup> looks at the relationship between society and necrophilia).

A defining characteristic of humanity is our capacity for abstract thought, and our use of symbols to embody the meaning of the social reality which we construct. Rich in symbolism, rituals are integral to the milestones of life, especially birth and death, for ritual behaviour is 'inevitably about time – its passage, its meaning, and its inexorable association with decay and death as well as with images of rebirth, reincarnation or regrouping'.<sup>3</sup>

The humanity of Neanderthals (*Homo neanderthalensis*) was confirmed by the discovery of artificially dug graves (no easy task using stone tools on rocky ground), indicating funeral rites of some type.<sup>4</sup> Stone Age burials too, including in southern Africa, show evidence of ritual and beliefs in an afterlife. Valuable goods were buried with the deceased, some gravestones were beautifully decorated, and bodies were positioned facing the rising sun in the east.<sup>5</sup>

Rare instances of cannibalism following death, including the opening of skulls to consume the brain, may seem contrary to notions of respect for the dead. A modern example of this practice was reported by doctors working in an isolated area of Papua New Guinea, who traced a disease of the brain known as kuru, which was leading to large numbers of deaths in the area, to this practice.<sup>6</sup> However, when such behaviour is viewed in the context of the body of shared ideas and understandings about the world – culture – of which they are part it can be understood as ritualistic, a type of communion involving the integration of deceased into the kinship network of which he or she was part.<sup>1,2,7</sup>

By contextualising such practices it becomes clear that they are very different to the type of mutilation and desecration deliberately inflicted on the bodies of enemies, including the traitors within one's own societies – those accused of treason and witchcraft.<sup>8</sup> Consider, for example, the difference between the mass graves of

Holocaust and other genocide victims to the dignified burials given to members of one's own group.

### Culture and human tissue in southern Africa

Cultural norms, values and beliefs impact in very significant ways in matters relating to the human body, especially as they relate to birth, death, health and illness. However, although broad patterns of these 'shared understandings' are evident, individual interpretations (within a linguistic group or region) vary. Culture is also dynamic, especially in times of rapid social change.

In the indigenous farming societies in southern Africa burial, surrounded by elaborate rites, has been the norm during recorded history (see e.g. Ngubane<sup>9</sup>). These practices are linked to beliefs and rituals centring around ancestral veneration, which are found in most societies in Africa, and many elsewhere in the world. While ancestral graves are regarded as sacred, it is accepted that they may need to be abandoned as people move elsewhere (as occurred during much of history), and there are specific rituals which keep the ancestors informed, and allow them to remain a presence in the lives of their descendants.

Burial serves to protect the bodies of the deceased not only from the predatory activities of wild animals, but also from witches and sorcerers who, through access to body parts of deceased relatives, are believed to be able to inflict dreadful harm on living family members. Edwards describes how, in the Eastern Cape, ants collected from graves, which are presumed to have been eating the flesh of the deceased – or even blood from an accident or murder scene – have been used to prepare medicine to induce a type of spirit possession known as *amafufunyana* in one's enemies.<sup>10</sup>

Beliefs in spirits and witchcraft (found, in different forms, in all societies), and the need to obtain different types of medicine to either harm one's enemies or protect oneself from such threats, fuel trade in body parts, taken from living or dead people. That there is a vigorous trade in body parts between South Africa and Mozambique, which is documented in a recent report by the Human Rights League, Mozambique, is therefore hardly surprising.<sup>11</sup>

Of the thousands of murders in South Africa every year some appear motivated by the need for body parts, which are removed either before or after death. Also of concern is the apparent failure to supervise or monitor those whose job it is to care for the living and the dead. During 2010 decomposing bodies of two women

were discovered in two different hospitals in Durban – Prince Mshiyeni at Umlazi, and Addington in central Durban. Also reported was the disappearance of the body of an infant from the mortuary at Prince Mshiyeni Hospital.<sup>12,13</sup> During a recent public sector strike, mortuary workers at Magwaza Maphalala (Gale) Street mortuary in Durban embarked on a deliberate programme to sabotage forensic operations, including switching off fridges and muddling the name tags on corpses, showing contempt for the human remains entrusted to their care.<sup>14</sup> There are longstanding complaints about the conduct of staff members at this state facility which the Department of Health has failed to address, and cases of insurance fraud using unidentified bodies are reportedly under investigation by the police. Whether or not allegations of dealings in body parts between certain staff and *umuthi* (medicine) sellers in Durban are true, the lack of proper management at this facility would facilitate such dealings.<sup>15</sup>

## Culture and power in southern Africa

Although culture is of crucial importance it cannot in itself explain human behaviour unless it is considered together with the structure of society, i.e. the network of relationships among its members, the status of whom varies greatly in terms of their access to socio-economic and political power.

Like anatomists dissecting a human body, social scientists use tools to try to understand and explain the workings of the social body, society. However, unlike those used by anatomists, the tools used for this purpose – such as culture and social structure – are simply concepts. While it is acceptable to use the term ‘cultures’ as a heuristic device (although it is more accurate to talk about societies), it is a distortion to accord these supposed entities some sort of objective reality dissociated from the human consciousnesses from which they are abstracted.

This point is important because in South Africa this term has been (and still is) badly abused, especially for political purposes. Not only was it employed by the apartheid state to disguise the racial basis of its homeland system, but it was also used to try to justify a special political status for what is now KwaZulu-Natal, linked to the historic Zulu nation.<sup>16</sup> After so many years of racial separation and indoctrination, it is not surprising that culture and ethnicity, like race, continues to receive undue prominence in South Africa. The *ethnos* approach to this concept, which underpinned apartheid and equated race with culture and nation, had its roots in the very same Scientific Racism of the 19th and early 20th century that spawned Nazism. After the atrocities perpetrated in its name during World War II it disappeared from political discourse everywhere in the world, except for apartheid South Africa and the former Soviet Union.<sup>17</sup>

It was this ideology too, together with its close associate Social Darwinism (that societies occupy different rungs on the evolutionary ladder), which led to many southern African Bushmen (San) being exhibited in Europe during the 19th century.<sup>18</sup> Among them was Sarah (‘Saartjie’) Baartman whose ‘well preserved, articulated and mounted skeleton’ as well as brain and external genitalia remained on display in a French museum until relatively recently, and whose remains were finally, with some difficulty, repatriated to South Africa in 2002.<sup>19</sup>

The treatment meted out to Baartman and others viewed as being of inferior races is explicable only in terms of the gross im-

balances of power, and the ideology which justified it, of the period in which these events took place.

Although the world has changed dramatically in the past century, the degree of control one is able to exercise over what happens to one’s body while alive and dead – access to health care, the type of burial relatives can afford – remains a function of one’s status in society. Issues relating to the use of human tissue in South Africa, and ethics surrounding this use, also need to be placed in the context of globalisation.

## The global context

The 1999 Human Development Report published for the United Nations describes the contemporary market-driven world as one in which ‘trade, patents and copyright’ determine not only the paths of technology but also those of nations.<sup>20</sup> Global markets are dominated by powerful multinationals, some of which have more economic power than some nations.<sup>21</sup>

Pharmaceutical companies are among the most powerful of these global players, and wield an extraordinary amount of influence, including over what is published in the media<sup>22</sup> (see especially chapters 33 and 34) and even in leading medical journals.<sup>23</sup> They also fund a great deal of research.

Recent decades have seen the exponential growth in the appropriation of intellectual property rights by both individuals and multinationals, including pharmaceuticals, and the growing numbers of biotechnology companies. This development has been compared to the historical enclosure movement of Europe, which saw ordinary people deprived of their common property and means of subsistence.<sup>24</sup> For the past 20 years, the overwhelming majority of patents registered have been held by several industrialised and, more recently, industrialising nations (China, Republic of Korea). In 2005 the largest number of patents granted were in the USA.<sup>20,25</sup>

Human genes are among the items patented. The Council for Responsible Genetics (CRG) cites research showing that in 2005 almost 20% of human genes were claimed by USA patents, as well as subsequent research suggesting that the percentage is actually higher. Universities and research institutes, as well as pharmaceutical and biotechnology companies, are among those holding such patents.<sup>26</sup>

According to one projection, commercial developments linked to the Human Genome Mapping Project – described by UNESCO as the common heritage of humanity – were expected to reap sales of \$60 billion worth of products per annum by 2010.<sup>27</sup>

If, as the CRG argues, ‘bioprospecting’ – ‘the hunt for new genes to exploit for profit’ – is indeed ‘a vast new frontier for science and industry’, what are the implications for South Africa?<sup>28</sup>

## South Africa and the global health industry

South Africa remains among the most unequal societies – if not the most unequal – in the world.<sup>29</sup> Large sectors of society, especially in impoverished rural areas, are still disempowered. True democracy has not taken root, especially in areas in which violence levels are high, and people fear to express themselves freely.

In matters pertaining to health power differentials play themselves out in various ways, including the type of health services one can afford, and relationships between health professionals and patients/research participants.

Research, including by overseas-based researchers, has grown dramatically in the past 20 years, largely because of the extremely high rates of HIV/AIDS and tuberculosis in South Africa. The vast majority of this research takes place in poor communities in which people use public health facilities (hospitals and clinics), and where people are often uninformed about their medical rights, especially relative to those who are better off, and who have access to the internet and medical reference works.

In rural areas under traditional leadership there are further power dynamics that impact on health. This essentially feudal system is not a democratic one, since appointment to this office is theoretically based on heredity but has, since colonial times, also been subject to political manipulation. The conduct of these leaders varies greatly – some strive to run their fiefdoms in a democratic manner, but most are extremely autocratic, some ruling by fear (see the example of Macambini Traditional Authority in KZN reports<sup>30</sup>). Although a few of these traditional leaders are now female, rural women in general enjoy little power, particularly in KZN where the legacy of codified customary law which diminished the status of women lingers.

When research takes place in such communities – for example, at the Africa Centre based at Hlabisa, northern KZN – researchers usually consult with, and obtain permission from, such leaders before proceeding with research. The leader may thus exert pressure on members of his constituency to participate in the research.

In much of the collaborative research involving overseas-based partners, it is common for human tissue samples, including (but not exclusively) blood, to be sent to laboratories, including in the USA. The poor thus become legal suppliers of human tissue – transforming themselves, through their involvement in medical research, into 'valued objects'.<sup>1</sup>

HIV vaccine research illustrates how the poor become the targets of medical researchers.

An initial vaccine trial run by the MRC in Durban, which solicited volunteers across the socio-economic spectrum, was closed down in 2005. Few volunteers had been enrolled, and there were concerns that the site of the trial (Durban) was 'not in a community where it would be easy to recruit large numbers of volunteers needed for Phase II and III trials'.<sup>31,32</sup>

In 2007 comment was invited from interested parties about the proposed vaccine trial of 'genetically modified organism' at a number of sites countrywide serving mainly black Africans, including vulnerable mineworkers.<sup>33,34</sup>

Despite the high number of people to be recruited – 3 000 – the African Centre for Biosafety (ACB), which made a submission about the trial, experienced a 'lack of information in the public domain'. It proved impossible for the ACB to obtain information necessary to launch a PAIA (Promotion of Access to Information) application in time for its submission. Obstacles included the unwillingness of the vaccine manufacturer, Merck & Co, and the National Institutes of Health (NIH) in the USA, to assist, and delays by various South African bodies, including the Medicines Control Council (MCC).<sup>35</sup> Working on the sketchy data provided in press

reports, the ACB raised a number of concerns in its detailed submission to the Registrar, and called for the application of the 'precautionary principle' and 'for a moratorium on clinical trials of AIDS vaccines based on adenoviral vectors'.<sup>35</sup> The Third World Network echoed this call.<sup>36</sup>

These calls were ignored and in January 2007 a start was made with enrolling and vaccinating participants.<sup>37</sup> In September 2007 the trial (dubbed the Phambili trial) was paused and, in October, suspended, after similar trials in the USA showed signs that 'the vaccine somehow raised the risk of infection'.<sup>37,38</sup> In November 2007 a weekly newspaper reported that there was a scramble to locate all participants to ascertain how many volunteers had become infected while participating in the trial (only 220 of the 308 participants in Soweto had been located at that stage).<sup>39</sup>

Since the sponsors in this research were American-based, at least some of the specimens taken probably left the country. Permission to take specimens must be given as part of the informed consent process and, in terms of international ethical norms, additional permission must also be obtained if specimens are to be stored, with the option of consent being withdrawn at a later stage. While this rule applies in principle, once the samples have left the country oversight into what happens to them is lacking – raising questions about whether they end up as the intellectual property of a researcher, a university, or a pharmaceutical or biotechnology company.

Given the ease with which patents are granted in the USA, and the scramble to patent human genetic material, the loss of control over human tissue when it leaves South Africa is of great concern. Access to an individual's genetic code through human tissue samples is an invasion of privacy – both individual and family – and should only be allowed with the full knowledge, consent and control of the owner. How many poor people understand the potential implications of allowing their DNA to be used for research purposes? Do they know that the whole genome can be 'scanned for all personal biological details coded by the genes', that extracted DNA sequences can be cloned and used for a variety of purposes, and that they may hold huge commercial value?<sup>40</sup> If donors do not fully understand these implications of providing specimens can they be said to have given truly informed consent?

Although financial incentives to participate in research are not permitted, there is a thin dividing line between 'compensation' for time and travel and incentive. This compensation is itself an inducement to poor people to participate. The Medical Research Council (MRC) guidelines, for example, stipulate a sum of R150 per visit by the participant to the research site, which is a significant sum of money for an unemployed man or woman. Addressing a microbicide conference in Cape Town in April 2006, controversial former Minister of Health, the late Dr Manto Tshabalala-Msimang, correctly raised concerns about the possibility of financial compensation acting as a 'perverse incentive' in poor communities.<sup>41</sup>

It subsequently became apparent that women were enrolling for more than one clinical trial as a means of earning money. Hlongwa and Zulu describe how participation in a microbicide trial had become a 'money-making scheme' for some young Durban women. Umlazi resident Zama Ncwane is quoted as having admitted to 'having been attracted by the money', saying she had 'registered in three of the MRC sites using three different names' for research she claimed she did not understand.<sup>42</sup> This particular trial was subsequently terminated early amid adverse publicity.<sup>43</sup>

At another MRC site testing microbicides, in North West province, teenage girls were reported to be 'bunking school' to visit a research centre and participate in the research. They were being paid a total of R1 700 over the 2-year research period.<sup>44</sup>

Although research involving human subjects may not take place without the approval of ethics committees, there is a conspicuous lack of oversight, and no independent monitoring of this type of research, in South Africa.

While not minimising the importance of collaborative research, two caveats are relevant: Firstly, how are HIV- and tuberculosis-infected people in general benefiting from the many millions of dollars that have been poured into research on these potentially lethal diseases? If, for example, the Merck vaccine had been shown to be effective, would South Africa have had to expend huge sums of money to purchase it at going rates, despite much of the research on the human subjects having taken place here? Would participants who contracted HIV while on the study receive top-quality antiretrovirals from the sponsors, or would they be referred to state health facilities?

Secondly, it is not clear why specimens are being sent out of the country. Why, if it is lacking, is appropriate technology not installed, and capacity developed, to conduct what tests are needed on research specimens (especially as, historically, South Africa has been among world leaders in medical technology, including in its pioneering work on heart transplants)? Why this dependency on overseas expertise and technology when, as the CRG points out, 'Patents held by the industrialized world on resources from the developing world will serve as a tool for the North to accumulate more wealth from the already economically impoverished South.'<sup>28</sup>

Saartjie Baartman, opines Phillip Tobias, 'epitomises an entire epoch of racial repression and colonial subjugation'.<sup>19</sup> Those exhibiting Baartman and others also profited from her degradation and that of other indigenous Africans. If powerful multinationals, and foreign-based institutions and individuals, are now profiting from the commercialisation of human tissue supplied by poor South Africans, have we not simply swapped one type of colonialism for another, in the form of bio-colonialism?

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