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**Transplant Anxieties: discourses about bone marrow / haematopoietic stem cell transplantation**

Emily Avera AVREMI001

A minor dissertation submitted in partial fulfillment of the requirements for the award of the degree of M Phil. in Diversity Studies

Faculty of the Humanities

University of Cape Town

2008

**COMPULSORY DECLARATION**

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature:

Date: 7.2.2008

Signed by candidate

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**List of abbreviations**

**BMT-Bone marrow transplant(s)/transplantation**

**EFI-European Federation for Immunogenetics**

**GSH-Groote Schuur Hospital**

**HLA-Human Leukocyte Antigen**

**LTI-Lab for Tissue Immunology**

**MUD-matched unrelated donor**

**PBSC-Peripheral blood stem cell donation**

**SFF-Sunflower Fund**

**SABMR-South African Bone Marrow Registry**

**WMDA-World Marrow Donors Association**

**Abstract:** This minor dissertation examines the various discourses in the Bone Marrow Transplant (BMT) network in South Africa. The organisations in the network which were observed using participant observation were the South African Bone Marrow Registry and the Sunflower Fund. To complement this, the researcher interviewed staff members at these organisations as well as at a public hospital haematology unit in the Cape Town area that conducts BMT. Additionally patients, donors, and their family members were interviewed. Some media related to the BMT network was also analysed. Informed heavily by Troy Duster's work on genetic and social feedback loops, it was found that the discourses reflect a complex interweaving of biological materiality, ethnicity, culture, mortality, health resource rationing, South African nationhood, and the limits of bodily integrity. There is extensive discussion of how the BMT discourses demonstrate the necessity of engagement with several issues: the hybridity of expert and lay intercultural communication, health inequalities, human rights, and the prioritisation of first and third world medicine, the meanings of race, culture, ethnicity, and nationhood in a diverse South Africa, conceptions of donor shortage, and the imperative of saving lives through medical practise.

## **Chapter 1: An Introduction**

In the case of health care in South Africa, the construction and inflection of diversity—in many forms (e.g. culture, nationality, race, ethnicity, class, and gender)—has been no less pronounced than in other sectors of society. While much of the health focus in South Africa has been on AIDS, other issues of medical treatment also present the complexities of a diverse South Africa. The subject of my work as it is outlined in the following pages, is a detailed analysis of discourses and practises articulated by a professionalised network of people and organisations involved in bone marrow stem cell transplantation (which I will henceforth call the Bone Marrow Transplant [BMT] network). It presents a compelling study of the discourses of health, mortality, rationalisation, race, ethnicity, genetics, and nationhood. This data was analysed in concert with accounts from patients, donors, and family members who interact with this network.

As bone marrow stem cell transplantation is a form of medical treatment with characteristics that differ markedly from other forms of transplantation and transfusion that are more commonly known about, i.e. organ and blood donation, this research may add more nuanced perspectives to current discussions about donor ethics, integrity of the body, and the social construction of donor 'need' especially as it highlights matters of life and death.

### **A Dissertation Roadmap**

The first instances of bone marrow transplants from a related sibling donor were pioneered in the 1950's by E. Donnall Thomas in the U.S.A. While there are other

treatments, e.g. chemotherapy, for patients suffering from life-threatening blood disorders like leukaemia, when other methods have been exhausted, a bone marrow/haematopoietic stem cell transplant is often the only option for survival. In most cases, the search for a donor begins with the family, where the chance of finding a match is highest. Siblings have a one in four chance of being Human Leukocyte Antigen (HLA) identical with the patient. Plus, with a related match, there is the least risk for graft-vs.-host disease (GVHD)—when the bone marrow stem cell transplant graft triggers an immune response in the body that rejects the attempted engraftment (Munker et al, 2007).

Only 10% of those searching for a compatible sibling will find a match. Some instances of cord blood donation have occurred, but it is not the primary donor source. More commonly, as medical science enabled matched unrelated donor (MUD) transplants, registries were established to manage a database of volunteer unrelated donors. Nonetheless, the registry search for an unrelated donor with the matching HLA tissue types is often tantamount to finding a needle in a haystack.

Robert Veatch clearly defines living donors as falling into four different categories of relation: 1) genetically related, 2) legally but not genetically related and more expansively, 3) close friends, and 4) strangers (2000). In medical terms, MUD means unrelated strictly from a genetic standpoint, though most matches must have very close genetic similarities in HLA typing. MUD usually implies that the donor is a stranger to the recipient, anonymously identified through a registry search. In chapter 6, the relationship of donor and recipient is considered.

The Anthony Nolan Research Centre in the U.K. was the pioneer in managing centralised marrow donor files, and provided an international template from which other

registries worked (Coppo, 1997: 431). The largest and the most ethnically diverse registry, is the National Marrow Donor Program (NMDP) based in the U.S.A. (Ruff et al, 2006).

In the mid-1970's the University of Cape Town in South Africa developed allogenic bone marrow transplantation as a treatment option in their facilities. With the purpose of creating 'a national organisation with the responsibility of processing requests for haematopoietic stem cells [cells that give rise to all blood cell lineages and recapitulate themselves] from unrelated donors emanating locally and from abroad' and 'because of the presence of rare HLA antigens, particularly in patients of African ancestry,' the South African Bone Marrow Registry (SABMR) was established in early 1991(Munker et al, 2007: 63, SABMR, 2007: 3 & duToit et al, 2005: 25). As it has continued with its efforts in this regard, they are the major organisation involved in coordinating MUD transplants in South Africa, making them a key site for participant observation in this research project.

In association with the SABMR, the Sunflower Fund (SFF) is the primary South African organisation that functions to recruit, educate, and fundraise for the tissue typing of potential bone marrow stem cell donors. I conducted interviews and participant observation at the Sunflower Fund. They are the organisation that generates the most publicity—of its own making or otherwise. Chapter 3 deals with analysis of media thereof, using theories of dichotomy of expert and lay communication in medicine. I will propose that the SFF is a hybrid of these two cultures of communication.

According to the dominant discourse in the transplant network, for the majority of patients who must search for an extra-familial donor, the best chance for a match is

someone of the same ethnic background. To fully benefit patients of all ethnicities there must be enough representation in the registry. This discourse will be explored in greater detail in Chapter 4. There are also attendant discourses about South African nationhood and genetics that are implicated in the discussion about ethnicity as it plays a role in ethnic representation on the SABMR.

Advanced medical technology and sheer amount of resources required in facilitating the possibility and actuality of a bone marrow stem cell transplant warrants contextualising in light of South Africa's stark socioeconomic inequality. Chapter 5 broaches this subject in consideration of AIDS and other nationwide health care priorities, as influenced by the orthodoxy of rationalisation of health care resources. Particularly looking at GSH, a public hospital that serves many patients who generally cannot afford private care, the issue of socioeconomic inequality is evident as an additional stressor for patients, donors, and families concerned.

Chapter 6 adds an additional layer of complexity to the case of discourses and practices of the transplant network, bringing to bear literature about bodily integrity, the construction of need and shortage of donors, and ultimately beliefs about human mortality.

### **A Basic Description of the BMT procedure**

Before analysing the discourses used within the professionalised network involved in bone marrow transplants (BMT), it is necessary to explain the basic medical understandings of BMT, or haematopoietic stem cell transplants (SCT). Henceforward, however, I will mostly refer to both procedures under the umbrella of BMT, as is commonly done in the discourse observed. When considering the discourses produced in

relation to such transplantation because those discourses often make reference to the procedure itself, it is important to explain it.

Haematopoietic stem cells are found in the bone marrow. The main method of harvesting was initially marrow extraction performed with anaesthesia and syringe insertion into the back pelvic bones where marrow is abundant. This is generally an outpatient procedure with some soreness, and the donor usually can resume normal activity within two weeks. Using the product harvested from this procedure transplanted to the recipient is referred to as bone marrow transplant (BMT).

Now in South Africa, the method almost exclusively utilised is aphaeresis. The haematopoietic stem cells are in peripheral blood, though not in the same abundance as in marrow. Haematopoietic stem cell growth factors are administered to donors, 5 days before harvesting to stimulate excess production of stem cells in the peripheral blood stream. The donor undergoes a day-long process 'in which a machine continuously withdraws blood from one vein of the donor, removes [the needed haematopoietic stem cells] by centrifugation, and returns the remainder of the blood through another venous access' (Munker et al, 2007: 68-71). Recipients receive the stem cells through transfusion

In both of these instances, the procedure the donor undergoes is markedly different from both blood collection and organ harvesting. While donation does not require surgery as organ harvesting does, it is a slightly more painful and longer donation experience than a blood drive. The basic differences in harvesting procedures are enough to call for a re-evaluation of donation and donor consent in relation to BMT.

MUD's are contacted only when they are identified as potential matches, sometimes many years after their initial registration. That those MUD's have been

recruited and given consent at an earlier stage through registration changes what attitudes and consent develops. This is very different from the usual timing of gaining consent from living organ donors and blood donors. Though in related BMT donors, the timing of donation request may be more similar to a transfusion or organ transplant consent. The SFF generally handles recruitment and retention of potential donors. The matching and contact of unrelated donors is undertaken by the SABMR. Matching of donors and recipients will also be covered in more detail later on. Suffice to say it is a very specific kind of matching more varying and nuanced than blood types requiring specific donor-recipient compatibility.

## **Chapter 2: Methodology, analysis, ethics and theoretical inspirations**

### **Ethical considerations**

Prior to my participant observation research period, and most of my interviews, I underwent ethics review with the social anthropology department based on a research proposal. I was advised to change some of my proposed research so that it was more smoothly operationalised. Upon revision it was further submitted to the UCT Faculty of Humanities ethics committee, and I received clearance for my research. I informed all organisations involved in my research that I had received clearance. To my knowledge, this was an acceptable level of ethical review for all parties involved.

### **Participation Observation Field Sites**

In November 2007 I conducted fieldwork at the Sunflower Fund (SFF) which included doing volunteer work for the organisation as well as observing everyday work practice. This office serves as call centre where inquiries from potential bone marrow donor registrants are fielded and their registration is handled.

My second three weeks of participant observation between November and December of 2007 was in the SABMR. As the site that manages the matching of related and unrelated bone marrow I hoped to learn about day to day organisational practice, understanding policies and rationale behind such practise. Aside from a day helping donor relations personnel and fraternising with staff during tea breaks, I spent a good deal of time in the office space occupied by the SABMR deputy director. Additionally, I spent a few days mostly in the Lab for Tissue Immunology (LTI). It serves the

laboratory testing needs of the SABMR, and for GSH, especially departments which handle transplantation. The LTI staff is located just downstairs from the SABMR, and they interact and work together very closely. However, the relationship born partly of proximity may change in the future as the LTI is moving to another GSH building in 2008.

### **Participant observation methodology**

I was guided in the method of participant observation by Kathleen DeWalt et al, 'hanging out' as a means of both observing and recording information about the participants and the site (1998). As H. Russell Bernard elaborates, 'hanging out builds trust, and trust results in ordinary conversation and ordinary behaviour in your presence' (1995: 152). Hence, the act of simply 'hanging out' with informants enhances the validity of one's work. Still, I do recognise the limitation of my time period in each site on the scope of participant observation, though it was enough to establish a fair degree of rapport. Both the data and its interpretation presented are, only a dip into an ongoing overall conversation about the BMT network with participants, which I hope to have.

\*\*\*In terms of field notes I was particularly inspired by the work of Clifford Geertz, whose principle of 'thick description' reflects the kind of ethnography I sought to foster. It is the task of the ethnographer to glean, in his words, 'a multiplicity of complex conceptual structures, many of them superimposed upon or knotted into one another, which are at once strange, irregular, and inexplicitly, and which he must contrive somehow first to grasp and then to render'(1973: 10). Geertz says that a virtue of anthropological work—and more pointedly thick description—is its ability to capture a rich tapestry of sociality in a very narrow context: 'The methodological problem which

the microscopic nature of ethnography presents is both real and critical....It is to be resolved ...by realizing that social actions are comments on more than themselves that where an interpretation comes from does not determine where it can be impelled to go.' (ibid, 1973: 27). As such, I attempted to take field notes which monitored as much detail as I could in order to provide the thickness required of ethnography, noting verbal and nonverbal information from the field and quotations from participants when I could manage to record them,.

However, James Clifford points out, 'thick description', while offering useful insight, cannot be the only textual account of cultural articulations. Along with descriptive field notes, transcripts, for example, 'may register quite different relationships to the people, discourses, and events studied in fieldwork' (in Sanjek, 1990: 68). I supplemented my participant-observation ethnographic fieldwork with semi-structured depth and focus group interviews.

James Scott's theory of hidden transcripts has informed my approach to research practice and data analysis. He asserts that there will always be facets of life, whilst perhaps highly relevant to the research at hand, that informants will not explicitly share. 'The practice of domination, then, creates the hidden transcript. The hidden transcript of subordinate groups [sic] in turn, reacts back on the public transcript by engendering a subculture and opposing its own variant form of social domination against that of the dominant elite'(1990: 27). 'Power means not having to act, or more accurately, the capacity to be more negligent and casual about any single performance...Less of the unguarded self is ventured because the possible penalties for a failure or misstep are severe; one must constantly be on one's "best behaviour"'(ibid, 1990: 29). Perhaps the

power relations with my participants in the research are not as imbalanced as those which Scott characterises in his work, but the endeavours of research are, in a way, a subtle form of dominance— requesting access, gaining knowledge from participants, asking questions, and inhabiting a space. Aware of this during my time in the field and in my reflection and analysis I have tried to lessen the starkness of dominance and subordination between the participants and myself as reflected through my ethical considerations. Taking both Scott and Clifford into account combines a healthy scepticism of the explanatory power of my research and the data I have collected with a dose of optimism about the possibilities of what the research may also reveal.

#### **Semi Structured Depth Interviews (SSDI) and Focus Groups**

I formatted my interview schedules using three categories of questions: The Central Research Questions frame the overarching objectives of the research so that an interviewer can always be conscious of those objectives whilst they conduct the interviews even though they do not directly ask those questions of respondents. Theory Questions (TQ's) are the conceptual objectives of the interview at hand, but again, not asked directly of the respondent. They are the foundation upon which the Interview Questions (IQ's) are built. The IQ's are directly asked of the respondent to hopefully elicit data that speaks to the TQ's under which they are organised (Wengraf, 2001).

In addition to individual interviews, I conducted a focus group shortly after the observation period with the Sunflower Fund staff. Before my formal research began, I held a focus group with the GSH haematology unit including a doctor, nurses, and the social worker to generate a collaborative discussion of the ethics of working with patients

and families in research, and also to gain a richer understanding of GSH staff experience around BMT and treatment of haematology patients.

### **Analysis of Data**

Ernest Laclau and Chantal Mouffe's method of discourse analysis in examining my data. To summarise: 'The aim of discourse analysis is to map out the processes in which we struggle about the way in which the meaning of signs is to be fixed, and the processes by which some fixations of meaning become so conventionalised that we think of them as natural' (Jorgensen & Phillips, 2002: 25-26). Taking the approach that social divisions and categorisations sprang forth from contestations of power through discursive frameworks (ibid, 2002), this is an especially interesting point to consider in the targeting of specific groups and their 'need' for more donors.

Michel Foucault's work on bio-power is also especially relevant in discourse analysis because it is a concept that he describes as 'what brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life' (1978/90: 143) Consequently, that is what is at stake in my research: A deeper understanding of the way the people I have learned from articulate certain discourses which reflect the character of this 'knowledge power' about what many say is the work of 'saving lives', and in turn, influence ideas about the body, health, illness, and mortality, about ethnicity, and about South Africa as they are intertwined.

Laclau and Mouffe also use Gramscian-defined *hegemony* as a descriptor in discourse analysis. This term is extremely useful to conceptualise the way in which discourse can momentarily galvanise meaning and a given political dynamic so that it

becomes naturalised—‘so much a part of common sense that they cannot be questioned...social consensus, which masks people’s interests’ (Jorgensen & Phillips, 2002: 32). However, as Andrew Spiegel points out, hegemony is not the only force that impels human activity, rather it affects the extent to which variations of practice may develop or continue (1997: 13). In fact, much of human activities’ persistence is often due to a sense of perpetuity, where people ‘go on’ in a given manner as there is nothing compelling them to alter practices guided by a ‘tacit knowledge’. Before thinking of ethno-cultural factors one must consider that practice may have arisen for political reasons, but it is not necessarily why they are still around. It could be that the imperative in the BMT network for ‘saving lives’, for example, is not a solely determined by political motivations. While bound somewhat by hegemony, they are perhaps part of alleviating unwarranted existential anxiety. Not in opposition, but in concert with notions of power embedded in discourse and practise, Spiegel’s viewpoint offers another level of analysis in such cases.

#### **Access and changing research focus: Thoughts on self-reflexivity**

A primary ethical concern is a shift in the focus of my research from the initial period of gaining access to the organisations I worked with. Two years prior to arriving in South Africa, my work in the U.S. with the Asian American Donor Program and interest in the ‘shortage’ of donors from specific ethnic backgrounds, led me to plan further research into the issue of cultural challenges in recruitment of donors from ethnically underrepresented communities in South African Bone Marrow Registry and its specific local context. I initially e-mailed the SFF and was passed onto the SABMR where my previous research plans were discussed with staff. My contact with the

SABMR and to some degree the haematology unit at GSH, as well as their openness and willingness to provide me access to their facilities and relationships with personnel, was with the understanding that this was my research objective. There was a hope and expectation that my work would help in getting more donors on the registry.

However, upon more recently being exposed to scholarship that frames the 'need' for donors as socially constructed, as well as literature about the integrity of the body, I shifted my research to investigating how that 'need' has arisen discursively in the first place, and its impact. To embark on research that assumes the construction of specific ethnic or racial communities, for instance, without first looking at that construction, would be scholarship that, albeit useful in some respects, elides deeper issues I have been inspired to probe.

Furthermore, I assert that the consequences of the discourses about ethnicity, culture, and HLA tissue types (and their genetic inheritance) in relation to South African nationhood and diversity are well worth a closer look. This speaks to my initially proposed research, but it looks at the questions of culture and ethnicity from a different vantage point. Examining the professional network of organisations where those discourses primarily originate hold as much value as comprehending ways that ethnic communities participate and are situated in those discourses. I include cases of patients and a donor to ensure that the discursive examination engages with varying perspectives.

### **Chapter 3: An analysis of BMT network-related media and its themes--A hybrid of lay and expert intercultural communication**

As a means to situate my data, this chapter begins with an analysis of materials produced by the Sunflower Fund PR. These include fundraising information, pamphlets, and official website content. This chapter also considers the public translation of this information through news articles compiled for and about the Sunflower Fund from the last three months.

Bradley Gorham argues that 'the media do not reflect the world in any empirical sense, but help construct and maintain it by *re-presenting* particular meanings and understandings of reality' (1999: 240). Media representation in turn, is embedded in larger social contexts where meaning is simultaneously closed off and opened up through the development of discourses. The contradictions and alignment with discourses that arise in the professional sector vis-à-vis the public as they are empirically shown in observation and interviews show where the organisations observed may want to recalibrate their PR efforts, for example.

#### **An intercultural communication approach**

Intercultural communication is a field which generally examines how people communicate across various cultures. The most interesting and emergent work in this field deals with breaking down notions of static, distinct and authentic cultures, while maintaining that there is still some element of communication (or silence) across difference. Drawing inspiration from this work, I hope to challenge a dichotomy of what may be called BMT network (expert culture) and patient/potential donor/general public (lay culture).

Taking the expert-lay/doctor-patient intercultural communication as closely aligned with the theory of strategic action, Graham Scambler asserts, 'The notion of unconscious deception/systematically distorted communication, significantly, allows for doctors (in particular) and patients (more rarely) to act with an orientation to success, not understanding, but sincerely and in good faith' (2002:122) The 'success' of saving a patients life can often lead to forms of communication where the expert often implements their status to elicit some sort agreement on treatment, even if it is not fully conscious.

However, it is problematic to see expert and lay cultures as immovable entities. In response to 'attempts to characterize contemporary medicine as a *cultural system*, a characteristic collection of assumptions, values and practices', Philip Atkinson argues that framing of medicine as a static expert culture has 'strong connotations of unity and coherence, rather than eclectic and pragmatic diversity' (1995: 25, 27).

S. N. Eisenstadt's theory of culture offers some direction in reconciling the two viewpoints, that cultures are not static, but expert and lay cultures do have concrete manifestation in the communication between doctor/organisation staff and patient/donor: The creativity that generates a distinct social order at the same time produces an attendant awareness of that order's limitations (1992). Paradoxically, the more that these divisions are starkly delineated, the more they are broken down. This is evident in the discourses regarding the Sunflower Fund, where medical knowledge and expertise is disseminated by its staff, but registered donors are also expected to be well-informed.

Professionalised (expert) discourses are based on a knowledge obscured from comprehension by the client (lay). But that knowledge is no longer solely the province of experts, as the balance of certainty and uncertainty tips the structures that seek to fix the

current expert/lay cultural boundaries (Turner, 1995). The fixative boundary drawing through indeterminacy is not unlike what has been described as a preservation tactic in gypsy culture, whereby secrecy and evasion are intrinsic to that culture to protect it from obsolescence and co-optation, just as expert knowledge acquired and produced through training is often framed as esoteric and unattained by a lay person (Banks & Banks, 1995). Richard Gwyn elaborates: 'the sequestering of medical knowledge as something exclusive and arcane, seem[s] to dictate that information should be excluded from the very people who are most directly affected by that knowledge' (2002:34). While medical knowledge is increasingly available in various forms and sought after by more lay people, medical professionals often maintain that they have more credence to interpret and disseminate information and subsequently recommend treatment.

This is certainly evident in an interview with the mother, of both a patient and his donor, who expressed her self-awareness of her own educational shortcomings vis-à-vis a professional network of doctors and other medical professionals:

I like a lot that Doctor.... Because ...he plays open cards with you. He's not going to turn things around to please you.... He said, "John, he has leukaemia." What do I know about leukaemia? Especially when you are not that well educated. "Doctor, what is this leukaemia?"...He called it all those names, those short names, ALL[Acute Lymphocytic Leukaemia] and I don't know what, other ALL's., and it's all about the ALL's

...And you know when you are in a situation when I am now you learn a lot. And I can tell you I learned a lot in those few months time. And I am grateful for that I've I learned. [The doctor] opened my eyes and my ears and I thank him for that because If it wasn't for him playing open cards with me, I wouldn't have known it. I throw my hat after that doctor because he played open cards from day one.

While Mrs. S does not feel entitled to understand everything medical, she expresses gratitude here, as well as her desire to learn. She recognises and takes issue with her limited knowledge of leukaemia as it affects her family. She values the doctor who 'played open cards', and is clearly frustrated when things are explained to her in a

manner which she cannot understand to her satisfaction, largely because the information is imparted too quickly, as she explains below:

well, I know about some things and if I don't know about a thing that they would've talked about I would've asked. I used to ask Dr. T because she can explain things very nice to you and in a way you can understand it. As I said again, especially if you are not well educated as I am. I am not well educated, but the little that I know of English and a little bit of Xhosa, because I can speak a little bit of Xhosa. ...

The thing with Dr. H I can't really understand him nicely because he is talking a lot faster. You see, and his words are a lot shorter. So you have to pick up quick. And sometimes I can't pick up quick....Even if it's my language, which is Afrikaans, if I stood and I said to you, it's that thing and that thing and that thing, you can't understand because I said it quickly.

But I don't have complaints about them because they know what they do. Especially Dr. H and the team of blood doctors--they know what they do. If it wasn't for them then my child would probably be dead...I pray that god must give them strength every day. More guidance on the road so they can give it to poor people like me, and like John, who can't afford to pay for that kind of attention.

Another compelling example of the way expert knowledge of some SABMR staff is similar to the doctor's position as an expert, as characterised by Arthur Kleinman, where the patient's beliefs are seen as contrary to a certain medical truth (1988). The SABMR's policy of communicating with patients is to not communicate with them about the results of a donor search, for example, but rather to primarily consult with the doctor and the transplant centre. Though an SABMR staff member notes an increasing lay effort of seeking of medical expert knowledge: 'patients go onto the internet to get information. But the internet is too crowded. But they don't understand the nuances of treatment.'<sup>1</sup> This can make explaining the procedure difficult; the complexity of the donor search and other parts of treatment knowledge take a great deal of experience and training in order to understand properly.

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<sup>1</sup> 29/11/07 SABMR w/ Dr. H.

This is not to assume that such protection of expert knowledge is solely about control of information to ensure a position of expertise and ultimate success. According to the SABMR Deputy Director, 'We never report to the family.' The communication with the patient is limited to academic and financial matters. The reporting of results from the SABMR goes to the doctor. And then the doctor will consult with the patient. She went on to say, 'We are happy to meet with patients with physician's permission. We can go over the file and educate them, but it is not a clinical relationship....if the patient dies, the doctor doesn't tell us, we only know that the client's status has changed, and there is every permutation of patient...' <sup>2</sup> Contrary to solely orienting communication around success, rather it is a way of sharing of information that protects parties involved. Though there is some didactic sensibility in the usage of phrase 'educate them', invoked heavily in other discussions in the BMT network, especially in recruitment and awareness efforts, perhaps useful, if re-framed as an exchange of knowledge, rather than unilaterally asserting expert knowledge.

The medical director is a doctor, and other SABMR staff are experts too. The deputy director has had professionalised laboratory technician training and possess knowledge of the molecular genetics involved, procedures of testing, and experience in organisational practise and meeting international standards as purported by the World Marrow Donor Association (WMDA). And the LTI has been the only South African HLA testing lab that is internationally recognised by the European Federation for Immunogenetics (EFI). Even as the president of the SFF pointed out in our interview,

You know your registry is your technical side. You've got your experts there that are involved in the actual analysis and in matching the donors and doing that last level typing and arranging that side of things. We are involved in the awareness, the education, the

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<sup>2</sup> 29/11/07 SABMR w/ Dr. H.

recruitment to get those donors... We're not experts at all in the actual matching. So you need both roles. You have to. One without the other is not going to survive.

Still, information sharing in the BMT network is sometimes contested, as demonstrated by an article in the South African Medical Journal which reported a dispute between the registry and the SFF about access to donor information (Bateman, 2006: 91-92). The tone of the article was somewhat sensationalist about the tension between both organisations. On both sides, when asked more recently about the working relationship, the collaboration seemed to be appreciative, and the delineation of roles was fairly clear.

I take cues from Atkinson, who is critical of the sociological myopia of the doctor-patient dyad. Much can be revealed about medical knowledge production beyond this dyad and into collegial conversations, or within professional networks (1995). There are some patient/donor/family accounts that do provide a sense of the 'lay' encounter with the expert knowledge of medical workers, and a quite strong 'lay' cognisance of social divisions that exist. Nonetheless, I am focused on the professional BMT network and what this particularly elucidates.

#### **SFF media platform: primary public outreach efforts**

A major outreach effort is donor awareness drives/information sessions. SABMR used to do these before the SFF existed, but now they only do a few each year. Up until 2007, potential donors filled out the registration form and provided blood samples at the recruitment event itself, the policy has now changed so the potential donor calls the SFF and registers over the phone. One of the donor liaisons sends them the form, they complete it, fax it back to the SFF, and go to a blood centre nearby to provide the sample for typing.

I accompanied the SFF PR officer to a company where she had arranged an

awareness drive with the Corporate Social Investment (CSI) manager. They had planned an information session for people after a board had been posted in the office lobby advertising the drive, as well as distribution of companywide communiqués that had been sent out by the CSI manger.

The CSI manager at the financial services company saw himself as a conduit and facilitator for information sharing, as the company person who could 'talk with authority' about the outreach initiative, but he viewed the SFF as the body of expertise which he could refer people to for technical queries:

I could prepare this information so I know how they go about the removal of the stem cells and now I am empowered. I can talk with authority within the organisation around what the Sunflower Fund does, I can talk with authority around what that process entails, especially for those people who do not have the opportunity to come to that information session to ask those questions [and I can pass them onto] the Sunflower Fund, ...when it becomes technical information, how is the blood stored. That information I may not have, but I have the source, wherein people can go through.

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Whether they are focus patient profiles and their search for a donor, donor stories, a fundraising or awareness event, the Sunflower Fund and its efforts are regularly featured in local and national newspapers and tabloids, lifestyle magazines, and very recently in publications that have a largely black readership like *Drum*. Articles have been both in Afrikaans and English, especially. While some of these are generated by the Sunflower Fund's PR people, many of them are generated by patients and their families who make public appeals. The Sunflower Fund is very adamant about avoiding misinformation, but sometimes it cannot be prevented as families will often approach media outlets before going through the Sunflower Fund. If they are specifically mentioned, the Sunflower Fund makes an even more concerted effort to ensure the information is seen by them first.

Furthermore, in the aftermath of any media, the SFF must handle a huge wave of

incoming calls from potential registrants and people with inquiries. This can put a huge strain on staff and impede other tasks. Staff members say they cannot get their work done unless they turn off the phones, as they do every day for one hour.

SFF's website is a major source of information and a site of discursive change, as websites must be updated. During observation, one of the things they were working on was a revision of the website content. I was asked to proofread the new website information they were working on. Major changes I noticed based on the staff's markups showed their priorities in changing the website content: They needed to clarify the donor sample requirement was two tubes of blood, not two teaspoons. Events were updated, and the number of SABMR donors was upped from 62 000 to 63 000. They also altered 'donor drives' to 'awareness drives.' There were notes encouraging more content on the black focus patient and updates on pictures of new staff. Through editorial decisions SFF staff members actively participate in shaping the BMT network discourse in a multitude of ways through constant reiteration and meticulous monitoring of the language and terminology used.

### **Findings: Major themes and preliminary analysis**

Now we turn to the media analysed and major themes which arose from their analyses. These themes somewhat overlap with the discussion in subsequent chapters and serve as an introduction to some of the arguments developed later.

#### ***The conflation of ethnic diversity and the South African national project***

*The odds are even more against South African sufferers due to the fact that our rainbow nation has more unique combinations of tissue types. Ethnic origin is important when matching donors and patients. The "markers" that are tested when searching for a match are genetically inherited and often unique to a particular race. It is therefore very important that South Africa has its own bone marrow registry and the larger that registry, the greater and faster the chance of finding a perfect match. The South African Bone Marrow Registry (SABMR) is in desperate need of donors from*

all ethnic groups and mixed ethnic backgrounds. Regrettably, the SAMBR does not receive any government funding towards the cost of tissue typing the blood samples and exists solely on donations from the public (Sunflower Fund, 2007a, emphasis mine).

This is an example from the home page of the Sunflower Fund's website that demonstrates how the need for donors is couched within a larger discourse of diversity as a hallmark, but simultaneously a challenge of great difficulty, to South Africa's nationhood (see also: Sunflower Fund, 2007b). It also reflects a lack of mainstream government funding, but points out the key determinant of public support which sustains the organisation. There is a dissonance here, rhetoric of receiving no financial support from national government, paired with SFF publicity from the education minister Naledi Pandor and major national figure Archbishop Emeritus Desmond Tutu during National Bandana Day:

The Sunflower Fund National Bandana Day is a national campaign that aims to raise much needed funds through the sales of Bandanas nationally. The campaign is endorsed by the Minister of Education, Naledi Pandor and the The Most Reverend Archbishop Emeritus Desmond Tutu' (Sunflower Fund, 2007a; for more examples see, 'Arch Aid', 2006 and 'Sunflower Fund Aims to recruit 100 000 donors', 2006)

Bolstering the sense of national unity through support of the Sunflower Fund, there are many articles about National Bandana Day during the time period of newspaper articles analysed.

Furthermore, 'the cost of using an international donor is unaffordable for most South Africans' (Sunflower Fund, 2007b). This discourse frames South African nationhood as distinct, but also that such national distinction is characterised by a unique gene pool draws lines of genetics, ethnicities and nation closely together. In the 'Sunflower Ball' programme, there is a page about the SAMBR in which there is a paragraph stating 'The South African gene pool is unique and thus extremely valuable to

the rest of the World. The SABMR is regularly approached to provide donors for African and Asian patients and patients of mixed ethnic origin' (Sunflower Fund, 2007c: 13). But the discourse still represents ethnic diversity as a difficulty and a plight as much as it is vaunted: 'In Africa, suitable donors are difficult to come by because of the wide variety of ethnic groups...some point at poor awareness and the lack of education about the topic among the different ethnic groups' ('Donors needed', 2007).

These elements of ethnicity in the discourse are more pointedly demonstrated in a series of recent articles about a particular black patient, Tlhogi Maseko. Here is just a sampling of the discussion of black communities in articles about Tlhogi:

'Thlongi's [sic] father, Mr Baker Maseko...laments the stigma attached to donating blood in the black culture. "It is not in the nature of black people to donate blood...There is almost no awareness among the black community. I believe black people will be more than willing to donate, if the right messages are communicated to them"' ('Child's Life', 2007).

Zakes Motene says family friends have created a committee to work with the [Sunflower] fund to increase the drive into black communities for more donors..."There has always been this thing about blood and body parts in black cultural beliefs, which have impeded people coming forward to donate blood" (Bega, 2007).

Tlhogi's story serves to also conflate ethnicity, race and culture, not only in these articles in relation to black cultural beliefs but also as motivating factor in an exoticisation of Africa in the publicity for the 2007 fundraising event in Gauteng: 'The perfect match is always someone from the same ethnic group. This special young man [Tlhogi] has once again highlighted the need for black donors on the registry, and for this, the theme of the inaugural Johannesburg event is now An African Banquet...We hope to capture the spirit of Africa with all its passion and beauty entwined with a sense of mystery and romance' (Marsh, 2007). Black cultural beliefs are characterised as stigma, and at the same time, there is a connection made between a black youth's story and a

reason to celebrate and theme a banquet as African, with mystical and warm connotations.

H. Rudolph Wicker describes the enterprise of ethnicity research as studying 'The ethnic borders themselves, and the mechanisms used to preserve them... are actively worked on from both sides of the boundary....the integration of ethnic groups in a nation-state is characterized by an imbalance of power...the explicit strengthening and mobilising of ethnic ties is a strategic device which may enable...specific emancipative objectives. Similarly the state may choose to work with ethnic categories for specific purposes of social and political control'(1997: 34-35). Wicker examines ethnicity as a proxy means of understanding culture, and the way ethnic categorisation is blended with the motives of the nation-state. Both of these discourses of ethnicity appear in the media by and about the Sunflower Fund and seem to function in this way.

### **Ethics of living donors**

A potential donor may decline at any time. There is however, *a point of no return for the patient...* This stage is reached about a week before the actual donation when the patient's own bone marrow is destroyed with high doses of chemotherapy in preparation for receiving the harvested stem cells. At this point the donor may be seen to have a moral obligation to proceed because without the donation of stem cells the patient will die (Sunflower Fund, 2007a, original emphasis).

The above quotation demonstrates an important ethical issue in the discourse in which the semi-professional media asserts, albeit gently, a point of moral obligation in relation to donation. However, 'The right not to donate bone marrow, despite an urgent life-saving request tests the principle of free consent to its limits' --sense of duty is not the same as obligation. In an actual case...the judge instead ruled that 'forcible extraction of bodily tissues would "defeat the sanctity of the individual"' (Varga in

Lamb, *ibid*, 1990: 106). The above quotation points to a limit case: that there is a fulcrum at which individual rights and consent are no longer as important as the obligation of life of a patient.

### **The ideal donor**

Harold Waitzkin touches on the way in which Gramscian notions of hegemony may affect medical encounters in the way that doctors impress ideological domination in 'desirable behaviour' (1989: 223). In the same vein, it is not just desirable behaviour that is communicated from experts to lay communities, the Sunflower Fund (along with the SABMR) disseminates certain desirable attributes of donors, and define who is a suitable donor. The Sunflower Fund outlines criteria and social groups that are valued as eligible to be on the registry.

Here are the basic criteria outlined: 'Donors must be between 18 and 50 years of age at the time of registration. They should be in general good health, with no history of hepatitis or sexually transmitted diseases. They should weigh over 50 kgs and preferably, but not necessarily be a blood donor' (Sunflower Fund, 2007b). In this process, they are able to define parameters in a manner of a gatekeeper and as an organisation that has the knowledge, semi-professional status and expert culture to be able to assess whether or not individuals meet these parameters.

Donors must be educated and well-informed, as outlined in the Sunflower Fund's own literature and in several news articles. For example,

The Sunflower Fund aims to educate and recruit well informed potential bone marrow stem cell donors that are ethnically diverse in an effort to save the lives of those needing a transplant when suffering from life-threatening blood disorders; Donors need to be between 18-50 years of age and in good health. "The harsh reality

is that 75 percent of leukaemia sufferers are under the age of 25 years old. We're currently making a concerted effort to recruit more donors, especially amongst Asian and African ethnic groups. "we're also asking men to come on board as donors since only 40 percent of current donors are male", said ...[the]CEO, of the Sunflower Fund. (Bandana's here again, 2007)

As mentioned above, another example of a targeted social group is young males. This is worth mentioning but would require more gender analysis than the scope of this research allows currently. Still, it is germane to be mindful of how the male body is valued by medicalised discourse--able to provide higher quantities of product, less likely to have conditions which prevent donation, etc.-- and how health is gendered in the context of donor suitability (Sunflower Fund, 2007a).

### **Blurring the boundaries**

A complication of divide line of expert cultures is especially evident in the case of the Sunflower Fund. They are main donor recruitment organisation and fundraising body for potential donor tissue typing, where staff members are not doctors or nurses, but rather do administrative work, PR, community outreach, fundraising and other activities that facilitate yet are not any direct form diagnosis or treatment. Still, they exercise a sort of expert knowledge. This signifies an in-between ground, which may operate in concert with medical experts as well as discourses about specific lay communities in an articulation of racial and ethnic inequality and hegemony of donor need and the perceived imperative of medical technology.

The media analysed generally seem to serve the purpose of communicating to a wider public, the distinct messages outlined above in such a way that often reflects multiple moments of translation, referring back to Gwyn's question of how translation might happen between expert and lay knowledges. In this specific case analysed,

translation happens at the point of medical and genetic concepts being interpreted in ways that the hybridised, semi-professional Sunflower Fund staff can comprehend. There is a translation of this hybrid knowledge into a discourse shaped by the 'lay' media, which then translates what is communicated to them by hybrid expert/lay individuals for public 'lay' consumption.

Terry Threadgold's summary of the 'sociology of translation' characterises the act of translation as bound up with power dynamics 'through which one group becomes 'spokesman' for others', and translation can often function in opposition to or beyond its intent, or betray certain relationships(2000: 198). Although Threadgold refers to translation in her self-reflexivity as a researcher, it can also be applied to the interlocution of Sunflower Fund related media which stands on the boundary of communication between expert and lay knowledges. For example, in appeals to specific communities through various publications, the 'urgent need' for donors specify certain medical 'truths' that experts have deemed relevant to communicate to 'lay' communities.

For instance, the hybrid stance is to communicate the genetic correlation to ethnicity in a way that may develop lay knowledges, understanding ethnicity as biologically essentialised.. This could be what Giles Deleuze and Felix Guattari describe as: 'A machinic assemblage of bodies, of actions and passions, an intermingling of bodies reacting to one another; on the other hand it is a collective assemblage of enunciation, of acts, of statements, of incorporeal transformations attributed to bodies' (in Threadgold, 2000: 197).

The SFF are very cognisant of their responsibility to impart expert information, translated for a public at-large. For example, the SFF president/CEO was in the office

and had asked the PR staff for a particular article she wanted to refer to for a school presentation she was making at a school that raised money for the SFF]: ‘There’s a piece on the bone marrow—that produces cells. You know the paragraph in our PR kit. The factory that produces the healthy blood. I want to simplify that. I just want to make sure I get my facts right. They’ve raised this money. They can’t be donors but I will just tell them briefly what a donor does. But to keep it very basic.’ She realises that her role is one to educate others about bone marrow transplantation as so-called expert, but she also recognises her own responsibility to translate, or in her words to ‘simplify’, for a lay audience. We must also take notice of her hybridised position; she is not entirely expert, so she feels she must consult the article to get her facts right, as someone with a partly lay perspective.

## **Chapter 4: Feedback Loops—The complex interrelationship of race, ethnicity, culture, genetics and nationhood**

We saw in the previous chapter that one of the major themes emerging in the media generated by and about the Sunflower Fund, is a suite of assertions about an interrelationship amongst genetics, culture, ethnicity, and South African national identity.

Here are the main points of this interrelationship articulated in the BMT network:

- 1) Some genetically inherited HLA tissue types appear in certain ethnic populations more commonly than others.
- 2) Patients who cannot find a HLA match in their family are most likely to find a match with someone in the same ethnic group.
- 3) Therefore, for ethnic groups not well-represented on the SABMR, patients of those backgrounds have little chance of finding a match.
- 4) Thus, the registry and the SFF are working to increase the number of black, coloured, and Asian donors so that all ethnic groups are represented on the SABMR.
- 5) This is crucial given South Africa's unique and diverse gene pool.

In this chapter I hope to explore these tenets in more detail. I will unpack the ways that genetic, ethnic, racial, and cultural diversity are connected and conflated in the discourse of this particular field. I combine the literature with the ways that the concepts of population genetics are reinforced and rearticulated in the BMT network. Secondly, I will look at how the BMT network, in their goals for greater representation of South Africa's ethnic groups cite culture as a major consideration in tandem with other notions

of culture that have emerged in the network, and the consequences thereof. Then I will address how the focus on the discourse as it incorporates ideas of South African national identity.

### **Population genetics, race, ethnicity and culture**

The school of cultural evolution purports that cultures are seen as bounded by discrete stages, and the view is that cultural and biological co-evolution are a testament to 'the inseparability of genes and culture in the process of human diversification'. Rate or frequency, is what determines the rate at which gene variants [alleles] appear per time unit...in a given population. (Stone & Lurquin, 2007: 3). The definition of those populations in a cultural-genetic partnership, seeks to fix a populations in static moments in time, simultaneously in their cultural characteristics and biological materiality. But I am more concerned with how discourse reflects certain struggles over the meanings of the relationship between culture, ethnicity, race, and genes. I explore this complex web of meaning, not taking those aforementioned interrelationships for granted, but rather seeing the ways in which they are under constant change and renegotiation, whilst keeping biological materiality in mind.

There is a slippage in the discourse between race and ethnicity in the BMT network. A discussion I had with the SABMR deputy director about how populations are defined exhibits this. She said: 'If you go to the website, it is done by self-definition ...but remember our population was politically defined...South African whites, but of course we are not as white as we think we are, South African blacks, if not defined by tribe, Cape coloured, Asian, but sub-continental, not as you would usually identify as

Chinese or Japanese.’<sup>3</sup> This explanation is complicated by my inquiry about the difference between race and ethnicity to which she answered, ‘Some people would use race because it’s the larger group. In this case we tend to use them interchangeably’.

Organisational practice and implementation of knowledge of ethnicity, is not always self-identified, nor is it based in genetic evidence: One of the donor relations staff at the SABMR says that she uses the name and the address of residence to identify ethnicity [as the field indicated on the database], or as she said, “‘race” though I hate to use that word,’ of the donor if is unknown on the SABMR database.<sup>4</sup> Part of her job is to generate where there are donors whose data fields are unknown and correct that when she can. It shows the persistent perception that areas throughout South Africa are still segregated enough, whereby location and surname are deemed by some as a generally accurate indication of ethnicity or race.

Some scholars make distinctions in a differing manner: ‘the argument is that race, grounded in a claimed biological reality, is in fact an ideological tool of oppression, while “ethnicity”, grounded in a political process of self-claiming and political mobilization, is empowering’ (White, 2002). The consciousness of the difference between using the term ethnicity rather than race in registering potential donors is recognition of the historical usage of racial classification to justify an institutionalised hierarchy and system of dominance and discrimination through apartheid. In trying to distance itself from this legacy while still expressing the urgency of certain populations identified as ‘in need’ of greater representation on the registry, ethnicity is used widely in the BMT network.

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<sup>3</sup> As she was addressing me as an American, since there is sometimes the understanding that ‘Asian’ in American English often denotes East Asian, e.g. Chinese or Japanese. 13/12/07 SABMR

<sup>4</sup> 26/11/07 SABMR

The SFF African language donor liaison provides an account of how registrants deal with this request for self-identification. I asked her how registrants respond to the question: 'What is your ethnic group? Are you black, white, Asian?' She said, 'They think it is political or it is racism. But I tell them we just need it for statistics. Sometimes they think it is funny. Because we went through apartheid and now people say we are all South African they want to know why we need that. But once I explain that it's for stats then they say it's okay.' I replied, 'What if people respond that they are Xhosa or Zulu?' She said matter-of-factly: 'Then I just put black and then type it in. Or if with [a Jewish focus patient], for example, they will say "I am Jewish", I will put in white and type in Jewish. But if they aren't more specific I don't ask any further.'<sup>5</sup>

This is not a clean line drawn between ethnicity and race, not only evidenced by the above quotation. But in such instances there is a closure of meaning. As a prompt, the SFF donor liaison also often says on the phone when fielding registrants: 'and your ethnic group? Black, white, asian, or coloured?'<sup>6</sup> Irrespective of their own ethnic/racial identities both women will frequently give potential registrants their ethnic group choices before they would second guess the question.

These elements of the discourse are such that the web of meaning situates itself in a debate around ethnicity and culture that many population geneticists try to avoid (Franchi, 2003). The textbook entitled *Culture, Genes and Human Evolution: A Synthesis* asserts: 'One problem with the issue of identity politics lies in the claim that population geneticists are really asserting that their knowledge is ultimate, or in some

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<sup>5</sup> 13/11/07 SFF.

<sup>6</sup> 14/11/07 SFF.

way superior to statements based on identity based on cultural construction. ...Modern genetics can tell us who we are *genetically* but that's all' (Stone & Lurquin, 2007: 233).

Although the desire to stand outside of the discourses of identity politics is understandable, this argument has the consequence of establishing a notion that if population geneticists relinquish their superiority it automatically means that their biological knowledge does not have any power. To the contrary, even the ability to publish a textbook of that title, covering population genetics, is already a wielding of discursive clout, not to mention the power that genetic evidence has in any number of cases.

Following Stuart Hall's summation of Foucault, though there may be things which materially exist outside of discourse, 'nothing has any meaning outside of discourse.' Hall goes on to summarise: 'physical things [e.g. biological materiality] and actions exist, but they only take on meaning and become objects of knowledge within the discourse...it is discourse—not the things-in-themselves--which produces knowledge' (1997: 45). Attempting to absolve themselves from the political fray of meaning making when it comes to identity, the very act of representing a genetic knowledge intrinsically implicates population geneticists and those who use this knowledge in the discourse. Who we are genetically, ethnically, culturally, etc. cannot be compartmentalised so easily. Although drawing from a different historical era, what Foucault says about the word 'population' is a compelling point that invoking genetic knowledge about populations cannot be distanced from politics, i.e. it exemplifies the mechanisms of bio-power at work:

One of the great innovations in the techniques of power...was the emergence of "population" as an economic and political problem: population as wealth, population as manpower or labor capacity, population balanced between its own growth and the

resources it commanded. Governments perceived that they were not dealing simply with subjects, or even with a "people," but with a "population," with its specific phenomena and its particular variables...All these variables were situated at the point where the characteristic movements of life and the specific effects of institutions intersected (1978: 25).

As the BMT network continues to articulate the extant discourse, what is at stake in continuing to 'go on' employing 'ethnicity' as a label which circumscribes genetic populations and frequencies?

There are two important accounts from my field notes from the SABMR and LTI, which show how the discourse and practise of identifying frequencies with different populations both fixes and destabilises their interrelationship. One instance was when the deputy director helped me learn the concept of associations by figuring out which HLA-B goes with which HLA-C for a patient, to determine where the best chance for match associations for untested loci would be. In the example we were using she informed me that with the haplotype A2 A43, the A43 is very difficult to match. '43 is a Khoisan gene identified in this lab [LTI]. So we already know there will likely not be a match.' As she went on to say, 'We're a mongrel population anyway. Like this white donor who has the A2 A43 haplotype...As I said, serology is an imperfect science, and so this 43 could be interpreted as an A26 or an A29....'

I also asked the lab manager about different HLA frequencies in different populations, since he had referred to his knowledge of this in other presentations to colleagues. The manager said: 'In the last 40 years or so I have picked up these things', as he took out large manila folders. He showed me these and said they were their own frequencies at the LTI for HLA types. The populations from these frequencies were from a total of 1000-2000 subjects from 1987. He explained the importance of these:

It is very useful because we had a case of a lady who needed a bone marrow transplant. We did a worldwide search and couldn't find a match. And finally a family member became pregnant and was expecting twins. We were able to use a cord blood transplant [which may sometimes serve the same purpose as a BMT] and we needed the two cords...By using frequencies we can predict most likely typing...also if you're doing disease studies people try to link HLA with diseases...In the scientific community we only use published frequencies.

What he says corresponds with the rise of allelefrequencies.net and other attempts to compile worldwide allele frequencies for specific populations, and identify new alleles in recent years.

The lab manager went on to describe an example of identifying HLA types in relation to population:

It is because black people here are unique we did a study on Mandingo around Gambia and we saw frequency differences. On the east coast people have a lot of Arab influence and if you look and Cape Coloured and Afro-Americans...descriptively it is an admixture of blacks, indigenous, San, whites, coming from different areas. So it's a completely different area...Classified Cape Coloured as their own race, as there is a lot of Southeast Asian because they were Dutch political prisoners. Antigens are present in the Thai classify Cape Malays as different from Cape Coloured. People talk about Cape Coloured and African Americans but you probably look Nigerian, whereas San is one of the most primitive races. Xhosa and Zulu came along much later...

He went on to say however, 'The only interest frequencies have for me is a chance of finding closure. Your frequencies are helpful if you find an increase in a certain antigen Type I population and compare it to your normal population, or disputed paternity.'

The interlocutors of the discourse believe that population genetics functions not to essentialise ethnicity or race for purposes of domination, but knowing that population genetics is not always a perfect science but practise which, as far as knowledge allows, provides patients the best chance at survival. Therefore, it is a fine balance between recognising the genetic materiality of HLA-frequencies that do seem to pair up with certain ethnic populations, and also an attendant awareness of the lack of purity in ethnic boundaries.

This ambivalence shows that there is still some degree of tension between the various ways people can self-identify when asked about ethnicity versus how populations are defined in population genetic studies, and in organisational practise, both in South Africa as well as elsewhere. In the examples above, the gene frequencies in populations may exist prior to their articulation in the discourse, but it does not mean anything to anyone until it is articulated as an object that has been discovered, named, and had knowledge produced about it.

A majority of scholarship on ethnicity purports that it can be seen in two main ways:

- 1) Primordial: ethnicity as a set of inherent qualities possessed since time immemorial.
- 2) Instrumentalist: utilising ethnicity to gain access to certain resources—sheer social construction utilised for political ends (White, 2002)

However, between the two poles of genetic essentialism of ethnic and racial populations, and a complete discarding of scientific and biological factors in understanding race and ethnicity, lies a profound and useful triangulation which the BMT network's discourse demonstrates in its very ambivalence.

This triangulation is reflected in a concept Troy Duster calls 'very complex interactive feedback loops between biology and culture and social stratification' (2003: 258). A feedback loop occurs when a 'social fact has biological consequences, which in turn has social consequences.' Duster adds, '...when race [or ethnicity] is used as stratifying practice (which can be apprehended empirically and systematically), there is

often a reciprocal interplay of biological outcomes that makes it impossible to disentangle the biological from the social' (ibid, 2003: 262).

Instead of essentialising race, a hegemonic notion bound up in an ideology of superiority as once purported, the current work of the BMT network highlights the materiality of race and ethnicity. It deals with social constructions, but also the salience of genetic materiality in HLA types, which encourages people to engage with the real consequences of ethnicity as it affects our bodies and the probabilities of life and death. It thereby encourages equitable representation, valuing diversity, and recognition of historical legacies that are inherited both social and biologically. Duster's feedback loop theory should be highlighted more boldly so as not to repeat or reproduce the problematic historical and essentialist discourses. Though this may serve a progressive agenda, there are other cautions which deserve a closer examination in evaluating the interrelationships discussed--culture and national identity.

#### **Articulations of difference and culture in the BMT network**

There is a perception that culture, as a proxy for ethnicity serves as a factor in how people deal with bodily donation, and indeed there has been prior work indicating this (for an example about South African Xhosa communities and cadaveric organ donation, see Kometsi, 1998). If we refer to Chapter 3, for example, black culture is seen as both stigma (barriers for black donors) and it is seen as something to be celebrated (in a charity ball).

The same ambiguity of white culture, in contrast, is barely mentioned in the discourse. The idea of a white culture is not really vocalised. Hence, I am reminded of Renato Rosaldo's words: 'zones of relative cultural visibility and invisibility derive in

large part from tacit methodological norms that conflate the notion of culture with the idea of difference...the more power one has, the less culture one enjoys, and the more culture one has, the less power one wields.'(1989: 201-202). This echoes a very powerful message about the persistence of an invisible white culture as the norm, with black culture as visible 'other', even as there is a progressive goal for the registry to representative of all ethnicities. Blackness is still the marker of difference.

Importantly though, SFF staff members are very aware of how their own organisation has been viewed as primarily benefiting whites. As the PR officer, who had just been hired in 2007, said in my focus group interview with the staff:

At the moment the Sunflower Fund is still very white but that's something I'm going to be working on and that we are working on....We need to just get more black donors and broaden....People have the misconception that the organisation is a white organisation and leukaemia is something that only happens to white people. It's like when [the African languages donor liaison] said there's a stigma attached to having cancer in the black community. People think that the Sunflower Fund is only there to help white people but it's not. And that's a misconception so it's something that needs to be changed. And if you look at quite a bit about our ads and the pictures that you see with the Sunflower Fund there are a lot of white faces. So that's something that needs to be changed. It's a gradual process I know but unfortunately the reality of the situation is that a white child looks sicker than a black child.

This recognition is often framed as a lack of education in black communities, and culture as it relates to ethnicity is a source of difficulty in recruiting donors. This also came up in the information session at the financial services corporation to which I accompanied the PR officer. The corporate social investment (CSI) manager mentioned that he was excited about the registry and its encouragement of diversity. He added that people have an experience with the dentist and think that bone marrow donation involves drilling into the bone. But to him it seemed 'mostly an education thing, and that people should also realise there are other ways to help.' The PR officer asked the CSI manager if he thought it was cultural reasons that made people wary about being donors. She

sked because other people informed her that people must ask their community elders in order to become donors.<sup>7</sup> He felt it was rather personal belief systems and fear of drilling the bone. In my subsequent interview with him, he similarly said,

...of course general information that your African black people don't necessarily suffer from leukaemia. But also that it's not necessarily leukaemia that we are talking about. Either blood related diseases that we need stem cells for your body to be able to recuperate. And that information being given allows your people to say, "Okay, Now I have some idea" and therefore to make up their mind based on the information. And it came out that there are those perceptions, driven again by different belief systems, which becomes an education area for the Sunflower Fund. Yes, you may have these but think of the life you can save if you are just able to say yes I am going to give a pint of blood'

In understanding willingness to become a potential donor, citing 'personal belief systems' as a reason is an interesting discursive turn. Making it personal distances it from a larger social landscape, and individualises the decision, apart from factors of culture or community. Yet there is an enthusiasm around diversity in representation of people from different cultural or ethnic backgrounds.

Another example of marking difference came from my interview with the president of the SFF whom I asked if there were challenges around awareness:

The education, breaking a lot of the barriers. We've got seventy different groups of people in South Africa and these all sorts of misconceptions about being a donor or even giving blood or donating organs. There's a lot of sort of taboo that you just don't do that. And it's breaking all those things along the way.... Well we broke a huge barrier within the Muslim community with a little boy who was ill and originally when I tried to recruit donors within the community, they all said, they would love to but they can't. It's against their religion. So I went to the big mosque and spoke to the imam. And he explained that it wasn't at all, they could absolutely and got him to address the public at mosque...and slowly spread the word that way which is wonderful because now the whole of that community in Cape Town know that is actually something they can do and a lot of people came forward. But was the thing of oh no, I can't do it, it's against my religion because somewhere along the line some story started and people just believe that.

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<sup>7</sup> 15/10/07

In this statement, education is a tool which is used to break barriers of difference in groups of various sorts. It is interesting too how a certain religious identity can be claimed in divergent ways—as requiring explanation of rules of bodily practices and as a means to excuse donorship—such that the discourse is again revealed as contestable.

The SFF African language donor liaison demonstrated an internalised sense of self-aware difference. Through our conversation, I learned that the SFF were not going to hire for her position until the next year but because of the ‘African boy, Tlhogi’ they needed someone who could speak many languages. She is the first black person hired by the Sunflower Fund.<sup>8</sup> In the SFF staff focus group, her language skills—and as black person who ‘understands them’—are clearly earmarked as a unique asset. As one staff member said:

Having [the African language donor liason]. It’s really crucial for the call centre. We struggled before [her] because of the language barrier. And [she] arrived just in time with Tlhogi Maseko when that patient...there was awareness around him and it was at the time that she started. We would have lost a lot of black donors if [she] was not here. We would have lost a lot. It’s happened before. For a few months here we also had a number of black callers. We lost those black callers because they didn’t understand us. We didn’t understand them. She knows their languages. So we can just leave her in the call centre! [Laughter].

But it is not just a difference of ethnicity and her set of responsibilities as the only black staff member of the SFF. She experiences difference within a largely Xhosa black community where she lives. She said that people don’t know that she is Lobedu and Xhosas assume she is Xhosa also. In her words, ‘We speak Xhosa, Lobedu also do, so people assume.’<sup>9</sup> Like the blurred distinctions between race and ethnicity, equivocal

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<sup>8</sup> 25/10/07 SFF

<sup>9</sup> 12/11/07 SFF

articulations of black culture are not always discretely shaped, but are fluid and ever-changing. Nor is the line between ethnicity and culture is clear either.

### **Genetic diversity, the Rainbow Nation, and International Context**

The quotation in chapter 3 which refers to 'the unique diversity of the South African gene pool' portrays South Africa as a national boundary for a given gene pool, one that is characterised by its diversity of ethnic groups. That capability of the BMT network to have a more comprehensive national presence was not always existent. In an interview with the president of the SFF she described the process of the organisation's development from a local operation to a nationwide effort:

When we started out Bandana Day...in 2003, then the national awareness really started because it's national radio and national TV and that's how we opened offices in the other two major centres. But also it depends also on patients' stories. When [my son] was sick he was based in Cape Town but nationally it was picked up by Carte Blanche Television which made the whole country aware of it. So people were phoning frantically to try to join. We didn't exist then. They were all trying to phone the bone marrow registry that didn't have the facilities or the call centre to cope with that volume of calls. So a lot of people never got phoned back or never joined. Also it wasn't accessible. You had to go to the registry...to become a donor. Now that's not practical, especially if you don't live in Cape Town...that's when South African Blood Service got involved.. You have clinics everywhere and they offered to take samples and then they give samples to the registry just to make it more practical for people to join....And now having a national call centre helps because people can call from wherever...we can direct them straightaway to the closest clinic in their region.

As the BMT network's capabilities have spread nationwide, representation of all ethnicities becomes more pressing as a national goal.

Literature which mainly refers to how race played a role in nation building would still be useful to apply the analysis vis-à-vis the usage of ethnicity presently since it has been discussed how the discourse has conflated ethnicity and race as a continuum of meaning. Anthony Marx, whose major study *Making Race and Nation: A Comparison of*

*the United States, South Africa, and Brazil* argues 'All these countries reached climactic "moments" when political reconfiguration was tied to issues of race. The emergent nation-states would then reconstruct a legal racial order, building upon past experience ...unity had to be reinforced, for solidified subnational loyalties remained' (1998:82). He traces the history of the South African nation-state as it was built upon this principle, that in order to supersede white 'interethnic' tensions between British and Afrikaners, domination of others (black, coloured, Asian) had to be ensured. 'South Africa thus emerged in its very formation as a "state of race," with newly enforced and unified segregation essential to state visibility and growth' (ibid, 1998: 117). Such state-enforced segregation not only bound whiteness together in the interest of consolidating state power, it reinforced the nationwide category of racially defined natives...unifying and provoking further mobilization among Africans' who had previously seen themselves as distinguished by cultural, geographic, and ethnic categorisation (ibid, 1998).

Usage of racial division in order to further calcify the nation-state as a means for consolidating political power, brings up the question of what serves as a basis for nationhood in the 'New' South Africa. Marx points out, 'The end of formal racial domination opened the possibility of inclusive nationalism cognizant of cultural diversity. ...This challenge of forging national unity not only had to overcome the particular pattern of South African antagonisms, but also the more general tendency to define and construct a nation in opposition to some "other"' (ibid, 1998 213, 215-216).

Differences cannot be erased. Racial, ethnic, cultural, and genetic 'otherness' are highlighted. Nor can the geopolitical gravitas of a nation-state be underestimated. Through the close interconnectedness of ethnicity, culture, race, and genetics as reflected

in complex feedback loops of genetic materiality and social construction, the goal of achieving comprehensive representation of the nation in relation to this particular feedback loop becomes a national imperative. This is reflected in the desire of many in the BMT network who voice the desire to get more funding from the government as something that they want to benefit and represent all South Africans.

Political science orthodoxy points to a sub-Saharan African regional sense of the persistence of territorial nationalism and the persistence of nationalism as not incompatible with ethnic difference within a nation, but that the maintenance of a plural nation rests in territorial need and economic stability (Young, 2002). Formulating an entirely different approach, Ivor Chipkin is bold enough to ask in his book's title, *Do South Africans Exist?* Hence, we are brought to a juncture in political thinking where South Africa conceived as a nation may not be the structure in which democracy functions best. For Chipkin

the point...is that the struggle against apartheid was not simply a struggle against a racist political system, its laws and its institutions. At stake was the reconstitution of the South African people...this is precisely that challenge of nation-building. It is driven to resolve two basic questions: Why should the nation be composed of these people and not others? And: What is the common factor, the X, on which to base a South African identity? (2007: 177-178)

Two major foundations upon which South African nationhood now rests are a common history and their collective identity as 'rainbow people of God', in Archbishop Desmond Tutu's words. Nonetheless, each of these foundations lack something that is uniquely South African for different reasons. According to Chipkin, common history is itself an inconsistent theoretical construction. And being 'children of God' does not mark anything that could be called specifically South African. But he does say that South Africans also base their nationhood on a given territorial entity. Although 'the principle

of territory, despite its conceptual intelligibility is not a compelling principle of political ontology' (ibid, 2007: 187).

It is important to note that the usage of genetic connectivity to geographic boundaries is not given its fair due in Chipkin's analysis. At present that discourse is nonetheless propagated through the BMT network, an identifiable, roughly circumscribed plurality of HLA types, just as it is in a larger scale in Himla Soodyall's work. She advocates population genetics as a means to investigate human origins in better understanding of what it means to be African and how it may bolster the much-touted 'African Renaissance and in restoring pride and a sense of identity in every South African' (2003: 205).

However, Chipkin's analysis can be applied aptly to the case of historical foundations as far as the social construction end of the discourse around genetic and ethnic populations as distinct but intermixing as a 'mongrel population'--a nation whose collective consciousness is one pregnant with the awareness that it is a nation precisely because it is unified in its hybridity. This is a return to the idea of the feedback loop, where the genetic evidence and the idea of a nation as functional polity are bound up in each other and affect one another.

While he does not deal specifically with this particular feedback loop of genetic-ethnic plurality/hybridity and nationhood, Chipkin does address an important quandary:

A democratic formation is one where...social actors understand that their identities, alliances, and commonalities are provisional, political and contingent. Yet in a popular formation (a nation), the popular identity is fixed once and for all...the moment [a nation's citizens, for example] are free to elaborate new identities, the very unity of the demos dissolves...a popular formation must constantly preserve that which it is driven to exclude...There we have a precise definition of the nation. It is that domain where people do not meet as equals, but always already as representatives of "peoples." (ibid, 2007: 209-210, 217).

Thus, while there are moments when South Africans 'developed a deep horizontal solidarity' the difference within the nation and national formation are negotiated undemocratically in ways that make the nation untenable as a proxy for a fully functional demos proper.

This critique obliquely problematises the particular feedback loop(s) under scrutiny. As one of the foundations that is instrumentalised for nation building as a fixed political entity, our aforementioned feedback loop may play a role in constraining the development of a 'democratic frontier.' Instead, though democratic sentiments exist in the discourse, it simultaneously functions to uphold and fix a sense of a national identity that restricts democratic practise as it is idealised by Chipkin. His analysis pushes us to the edge of considering another political formation in which democracy can be more fully realised. But given the persistence of the South African nation as the main body for practically functioning in a global context, what, then, has occurred in practice and the BMT network as it sees itself on an international scale?

The president of the SFF provided a rich description of how the BMT network's endeavours play a role internationally:

This registry [SABMR] is essential obviously for Africa but it's also critical to the rest of the world, because they are searching this registry for their black donors because they're not represented on the international registries. So I mean we had the little girl in America, we found a black donor here and hopefully there will be more and more cases like that. So it is important to the rest of the world I think that this registry is booked. It is just to convince them to help us do it....You know you've got a child, you're sitting in New York or Spain or whatever and your child happens to be a black child who needs a donor and they can't find one over there it's essential that there's a pool of donors where you can find a pool of donors and that's Africa. I obviously feel very strongly about it because I've lost a child. You know when you're child is sick that there's a donor out there somewhere because just statistically there has to be one. But obviously they're not on the registry. If everybody was tissue typed at birth and just put onto a database, you'd probably find a match for just about everybody. But that's a sort of dream scenario.

Not only does this highlight the importance of the role that the SFF and SABMR play in creating a greater chance of anyone finding a match, but it invokes the specific role that

the South African population as a rich resource for specific ethnic populations less likely found in other registries. Recent figures state that about '20% of the unique HLA types in the international database are from the SABMR' (DuToit et al, 2005).

Practise at the SABMR reflects international standards and regulations as set forth by the larger organisations of which they are a part of, Bone Marrow Donors Worldwide and the World Marrow Donor Association. Also, the LTI is accredited by the European Federation for Immunogenetics (EFI). I examined the 2006 WMDA Donor registry conference and working group meetings conference book which showed a wealth of the worldwide work that is being done. A couple of the conference abstracts illustrate topics that concern the larger international BMT network and illuminate the ways the SABMR may position itself with these broader issues in a global sense:

In an attempt to better understand the HLA diversity within the UK population we have developed a software package...that allows for patterns of diversity to be calculated using allele, haplotype, and phenotype frequencies....In addition to mapping the variation in HLA allele and haplotype frequencies across the United Kingdom, we have been able to determine regions with high and low HLA phenotypic diversity. Such analyses can help target future recruitment, either in areas which have high frequencies of alleles or haplotypes that under-represented in the registry, or to areas with high phenotypic diversity, with the aim of improving efficiency with which we add further diversity to the registry (Marsh, 2006).

South Asians are genetically diverse as a result of inter-raical marriages from the foreign invasions into India. We have seen South Asian donors matching other ethnic groups and vice versa. The South Asians registered worldwide does not reflect the size of this ethnic population. Because of this severe underrepresentation the South Asian patients are at a disadvantage to find a life saving match. SAMAR has pioneered an awareness program in India hoping to increase the recruitment of volunteer marrow/stem cell donors for availability of matches for South Asians and other global communities (Khan et al, 2006: 56).

The excerpts from these selected conference abstracts demonstrate that there is a particular kind of discourse around the genetic and ethnic interconnectedness as well as a strong focus on finding the rarer HLA types through various means. Much of the discourse as it takes place in the South African BMT network is interwoven with the international

viewpoint on this. Consistent in these abstracts are definitions of populations, registries developed along national lines, concerns with HLA frequencies, and the need for recruitment of donors. Further evidenced by the extensive quotations above, national registries, and thereby nations, serve as the earmarked entities for transferring knowledge in the global network.

Alternatively, the potential for transnationally-defined relationships of genetics and traceable biological and ethno-cultural feedback loops made elastic by diaspora may produce an awareness of an identity and community that provides empowerment outside of the hegemonic discourse of nation. There is, in the work of the BMT network a latent ability to 're-imagine and complicate identities and communities that we did not think were possible before with the constraints we were working under' (Hall, 2000: 152). Freed of those constraints, imagining possibilities beyond this overarching macro-social framework of the nation, offer some exciting avenues to pursue inquiry. However, as it presently stands the strictures of the international system and the hegemony of nation-state still control this possibility.

## **Chapter 5: Inequality and rationing in the BMT network**

Because I think if we are to cater for the local need then obviously you would need people of colour, if you're looking at the demographics....[but] where is the need coming from now, predominately people with money. And unfortunately, because of the previous dispensation...it's white people that have money...yes, there are people of colour with medical aid. But I mean if you are looking at the entire population demographics, the people that are not getting transplantations are people going to state hospitals, and people going to state hospitals, majority, they're people of colour, because the government is not subsidizing unrelated transplants....So to whom are they actually donating? To the international world? Because the people of colour that's getting sick and going to government hospitals can't do a transplant because the government is not subsidizing it. So you'll find that it's people that go to private hospitals. So there's this dichotomy involved.

Because how do you judge the quality of life? One person that's sick is not as bad as 10 children with diarrhoea? Because in South Africa you've got this disparity of first world and third world medicines. I think the government has concentrated a lot on the third world, sorting out the TB, sorting out the malnutrition. I mean, and not that the one weighs more than the other, but they haven't really concentrated on unrelated transplants (LTI staff member, 2007).

The above quotation from an interview with an LTI staff member is at the crux of many issues fundamental to the enterprise of the BMT network: First I want to examine the relationship of socio-economic status and health inequality. I consider how the BMT network fits and challenges health resource rationing in South Africa's current health care landscape. Then I summarise the immense amount of resources required to facilitate BMT as a viable treatment option for patients. Further addressing the issue of resources, I convey the scale of the SFF's fundraising efforts. Lastly I ponder whether there are possibilities for coalition building in light of the hegemony of rationalisation of health care in South Africa.

### **Class and race and ethnicity as determinants of health care**

The interview excerpt's respondent is not only keenly aware of her role in as a lab technician in the BMT network and as someone with experience with potential donor outreach and being a haematopoietic stem cell transplant courier, she also expresses

knowledge of the 'current dispensation' in a local historical context. Her family was forcefully removed during her childhood, and she knows firsthand the effects and divisions of societal opportunity. Informal chats that we had also broached this topic. This history has deep consequence for her in how she sees the quandaries inherent in the work that she does and the hope that it will be gradually beneficial to a wider spectrum of people in South African society. She went on to say,

with this new dispensation...things are changing. I can see in my community that there is a change. And I've got an issue with people that complain. Yes, I said I would like more government interaction.....It will happen in due time. And basically for people just to have the patience for that...it's not going to be undone in a period of 10 years or 12 years....if people in government are made aware of the importance and if legislation would pass then obviously you would find more people of colour as donors, because then whoever's recruiting, they will have to have certain numbers, basically for the establishment still to survive.

The BMT network frames itself as a set of organisations that now endeavour toward greater representation and make overt efforts to broaden the population groups that benefit from its work. There is some recent programming trying to address the issue of affordability of treatment and importance of providing more local donors for patients. But the issue of class is not as prominent as the culture-ethnicity-race element in the BMT discourse. In an array of instances in my contact with the BMT network, the solutions people proffer and pinpoint their efforts on are awareness and education.

There is work on how ethnicity (and race) still concretely affects health care in concert, but distinguishable from socioeconomic status (see Nazroo & Williams 2005, Nazroo, 1998, and Lalloo et al, 2004, for examples). When it comes to assessment, there is a tense dispute to find an objective measure for socioeconomic status and ethnicity. James Nazroo advocates for appraising ethnicity as a self-defined concept as it is with the

SFF and SABMR. However, as previously dealt with in Chapter 4, it can be more complex than simply asking for self-identified ethnicity.

The measuring of socioeconomic status or class, is unsettled and intricate too. Bond points out: “means-testing” of black South Africans with irregular informal incomes is notoriously difficult.’(2005: 291). Likewise there are problems with systematically accepted measures of inequality. Due to these quibbles with measurement and my own methodological preference, I present a qualitative picture of the added struggles patients and their families endure rather than simply using indices to grasp socioeconomic status. Self-definition restores some degree of agency, and the way that people characterise their own financial situation along with accounts of people who work closely with them humanely acknowledges the deep-seated challenges facing such a subject.

My interview with the GSH social worker illustrates the ways that patients experience strains from their class position. She deals with many patients and families who come from great distances. They go to Cape Town and GSH since it is only one of two public hospitals in the entire country that has an isolation ward for haematology patients and conducts BMT. Due to limited facilities, there is an extensive waiting list. The resources required for their stint in Cape Town must be arranged by the social worker, in addition to navigating varying socioeconomic situations. As she outlines below:

You must also assess home circumstances. You find out most of them if it's someone staying in a shack, even water, they have to walk a long distance, and the toilet, there's no electricity. The conditions there are not good for a person who is getting a transplant. So we try to get a place where they can go and stay and we've got a home, an interim home where they can go and stay during that period of treatment.

Others you will find out they are breadwinners and now because of them being sick and find maybe their wives never work before. And now they have to get the grant

and it is only R870. If you used to get R5000 or R6000, how are you going to survive the whole family on R870? You see it's very distressing. Because even now last week I had a lady, she's from Mosselbaai. She used to work as a chef. Her salary was R8000, used to stay at her own flat, got a child, never involved the father of the child and because she last saw him when she was 5 months pregnant, and now the baby is three months. And she had to give up the flat because she can't pay for it. Lucky, she's got friends who gave her accommodation. But even those parents are pensioners. And now there are things she can't afford and she's relying on the family

...Even when they apply for this disability grant it's a long process because the department of social services, they will want a letter from your ex-employer, proof of residence. They want someone to write a letter supporting you. They will also need a bank statement. You must also write an affidavit saying that you don't have properties, you don't own a house, don't have insurance, no investment, and a person here will be sick for 6 months, then how are they going to do that? But lucky now they do applications here in the hospital. We've arranged that with the department of social services. And now there's this organisation, called the Benevolent Association, that assists them with food parcels while they are waiting for the grant. And people who are far from Cape Town, I always encourage family just to come and be with them for a month or two and I ask the benevolent association to pay for accommodation. There's a house where family members can go and stay, so we ask benevolent to assist them with the food parcel and accommodation fee. Because even the donors when they coming they stay three weeks in Cape Town they also stay there at chaplaincy house

The social worker's daily workload, as she described it, also include translation (she speaks Afrikaans, English, Xhosa, and Zulu), meetings with hospital staff, and handling patient cases from both haematology and ophthalmology. She also told me of three patients who had died in recent weeks. For the family of one patient who was the sole earner for their household, they could not even afford transport of her body after she had passed away. The social worker's accounts indicate strongly that families who cannot afford private care have greater challenges that impact not only the health care that a patient receives, but added emotional stress from financial concerns. Patients must deal with much more bureaucracy than those who have private care, to receive public benefits, made worse because if they must go through the process of filing these applications while they are sick.

Additionally, in my focus group with the GSH haematology unit staff, they earmark class as a major difficulty in related transplants. This is particularly acute when

a donor must come in a second time to provide more cells to boost the effects of the transplant if the graft has not been entirely effective. One nurse told me of a patient whose donor 'was very upset because she had to donate twice and she had to stay out of work and go through trauma financially too, and emotionally, and she got no satisfaction out of it. She didn't actually want to donate. So she was without the satisfaction of being a donor.' During this focus group session the social worker also mentioned a case of a patient and his sister (the donor) both of whom I had actually met during some preliminary fieldwork in the ward:

This was the second time with her as well, she was coming to donate but this time the family promised facing, he even threatened to the donor if you don't go and do the bone marrow and donate, then I am going to take you the police. She was just doing a favour for him, and now he was threatening her and she didn't know that if she doesn't donate there won't be anything that will happen to her. She was just thinking, okay, if I don't donate then I will be in trouble.

This particular focus group session brought forth powerfully compelling stories of patient and donor tensions which resulted from related transplants: strained family relationships can be exacerbated by the pressure of donation, and the singularity of being a match. And socioeconomic hardship only intensifies the situation.

But even for patients whose families can initially afford private care, there are still huge sacrifices made. In one patient's story, her family raised R450 000 through their town in anticipation of the cost of donor search and transplant. In this particular case, eventually the state actually had to bail them out, and she was moved to the state side of the ward at the end of her treatment when her care was overseen by Dr. H.

My interview with the father of a four year old boy suffering from ALL (acute lymphocytic leukaemia) is a case where people have sought private care in Cape Town.

Not only are huge sacrifices impacted by class alone—although in this instance the socioeconomic situation is still hard—they are trammelled up with nationality and religious belief at times. Although the young patient was receiving chemotherapy and not BMT, it still demonstrates the difficulties for a patient and families dealing with blood disorders/diseases. The father detailed the situation:

We are Jehovah's Witnesses, as I told you the first time when we met, we don't accept transfusion [the only way they treat ALL in Namibia], but we expect a very good treatment.... We got in touch with [private hospital doctor in Cape Town], and he says he's willing to treat him without transfusion [with chemotherapy].... I don't know what happens tomorrow, but there is much improvement in my child....

I leave behind a job, yeah. I was working for the...private sector, and I was just starting also, 'cause...yeah, and there was no choice for me to leave behind everything to come and sacrifice for my child. For the first two weeks my wife came, and my wife is working for...the ministry of Namibian government.... It is better for her to come back home to keep the job, which is going to pay 80% of the cost of the treatment, and we still have to pay the other 20% on our own cost... Then we decide for her to keep the job, and ...sacrifice my job... That is what we are doing now for my child's life.

Equally important as how ethnicity, race, culture, and biological materiality interact in complex feedback loops as they function in the BMT discourse, there must be a similar understanding of socio-economic status and class in the discourse and how it also intervenes in those feedback loops. As these are all elements which are tough to quantify, they have definite consequences on practise and how resources are distributed.

#### **Health, human rights, and difference.**

Under what mantle can we suggest that, in the words of the aforementioned lab technician, 'first world medicine' should be more weightily considered in the balance of public health care? One approach is the advocacy of health as a human right. This may offer some interesting possibilities to provoke discussion in the discourse of resource allocation in the BMT network. In a recent article it asserts that the

[The South African] Constitution guarantees not only the right of access to health care but also the right of access to...a range of other social and material needs essential for

good health. Health is also related to human rights in a set of operational relationships.... health services can impact on people's rights, either positively (e.g. through affording them access to health care, or control over their bodies) or negatively (by depriving them of access to health care, or dignity in the way they may be treated as patients). Secondly, human rights violations themselves result in health impacts. South Africa was witness to numerous deaths in detention as a result of torture and security force action. Apartheid planning led to massively increased rates of death and disability from preventable diseases amongst black South Africans, particularly in rural areas. Human rights and health interventions are inseparable features of the PHC [People's Health Campaign] approach. Both are essential to maximize human well-being (London, 2005).

This is an interesting vantage point from which to analyse the BMT network goals to represent all ethnic groups in South Africa, make treatment available to more people, and work on recruitment in populations with higher frequencies of rarer tissue types in order to heighten the possibilities of life-saving treatment. Efforts to the contrary, or without the rhetoric of representation, would make their efforts less compelling, as some SABMR and SFF staff recognise the still-lingering public perception that BMT is a treatment seen only to benefit whites. To aspire for government funding, and to evoke a discourse of national importance of the South African gene pool on a global scale (see Chapter 4) bring to bear how the BMT network functions with respect to constitutional rights. Though it is not my purpose here to judge how much of a human rights imperative there is in the cause of the BMT network, health as a human right in the South African constitution and the National Health Act is an important perspective. It is helpful in evaluating the purpose of lobbying for government funding and justification for the goals of the BMT network.

But what is the best way to go about evaluating BMT as a viable treatment which deserves inclusion in the provision of health as a human right? Should energies be focused on certain communities and cultural issues as the best way of recognising the human rights imperative? This is a concern that Thandabantu Nhlapo brings up: 'to attribute to

human rights an authority that ignores these shades of emphasis in cultural traditions around the world is to misunderstand the practical political and social background against which international human rights business must be transacted' (1994: 182). This speaks to the idea that Edwin Cameron articulates about advanced or expensive treatments, that in essence you can 'buy your life', where class differences mitigate access to medical services (2005). Fearful a prospect it may be, but ostensibly, human life is bound up in a system of transaction and economic exchange. In seeking to achieve justice and human rights, is there ever a way to see and understand difference in way that doesn't also include issues of resource struggles?

Nuances of difference are 'subsumed in the demand that the new South Africa should have a 'human rights culture' such that we must be very wary about the ways human rights are discussed and how there is a fast-developing human rights discourse which has staked a position of trumping other possible 'values' discourses around negotiating difference, dealing with historical oppression, and just dispensation in 'glocal' societies (Nhlapo, 1994: 183). So is there something that matters beyond the potential hegemony of recognising human rights as *the* core moral principle worldwide? Does health take priority among the values of human rights as the main determinant of life and death? While unresolved here, these questions must be asked of the BMT network's endeavours.

The current discussion on the possibility of establishing a South African umbilical cord stem cell (or UCB—umbilical cord blood) bank reflects related concerns, especially because cord stem cells sometimes offers a treatment alternative to BMT. In response to the right to health imperative, an article on the role of the state in cord blood banks says:

Public UCB banks also address the issues of inequitable access to stem cells in systems such as the South African Bone Marrow Registry ... The crux of the matter therefore is whether establishing a public UCB bank is a health priority in South Africa. The Bill of Rights addresses the issue. Although all have the right to access to health care services, this is qualified by the statement that the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of such a right. The National Health Act...embraces policy, priorities and norms relating to the equitable provision and financing of health services and the responsibilities for health of the individuals and the public and private sector. Preventative medicine and providing basic health care to the population are the current priorities in South Africa. The state at this stage therefore would not consider a public UCB bank a priority. This is not an ethical issue, but a health priority issue in the face of economical constraints.... the state, as part of good policy decision-making should take the initiative and convene an appropriate forum to discuss what would be an appropriate policy in this regard, how a public UCB bank can possibly be funded and to rank regenerative medicine as a health priority (Louw & Heyns, 2005).

This suggests a mix of state regulation and private funding which accounts for equity, but also does not strain state funding limitations similar to the current status of the SABMR and the SFF's semi-private fundraising endeavours. Some interviewees as quoted before, feel state funding should also come into the picture. Although it does not really deal with the nation-state as a distinct concept, the article points to the dilemma with state funding for regenerative medicine: rationing.

### **South African Health Care: AIDS, poverty, and the rhetoric of rationing**

The BMT network is highly conscious that in the realm of health issues, their endeavours to facilitate BMT are often overshadowed and deeply affected by the AIDS epidemic. The president of the SFF said in our interview:

Well there are just not enough funds I suppose at the government level...millions of people are suffering from AIDS and basic poverty, so leukaemia is just not at the top of the list...I think Australia and the States the governments help fund the registries and pay for donor recruitment \*and all of that but they're not sitting with the other health problems that South Africa has. ...

the prevalence of AIDS in South Africa is enormous and you can't have AIDS and be a bone marrow donor....because we can recruit donors today and in ten years time their HIV status could have changed...But it is a big reality because there are millions of

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\* See [http://www.marlow.org/NEWS/News\\_Releases/2002/20020926\\_young.html](http://www.marlow.org/NEWS/News_Releases/2002/20020926_young.html), which provides an sample account of the legislative action to federally fund and support BMT and the national marrow donor program (NMDP) in the U.S.

people with AIDS in this country and there also are millions of potential donors that are no longer potential donors.

What the SFF's president says here demonstrates a consciousness of the way that health issues and diseases are arranged in a certain hierarchy in South Africa. But also she recognises that AIDS is not only near the top of that hierarchy relative to BMT-treated blood diseases, but that a wellspring of potential BMT donors are severely diminished in a society that is grappling with AIDS as much as it is in South Africa. It has also impacted the SFF's fundraising strategy, as they could not get non-profit status until recently because it was restricted to AIDS charities.

South African media coverage is highly focused on the holy trinity of 'third world medicine': AIDS, TB, and malaria. One example is the major national newspaper the *Mail & Guardian*, which even has a special report devoted to this ([http://www.mg.co.za/specialreport.aspx?area=aids\\_report](http://www.mg.co.za/specialreport.aspx?area=aids_report)). It also includes an AIDS barometer which keeps track of the deaths related to AIDS in South Africa on a monthly basis.

From a health policy standpoint, AIDS is at the forefront, though not for positive reasons. Nicoli Nattrass's *The Moral Economy of AIDS in Africa*, demonstrates that with hot button health issues like AIDS, the South African government's track record has been poor. In response to public pressure, they often implement 'high profile "quick-fix" solutions' that precipitate a worsening of the epidemic and obfuscate the deeper problems in making treatment accessible to a wider swath of the populace (2004). Nattrass also analyses the interrelationship of AIDS, poverty and inequality in South Africa, further highlighting the epidemic as a social and economic matter of consequence.

In a climate of prevailing health discourses of AIDS and 'third world medicine', it is particularly difficult in South Africa for the BMT network to argue for the urgency of their cause, when it comes to distributing health care spending. But prioritising one life-saving treatment over another—which personnel in the BMT network realise is a part of the current health care funding dynamic—is a hard pill to swallow as evidenced by Leslie London's view on the framing of choices made through prioritisation of treatments:

Public health policies are rarely dichotomous choices. Since when do we choose to do TB treatment or Hepatitis immunization? In real life, we look at a package of basic needs and decide on an optimal level of resources allocated to different programmes. Discrimination, vulnerability and marginalization are the key criteria in making such choices and are as important to a human rights approach as they are in (progressive) public health (London, 2005).

Inequalities in health are categorically skewed as something borne predominantly by 'the most vulnerable in society' (Higgs & Jones, 2001: 152). Which brings us again to the heart of the matter: evaluating who are the most vulnerable and what it means to ration health care resources and funding, measured in varying ways through ethnicity, class, nation, and human rights.

A huge challenge is the hegemony of rationing as it characterised by Paul Higgs and Ian Rees Jones:

Rationing was presented as the unavoidable nettle to grasp in any publicly funded health care system. Axiomatic was the view that there was not enough resources to meet the health care needs of all citizens and that some form rationing was therefore inevitable (new, 1996). This position is now so widely accepted that it forms the orthodox position in health policy circles....The meeting of everybody's needs is impossible because as fast as old needs are met new ones come to replace them—all the time demanding more and more resources (2001:144).

They go on to offer a rubric to use in considering the idea of rationing, since its orthodoxy is unavoidable in the current health care climate:

An important aspect of the growth of technology is the significance of assessing the opportunity cost related to the introduction of new techniques and products. What

benefits and options are created or given up are an essential part of the rational decision making process. This fuels a demand for reliable and accurate information on the relative effectiveness of treatments and their comparative costs and benefits (ibid, 2001: 147).

This leads to an examination of the costs of BMT as a treatment. In the description of the resources required in many BMT transplants, the question of how to measure and evaluate the benefits relative to the costs must be weighed. Is the human rights imperative enough of a benefit? Can the BMT goals of representation and national identity count as benefits? Do sentimental plights matter? Are the fundraising efforts and community education evidence of positive externalities that serve as additional benefits? I do not seek to provide definitive answers at this juncture, but in outlining resources devoted to BMT, this can jumpstart a discussion of the costs and benefits and the meaning of rationalisation of health resources and funding in contemporary South Africa.

#### **BMT: An account of the resources required at each step of the process**

The first step of the process for the patient in a condition requiring transplant is testing family members to determine if any matches. If there is no match, it is still useful to determine a family tree tracing the patient's inheritance of HLA haplotypes (pairs of HLA alleles inherited from each parent). The test results are analysed by SABMR staff, primarily the transplant coordinator and the deputy director, given their medical technology background and strong knowledge of HLA typing and frequencies. They will draw up a family tree and assess for matches. Individuals' HLA types are inherited from both mother and father. With HLA-A and -B for example, one A and one B are inherited from each parent. Each pair of A and B alleles are called haplotypes. For family not yet tested, the genealogy may help determine if there are any prospective matches. Drawing

up these family trees myself using real test results, with tutelage from the deputy director, helped me to understand this part of the process.

If there are no related matches, the deputy director can perform a cost-free preliminary search for potential unrelated donors on the SABMR and worldwide. The deputy director often communicates the results to the physician and the patient's options, but there is no further testing of potential donors at this stage. An activated search in the SABMR costs R7500 plus the cost of any donor typing/testing.

When there is a potential local match among donors in the SABMR, this is the donor(s) which they attempt to contact. It is much cheaper to have a donor within South Africa. Potential donor(s) are contacted for confirmatory typing and a medical examination. The policy is that if it is a local donor—related matches included—this can be funded publicly, another reason a local donor is generally preferred.

When a potential donor is identified, a donor is contacted by donor relations personnel at the SABMR. But this can be a challenge, especially if the donor's information has changed. Finding them quickly is of utmost importance. As the SABMR deputy director stressed, 'You must let the donor know you are doing further tests. The donor needs to be aware every step of the way' and with further testing you should 'take every opportunity to stick that needle into the donor' because you run into problems with donors. For example, 'the donor may be happily pregnant and not even know you are looking for her.'

In the case there is no potential local match an international search ensues. The registry notifies the physician of matches identified internationally. Where the transplant is unrelated, local or international, the donor search is in under the jurisdiction

of the SABMR. When assessing potential donors, the deputy director described donor selection:

'I [choose] in consultation with the transplant centre. Sometimes it is clear.' If it isn't [fairly obvious], we alert the doctor to the problem and we have a discussion about blood group, gender, but sometimes there is only one and you just go for it, because time is money for these patients. The mismatch standard is 1 antigen or 2 alleles, but 'we are conservative'.

For many patients the search process is a race against time, as histocompatibility is weighed with expediency of treatment depending on the condition of the patient; the resources at stake are not only monetary they are temporal.

Once the donor selection and testing have all been reviewed, they proceed to completion of the proper forms. After logistics are carried out, this is the stage where the transplantation procedures take place (see Chapter 1). International transplants require a courier to transport the donated haematopoietic stem cells overseas to the recipient's location.

Couriering requires a fair amount of resources. The process of even setting up the courier leg of the transplant has many criteria to meet according to the deputy director:

When book[ing] the flights, you must have a primary flight, a backup flight, ....There are rules for couriers. The family cannot collect, they should be relied upon not to panic. The person must be assertive and with a medical background.

People who serve as couriers are generally lab staff and they have to have international travelling experience.

I was able to have contact with a courier during her first experience with the responsibility. In addition to her, those I spoke to with courier experience maintained an awareness that the whole process is for the purpose of helping a patient. They have a strong sense of responsibility and participate in the BMT network because they believe it is fulfilling. As the lab technician said,

As a courier at the back of your mind there's always that "this is for the patient"...It's not just a test tube you know, someone that is ill, someone more than likely whose disease you've followed because you've tested generally the siblings, etc. and now it goes for an unmatched donor....I regard it as a privilege to be a courier and to be able to perform a service for someone that is ill, quite ill, in essence, save a life.

Every international transplant, in either direction, is costly, but for many I spoke to who contribute their energy to the process they believe it is worth it. This sense of purpose, that the bottom line is 'saving lives' is a very strong element in the BMT network discourse, one that propels the work that they do and ensures that it 'goes on' as justifiable practise.

As seen above, the hegemony of 'limited resources' is a constraint on what the SABMR is able to do. It is also an impetus in the fundraising activities of the SFF. To expand the capacity of typing more donors and facilitating BMT, the SFF staff repeatedly cites funding as the lynchpin on which everything else hinges. As the president of the SFF says,

Well the biggest issue is fund raising because we really do survive year by year on what funds we can bring in and it's difficult raising funds in South Africa because there are so many charities. We're starting to move abroad in terms of fund raising, we have to...But that is our biggest thing. The actual donor recruitment is not difficult if you have the funds...people come forward. But then you've got to have the thousand rand to pay for each test. The biggest thing facing us is going to be the funds and once we've got the funds we can do the ongoing recruitment. But that's an annual dilemma. There's a lot of pressure on the staff here because you are all working trying to create events, trying to get money out of the same companies. It's the most difficult job I've ever done. Stress levels are high.

And the staff concurred with this in the focus group interview:

The ultimate goal would be to get them to join the registry. Yes, as many people as possible but ultimately to get funds,

Yes because to get those people on to the registry is one thing but at the end of the day we need the funds to pay for those tests. And we don't have funds. We can't pay for those tests and we target a community that can't afford R1000 for a test.

The costs quintupled recently, as the policy is now to type more potential donors at the HLA-DR level in addition to HLA-A and -B, which originally cost R200 in accordance

with WMDA policy adopted in order to make it easier and more efficient to assess possible donor matches. The SFF's policy is that they will pay for typing all donors of colour and blood donors under 40 at the higher level, since they are more likely to be committed and/or increase representation. The extra workload national labs have with the new level of testing for more potential donors, without much new hiring has put added pressure on the SFF to raise more funds than before to register the same amount of donors. This is further corroborated by the intense amount of energy that the SFF devotes to fundraising.

The largest annual fundraising event is the Sunflower Ball. Prior to the ball, there were countless tasks that all the staff, the ball convenor, and the PR company did. The broader work included soliciting in-kind donations used as prizes and auction items, sending out invitations, managing ticket sales, and arranging for dinner, entertainment, and cocktail hour 'street market'. The work yields a good source of fundraising and elicits wealthy donors. One of the SFF staff members mentioned to me, 'Last year I helped at the ball and....I couldn't believe it....I didn't know people were that rich. Most them are so down to earth you have no idea. Goes to show you can never judge people by appearance.'

The details of the event this year were also particularly striking from a cultural standpoint. The theme for the ball was 'One Night in Bangkok'. The foyer was very elaborately set up to be a Bangkok street market. Stalls that were adorned with paper accordion lanterns, fake parrots, and giant bamboo stalks everywhere as well. Each stall had a name, e.g., 'Velly nice rice' sold various sushi. 'Temple of shame' was where those who had not dressed according to theme, had to either buy a fake moustache or fan.

These are just some of the examples of the huge effort put into the aesthetic aspect of the event alone.

But there is a deeper meaning communicated in the way the event sought to blend Asian cultures. In both examples of the ball themes for 2007 (see also Chapter 3), culture is portrayed as an entertaining theme, something to add to the festive nature of the event. In interesting juxtaposition, the purpose of the event is to raise money for the SFF's work, strongly characterised by initiatives to improve community outreach and working on cultural issues in relation to BMT, reflecting contrasts in how cultural difference is perceived and acted upon in a range of contexts.

### **Coalitions and Rationing**

In the orthodoxy of rationalisation, Kobena Mercer highlights key concerns in this regard:

The possibility of coalition building was preempted by the competitive dynamic of who would have priority access to resources....The rationing of meager resources became a means of regulating and controlling 'difference' because, as the various actors that perceived it, one group's loss was another group's gain (Mercer, 2000: 505-506).

It is important to engage with this quandary in terms the lack of donors from certain communities on the registry, which according to the BMT network discourse, has led them to concentrate their recent efforts on those underrepresented communities. This marks difference in ways that present possibilities for coalition building across those differences through the ideals of equity, nationhood, and representation. But there are also ways that difference is marked in the discourse which may have other unintended effects: the conflation of ethnicity and culture, or further highlighting the class distinctions and who currently benefits from the registry and BMT most, versus the vision for who it benefits in the future.

Given the geopolitical inequality amongst Southern African nations where South Africa has regional hegemony, as SABMR is the only hub centre for Africa in the international BMT community, it matters who the registry serves. Higgs and Jones point out: 'Most attempts to create socially acceptable criteria for the rationing of health care services are doomed to replicate system world priorities because of the way that they are set up' (2001: 143). The SABMR is grappling with international market pressures in terms of the resources devoted to high-level donor typing, and which countries they choose their donors from in international searches for local patients: 'When you do a search the more fully typed donors are at the top and these registries offer them up like commodities. They're not, but if you see that there is a fully typed donor and then an Italian donor who is not fully typed, you can't just say, "Oh, the Italians are very nice to work with" when you have a fully typed donor sitting right there' <sup>10</sup> Although there is a strong consciousness on the part of many intelligent practitioners in the BMT network who feel very strongly in the importance of constant awareness of dealing with people, not just commodities who happen to be sentient, this still competes with the way the discourse commodifies bodies. Indeed, what do BMT network practises mean for the integrity of the body? These concerns are addressed in the following chapter.

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<sup>10</sup> 6/12/07 SABMR, Deputy Director

## **Chapter 6: Haematopoietic stem cell donation, integrity of the body and human mortality**

Saving lives is the utmost discursive imperative in the BMT network. Weighing the resources invested in the BMT network in the previous chapter, we must still ask the question: What is at stake, not only for the patient, but also the donor, in relation to their bodies and sense of self? I will review different theories of bodily integrity, further informed by issues of commodification of the body as well as cultural difference, incorporating the work of Margaret Lock. Her thoughts on mortality provoke a serious re-thinking of the life-saving imperative in the BMT network.

### **Characteristics of the ideal donor: Commodification, fragmentation, and difference**

During my interview with the donor liaison she spoke at length about the issue of commitment in potential donors who have called in response to outreach or patient stories:

What one is trying to do is ... find committed donors on the registry and so what hurts me the most is when people will phone up and say they want to come off the registry because it is quite clear that the person who motivated them has either gone on and passed away or found another donor, and they clearly only wanted to do for that person, so in other words they use the Sunflower Fund as a mechanism to be tested free of charge, as they are not even paying for it, to see if they are a match to a specific person and when they've found that that person no longer needs the donor for whatever reason that they want to go off the registry....

We try our best to weed out those [noncommittal donors] but you can't always tell. I mean sometimes I can tell the people are lying...I can hear by their voice and by how they word it ...you reluctantly have to register people.

What she says is a reflection of the immense power that both donor liaisons and the BMT network have in defining the determinants of what constitutes a committed donor. This may be part of a success oriented quasi-expert and lay communication (see Chapter 3). Sometimes it is a judgment call they make where you 'can just hear by their voice and how they word it,' an intangible sensibility, that, even if they cannot outright

refuse someone's registration if they meet the donor criteria, they can limit the testing to the lower level, and by proxy, reduce the funding that is allocated to that person. They can ask questions which they believe to be instrumental in determining whether or not there is a better chance of the person being committed donor. They also make an effort to explain and answer questions to make sure the donors are 'well informed.'

Naming target groups in the BMT network discourse creates dual elements of difference and representation. Much of the outreach literature states criteria in this way: 'the SABMR desperately needs volunteers from key areas of the community...*Due to current shortages, you are even more precious if you are male and/or from a black, asian or mixed race ethnic background*' (Sunflower Fund, 2007a). The word 'precious' connotes commodification of the donor body. Identifying specific groups as necessary for reasons already discussed, transforms persons and their bodies from human categories into objects of desire (Sharp, 1995). However, the point of commodification is somewhat unclear with haematopoietic stem cells. It is a matter open for questioning the determination of the cells' external socio-economic utility. Is it the very act of typing a donor that marks them as a potential commodity, or is it something else?

Utility, as it can be mitigated through personnel in the BMT network and the donor search and testing, is not explicitly referenced. At the same time that there is a concerted effort to discursively elide the ways in which donor bodies are commodified, even if there is still an acknowledgment of their humanity, one cannot ignore the elements of the discourse which frame donors' cells as 'products' to be 'harvested', and as specific target group donors are seen as 'precious.' The donor and the donor's cells are affected by the reproduction of knowledge that frames them as commodities. The effects thereof are

described by Leslie Sharp who makes the assertion that 'scientific forms of knowledge currently fragment the body with increasing regularity, increased desire in medical-scientific arena for cadavers and skeletons, organs and blood, etc And increasing dualism between body and self' (2000: 290).

For example, with the 'product' sent from the overseas donor to a patient that Dr. H was treating, he recalled, 'We spun the bag and it burst! Luckily, we were able to salvage the cells, about 2.7. And of course, anything below a 2 is not enough.'<sup>11</sup> Cells are no longer spoken of in relation to the donor as a person, they are objectified, as a limited resource, which if handled incorrectly may not be enough for a transplant, and therefore must be salvaged. Extending the sense of fragmentation of the body, that there is a minimum of cells required for a transplant puts a baseline on the utility of donor cells: if not harvested to a particular threshold they have no practical use as a commodity.

For both donor and recipient, if the exchange is characterised as an anonymously but mutually agreed upon exchange of property, then 'it is important to consider how and under what conditions body parts accrue value...and what local resistance there may be to the alienation of body parts discussion of value on body parts only given external value when culture intervenes and medical expertise permits potentiality' (Lock, 2002: 47).

Lock deftly incorporates Marx, noting the fetishism of commodified objects—their objectification as things-in-themselves—disguises the relations among individuals involved in production and consumption of these commodities (2002). As related to organ donation, organs are given value outside of the originating body as objects of value for another. Their life-saving properties are only conferred upon the organ when another

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<sup>11</sup> 29/11/07 SABMR

can use it and the medical facilities make that use possible. With BMT living donation, until a donor is found a match for someone in need, there is only the potential value of the haematopoietic stem cell. In fact, in the case of aphaeresis, the donor must take growth factor approximately 5 days prior to the harvesting of cells in order to produce an adequate surplus of stem cells to donate.

Sharp's argument is also useful in thinking about how there may be possibilities for different conceptions of the body and self which may be context specific. It is helpful to look at some of the literature on organ donation and blood transfusion, historically in South Africa. Organ stealing rumours have become widespread globally because organ trafficking is an actual practise (Scheper-Hughes, 1996). The general public does not immediately comprehend that the specificity of HLA matching renders a black market economy nearly impossible. Fears of marrow harvesting arise since aphaeresis is not people's first association with bone marrow donation in many cases. When many South Africans are first introduced to the idea of being a potential bone marrow donor, those narratives of global trafficking of purloined body parts influence them, even if BMT is not technically implicated in such narratives.

Although the aforementioned account deals with donor theft from a cadaver, often of an organ that cannot be regenerated, there is a distinct extension of her analysis to haematopoietic stem cell donation. Widespread misconceptions about the nature of BMT/aphaeresis (not understanding major differences like living donation, stem cell regeneration) means there is a strong possibility that people's associations with donation of biological matter and body in the context South Africa also apply to bone marrow/stem cell donation. But it is the very paucity of literature engaging on how these organ-

stealing fears may (or may not) affect an understanding of BMT that compels this discussion.

Rumours act as narratives for the actual bodily and collective fragmentation that occurs in societies stricken by violent conflict and where people are unable to articulate their trauma otherwise. In the specific case of South Africa,

The rumours express the subjectivity of subalterns living in a 'negative zone' of existence where lives and bodies are experienced as a constant crisis of presence (hunger, sickness, injury) on the one hand, and as a crisis of absence and disappearance on the other. The stories are told, remembered, articulated because they are fundamentally, *existentially* true (Scheper-Hughes 1996: 9).

This highlights the way highly socio-politically motivated violence during apartheid created a climate wherein rumours arose from a history which necessitated a truth-telling through intricate webs of 'fanciful narratives that...function as evidence of the crisis of the body in the wake of such violence that still persists in South Africa' (ibid, 1996).

The African language donor liaison's story is one of a plethora of examples in contemporary South Africa of the very crisis described above by Nancy Scheper-Hughes. But it is more significant in light of the donor liaison's work to change notions about violability of the body and self to facilitate donor registration from black communities. She had been unable to attend the Sunflower ball because her nephew was killed. Boys in neighbouring section of the township where she lives heard that he was in possession of a gun. She described what happened: 'He said he didn't have one and they shot him at the side of the head and took his cell phone, realised he didn't have a gun.'<sup>12</sup> In these situations she said people often will not tell the police, for fear that others will come after them. In this community, where young men's lives are precarious and bodies are

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<sup>12</sup> 6/11/07 SFF

disposed for the sake of firearms, one can only begin to conjecture that the sense of pending corporeal vulnerability is heightened. In K.T.J. Kometsi's work, the reluctance of families granting consent for cadaveric organ donations is sometimes related to the crime-related circumstances around death of the potential donor (1998).

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Lock mentions that this question of 'who is my stranger?' persists today even as both blood and organ donation become more widespread, and that the apprehension around this question is still connected to race and ethnicity among other things (2002). Recipient concerns around their donors, if anonymous, are often influenced by notions of ethnicity, race, and other forms of difference. While cross-ethnic matches are not unheard of, the likelihood of similar ethnic background may mean that this anxiety is reduced in BMT. The donor's perspective is also affected by a match likely being of similar ethnicity, thus alleviating some portion of the question 'who is my recipient?' It offers another possibility for community building, and another avenue of research. In the U.S. for example, registering mixed race donors has become a flagship issue of multiracial activists, a community where coalition is built across difference (The Mavin Foundation, 2007).

### **Discursive implementation of donor shortage**

The question of who is benefiting from transplant technology and the disproportionate and ethnicised health concerns reflects the social politics of donor 'shortage.' Thematically, it seems that black and coloured donors are always in shortage and white donors are always in abundance. In the case of blood donation, whites were historically seen as providing the bulk of supply for everyone when the responsibility for donorship should be increasingly the onus of blacks (Titmuss, 1970, Palmer, 1984). The

specificity of matching HLA, highlights commodification linked to target groups, and a donor as a one-to-one resource. Registries have their own policies on donation multiple times, but as the deputy director stated, ‘The donor is a donor for that patient and we don’t know if they no longer require DLI [donor leukocyte infusions]. How many can they support? So the SABMR’s policy is to take donors off the panel if they have already donated stem cells. We advise that you don’t disclose the outcome of the patient to the donors. “Walk away, you’ve made the donation.”’ Donors are seen as a finite resource, made to feel that they are special, a singular match for one person.

The related BMT donor is also aware of their uniqueness. In my conversation with the man who donated to his brother he said:

It was a little bit difficult but for me it was very nice. Because not everyone can give bone marrow to his own brother... I am a very lucky person that I can give it to my own brother....Other people are not so lucky as I am . God gave me that power to give bone marrow to my brother, that’s why....

While theological matters are not dealt with extensively here, it is a reminder that religion—he identified as an apostolic Christian—is a factor meriting inquiry in relation to people’s sensibilities haematopoietic stem cell donation.

Veena Das makes an argument for contextual distinction in the way shortage of donors is presented as a ‘crisis’ (2000). Her critique of donor shortage discourses provides some crucial points, but she does not deal with the unique case of haematopoietic stems cells or renewability in her analysis. Nonetheless, she identifies cases that very much align with the valuation of donors as they are intertwined with other narratives of citizenship, national pride, and altruism to bolster the ‘creation of legitimacy for the new medical technology’, i.e. transplants (ibid, 2000: 273). This relates to the shift that Donald Joralemon refers to, wherein the increasing validity of transplant

technology enables new bodily transgressions to be placed in tension with recalcitrant physical and cultural boundaries, contributing to a bio-cultural reconstruction of the body that becomes socio-culturally mainstream (1995), and an inflection of Foucaultian bio-power (see Chapter 2).

### **The Bodily Frontier: The boundaries of bodies and transplant technology**

This brings us to idea of the body in relation to its limits. I want to reintroduce the idea of the 'frontier,' a concept Chapter 4 cites from Chipkin as he examines it through Laclau and Mouffe. But rather than the nation as a limit of democratic practise,, I want to discuss the frontier of the body. Judith Butler, who makes a very similar but distinct argument about bodies' boundaries and the 'discursive limits of sex,' is worth quoting at length:

...regulatory schemas are not timeless structures, but historically revisable criteria which produce and vanquish bodies that matter....The limits of constructivism are exposed at those boundaries of bodily life where abjected or delegitimated bodies fail to count as "bodies." If the materiality of sex is demarcated in the discourse, then this demarcation will produce a domain of excluded and deligitmated "sex". Hence, it will be as important to think about how and to what end bodies are constructed, as it will be to think about how and to what end bodies are *not* constructed, and, further, to ask how bodies which fail to materilize provide the necessary "outside," if not the necessary support for the bodies which, in materializing the norm, qualify as bodies that matter....What challenge does the excluded and abjected realm produce a symbolic hegemony that might force a radical rearticulation of what qualifies as bodies that matter, ways of living that count as "life", lives worth protecting, lives worth saving, lives worth grieving?' (Butler,1993 : 10, 14-16).

While Judith Butler expounds on sex and sexuality, her argument is important for how bodies are discursively constructed in the BMT network. Discourse is a source for understanding the ways in which population genetics, ethnicity, race, nation, etc. function to simultaneously fix and destabilise certain ideas about those concepts. The same can be applied to the boundaries of the body and the practise of transplantation itself. There is a traceable process at work where donation and transplantation in its various forms, from cadaveric harvesting to aphaeresis serve to stabilise organ transplants, BMT and a wider

range of medical technologies as acceptable transgressions of bodily boundaries, what ways bodies may be utilised, and the anatomical sensibilities of donors, recipients, and their communities. Before transplantation was common medical practise, the transferability of body parts and cells were inconceivable or experimental, outside the boundary which determined corporal being. Enabling transplantation as practise was a way of defying the previous limit of bodies, and in time, created a new limit. Cecil Helman's work, for example, identifies transplantation and spare parts surgery as the beginning of a 'modern industrial body.' Albeit connected to a deeper mythology of bodily fragmentation, it is also a new formulation of liminal bodies, and an extension of novel contemporary social relationships (1988).

This process also reveals what might lie beyond these contemporary particular hegemonic meanings that circumscribe bodies, those conceptions (or would-be conceptions) of the boundaries of the body which Butler calls, 'abject' and excluded. Joralemon articulates what is at stake in the shift that is happening as biological donation becomes standard practice and the need for and scarcity of donors is the dominant discourse:

Are the efforts to reconceptualise the body as distinct from the person inhabiting it like cyclosporine [immunosuppressant drug] for the social conscience, suppressing but never eliminating a cultural insistence on self/body inviolability? Or are such efforts destined to accomplish at the cultural level that which our biological responses prohibit, a permanent reconstruction of the self in a manner that separates identity from its corporeality and permits a blurring of the boundary between self and other? (1995: 340).

Hopefully continuing discussion can come to some sort of answer to the consequences of such possibilities of cultural accommodation given transplant technologies' advancement. The BMT network emphasis on ethnic difference highlights the struggle of pushing our bodily boundaries and identities to the limit. It is important to consider a meaningful resistance against such a push. This struggle is additionally

compounded given the South African context of a society deeply divided by inequality and history of structurally carried out violence. The discourse is punctuated with themes of rationalisation of resources, scarcity, and desire which link to a commodification and fragmentation of the body, while it also exposes the ways that the boundaries of the body are both created and challenged. But there is another element in how people conceive of their own bodies as well: the concept of altruism and the gift.

### **Notions of altruism and gift economies**

There is also some scholarship that indicates the likelihood of registered bone marrow donors to fill a certain profile that is a bridge between blood and organ donation:

Bone marrow donors have possibly found an altruistic niche—bodily donations—which demands that they have to come to terms with their fear of physical injury, death anxiety and fear of chaos. A pragmatic conclusion, finally, is that bone marrow donors are the ones best suited for recruitment also to other bodily donations—and maybe also to other altruistic action (Sanner, 1997: 75).

With bone marrow donors as the middle ground of consensual bodily donation, we must ask: What is the psychology of this particular donor state? What implications does this have for the continued dialectic about boundaries of the body, technological and cultural interfaces?

Joralemon describes the discourse around donation with reference to these questions: ‘References to the “gift of life”...not to mention the connotations that accompany the terms “donor” and “recipient” link the medical procedures to complex notions of generosity, altruism and selflessness’ (ibid, 1995: 343). Lock distinguishes these notions further: ‘While some potential donors assumed assignation of gifts to

ethnic groups or individuals...altruism, in contrast to gifts is not directed toward individuals, altruism is a modern form of fellowship building' (2002: 206).

When considering that the donor often feels motivated to donate due to the discourses elements of gift-giving and/or altruism, if those particular hegemonic notions of property and the individual's right to give that property freely as they see fit are part of a greater ideological structure that marginalises a potential donor of a given socioeconomic status, this would logically also temper that potential donor's interest in consenting to donation. Here I must return to two points made earlier. 1) The SFF donor liaison made an issue of donor commitment, and how many prospective donors may only feel that they would only donate to a specific patient. 2) Donors may duly endure the 'who is my stranger?' anxiety commonly experienced by recipients. These are both major factors in donor willingness which should be included in addition to the motivators of altruism and the 'gift of life.'

The contact between unrelated donor and recipient is restricted because of issues of 'morbid attachment, undue pressure exerted on the donor...and a sense of failure on the part of the donor, should the transplant have failed' (SABMR, 2007: 18). Even if relations between donor and recipient are non-existent, the initial registration process is conducted in a highly contextualised fashion. The SFF makes efforts to educate donors in advance and take them through donor criteria. In contrast, many organ donors' families often have to deal with the sudden death of a loved one and the decision of organ donation at the same time.

BMT donor recruitment is often carried out with a focus patient in the community that needs a donor match, and in fact a community-centric approach is a large part of

process. This context informs the ethnically based 'need' and the increased probability of matching within the community. So the need is supposedly understood by the donor, and the donor is still alive to make the ultimate decision about donation, in the case of matched unrelated donors (MUD). However, this community-specified need could also be seen as imposing a certain unwelcome pressure on the potential donor to identify with an ostensibly dire situation in their community and acknowledge an inequality in treatment that they are supposed to feel the need to rectify. It may also be perceived as pressure for an individual forcibly documented under a certain identity and community, even if that is not how they would otherwise self-identify. Is this justifiable because of need? Because of the purported connection of ethnicity and biological materiality? Does the strength of altruism and the 'gift of life' offer a compelling enough reason for people to reconsider their connections (or lack thereof) to a particular social identity or community?

More anonymity between donor and recipient, rather than less--as in the case of highly probable donor-recipient ethnic similarity in BMT--can often be more valuable. As in a discussion of the 'gift of blood', Godbout asserts that 'it is this cultivated ignorance that makes the transfer between donor and recipient feasible' (1998). On this tack, Richard Titmuss makes an important point too: 'there is in the free gift of blood to unnamed strangers no contact of custom, no legal bond, no functional determinism, no situations of discriminatory power, domination, constraint or compulsion, no sense of shame or guilt, no gratitude imperative' (ibid, 1970: 239).

But even in related transplants, donors can exhibit a greater awareness of how their actions on behalf of family may also be extended to strangers. During my interview

with the related donor who donated to his brother, he spoke about some sort of karmic reward later, which could transcend kinship. As a religious young man, he also expressed that God endowed him with some of the ability to be a match and that he knows any good work must inevitably yield some good in his life which he can later attribute to his act of kindness toward another: 'I am proud to give the bone marrow to [my brother]. I can do it for anybody else also. Because it's for me, everything that I give out, I get it back twice and I don't know where does it come from. And one day I realise it's there that I do, it's there that I do something good.' But even though a donor may have autonomy to make the decision to biologically donate motivated by any number of reasons above, whether knowing anything about the recipient or not, the BMT network must still wrestle with serious ethical considerations, issues of property rights, the materiality of the body, and, more acutely, mortality.

### **Mortality: The 'failure' of death in the BMT network**

Shortage and need are rooted in the medical discourse around saving lives and prevention of death. 'Death is "evaded" because we moderns have become, thanks to medicine, preoccupied with life. In effect, to medicine, all deaths have become 'bad' and untimely: each represents a humiliation of the expert....organ donation [is then] the ultimate act of charity, as the 'gift of life'—a technological fix to transcend the "scandal" of biological death' (Lock, 2002: 203, 206). This hegemonic notion of preoccupation with life is tied very closely to the imperative for 'saving lives' that both drives the BMT network. It is very hard to argue against saving lives, because life has become a naturalised priority, and that death is seen as a failure. The fear of failure and the

humiliation of the expert in a patient's death, is also attributed to the system, to shortage, to under-representation of ethnic/genetic diversity, to cultural barriers. Is our mortality to be seen as unacceptable in all cases? Or can we see evidence of our mortality in 'failures' of death as profound reminders of vulnerability and the temporary state of living?

The initial search for a match within a family also can make a family feel as they are failing their relative in a way that the community can also 'fail' the patient if the shortage persists and they are a 'victim' of that shortage. Either way, integrity of the body and its violability challenged by this constructed scarcity persisting in specifically earmarked ethnic communities could also be seen as a sort of ethnocide if the shortage is blamed on ethnic and cultural factors that must be overcome for the preservation of life. But I must tread delicately here. No one has gone to this extreme extent in the discourse observed. It is not blame and resentment toward communities that gets in the way of the hegemony of life over death in the BMT network. Instead it is education, outreach, advocating equity, diversity, and national unity, which bolster the imperative of life. I am simply voicing a cautionary caveat here that the discourse has the potential to move in a detrimental direction if the actors in the BMT network do not remain vigilant. Ethnicity and culture may become discursive signs of backwardness, socioeconomic means and rationing may continue to benefit privileged sectors of society at the expense of vulnerable and historically disadvantaged communities despite urges for health and human rights.

However, I must stress that the discourse is presently positive, life-affirming, and socially just in its intentions. My deep respect for all of the people who I spent time with

during my research are a testament to these conscious intentions, as are their openness and willingness to allow me to observe their discourses. I have learned from everybody who participated, and seek to situate this work as part of an ongoing conversation about meaning and consequence in the BMT network, with relation to themes of strong social import. One may have noticed there are still many questions, and they are all posed in the spirit of further engaging with these people whose work I am concerned with.

In many academic undertaking, the analysis is biased towards negativity, warnings, and criticism. But I must stress in the concluding pages of this work that the BMT network, as well as the patients and family all present powerful arguments in favour of their endeavours that aim for social justice, as much as there are quandaries and difficulties with those endeavors that I have found in my research. While the ideas of communities and ethnic identity are loaded with the potential to create domination, discrimination and other dangerous forms of social oppression, we cannot erase the relevance of communities and socially constructed identities, but their meaning can be altered and negotiated for humane purpose. Certainly, what motivates those working in the BMT network is to reconstruct communities as groups who work together to make sure there is equal representation, facilitation of life, and a certain standard of health care. And the families, patients, and donors, do not act out of some sort of social guilt-tripping, more often than not. In fact, they are most compelled by the strong belief in the value of human life, love, wanting to be able to ask for help. These energies must be harnessed, but not without considering the points I have broached throughout. Hopefully, by heeding these points, those endeavours of the BMT network will be enhanced, and even more well-conceived.

## Chapter 7: Conclusion

Using discourse analysis, and an awareness of the need for self-reflexivity and rigorously thick description there are themes that emerge which resonate broadly in this research. Chapter 3 demonstrates the ways in which expert and lay communication are hybridised by the BMT network discourse various media. Guided by the analysis of Duster, BMT discourse perpetuates intricate feedback loops of ethnicity, genetics, nationhood, culture, and mortality and reveals ambiguity of boundaries amongst these things. Feedback loops about bone marrow stem cell transplantation and the organisational work done to facilitate this are also influenced by issues of rationalisation and South Africa's particular situation in issues of health and human rights, where consideration must be given to the immense amount of resources devoted to BMT network endeavours. Rationalisation orthodoxy even permeates the very personal space of body and self. The BMT network discourse powerfully reinforces the imperative of life as it is bound up with a multiplicity of profound societal and biological consequences. I hope that my account and analysis of that discourse offers insight into these fraught intersections of the scientific and the social.

BMT objectives can be a part of greater social justice initiatives in South Africa and ways of rethinking race, ethnicity, health care, and nationhood. But as I have cautioned before, there should be a clear understanding of the feedback loop as it currently operates by those parties interested in the goals of donor recruitment/representation, community building, and social justice. There must also be a consciousness of how these parties are actors who have the power to intervene in these

feedback loops and also reproduce them. Great care must also be taken with regard to these goals as they relate to the use and distribution of health care resources, both nationally and internationally. Certain socioeconomic structures in place can both mitigate and enable such goals to be met, depending on the ways resource usage is justified.

We must look carefully at the ways in which communities and social categorisation are constructed and reconstructed in every piece of PR, interaction in treatment, and in the entire process of BMT in relation to donor, patient, families, and their communities in relation to priorities in medical care, life and death, and genetic materiality and the influence of population genetics.

Finally, we must consider the fundamental issues of bodily limits, how we see death, shortage, and value of donors in medical practice as a whole. BMT is another prime example which forces us to engage on these issues. Carrying out these key discussions in recruitment practices and registry practice as well as treatment and information sharing (education) are very important for identifying and revising standards for such practice.

Of course, while the scope of this work is admittedly wide, there are still many other avenues which I hope I (or other researchers) can pursue. While the scope of this work focuses on the BMT network, it would be very fruitful to pursue a deeper understanding of public perception (especially in communities that are being targeted for recruitment) of BMT and other related issues. There are also some fascinating possibilities for comparative work. Examination of BMT networks in other countries could offer their own illuminations of the interplay of social identity and genetics, as well

as interesting contrasts in organisational practise and discourse. Such comparison may also give a richer sense of the global context of interconnected BMT networks. I hope that my work is a source of inspiration and engagement for these organisations and for the people with whom I have interacted. I also hope that it encourages others to seriously examine the issues that have been covered here.

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Appendix I: Consent form sample

**Consent form**

**Research Project:** *Transplant Anxieties: donor attitudes and consent about bone marrow/haematopoietic stem cell transplantation.*

Principal researcher: Emily Avera

University of Cape Town  
Faculty of Humanities  
In conjunction with Intercultural and Diversity Studies Unit of Southern Africa (iNCUDISA), Sociology Department and Department of Social Anthropology

Address:  
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Researcher Telephone: 078-579-1209

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**Name of Participant:** \_\_\_\_\_

**Nature of the research:** A medical anthropology and diversity studies approach in looking at challenges in representing donors on the South African Bone Marrow Registry (SABMR) that reflect South Africa's demographics and furthering an understanding of haematopoietic stem cell donor attitudes and consent.

**Participant's involvement**

What is involved: Spending time talking with researcher about transplant and donor awareness processes from personal experiences and allowing researcher to shadow participant in daily work activities (if staff member of organisation under observation)

Benefits: Information shared will further learning about donor attitudes and consent, contribution to educational enterprise, self-learning and reflection, exchange and creation of knowledge with researcher

**Costs:** Time during interviews, focus groups, and other interactions with researcher

No compensation. Voluntary participation only.

\*\*\*

I agree to participate in this research project.

I have read this consent form and information it contains and had to opportunity to ask questions about them.

I agree to my responses being used for education and research and on condition my privacy is respected, subject to the following:

- I understand that my personal details may be included in the research but my name will remain anonymous in materials produced or distributed by the researcher.
- I understand that I am under no obligation to take part in this research project.
- I understand that I have the right to withdraw from this project at any stage.

Signature of participant/Guardian (if under 18): \_\_\_\_\_

Name of participant/Guardian: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of person who sought consent: \_\_\_\_\_

Signature of principal researcher: \_\_\_\_\_

Date: \_\_\_\_\_

OR

**I decline to participate in this research.**

Signature of participant/Guardian (if under 18): \_\_\_\_\_

Name of participant/Guardian: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix II:

### Haematology Unit Staff Focus Group Outline

#### Research Foundations

##### Project Objectives

- **Central Research Question:** Are there cultural and socioeconomic factors specific to ethnic communities affect haematopoietic stem cell donor attitudes and consent?
- Gain a more systematic and detailed understanding of organisational participation in transplant process in relation to donor attitudes and consent
- Carrying out research with patients, donors, Groote Schuur haematology unit staff, and SABMR/Sunflower Fund personnel to gain firsthand insight into attitudes and consent and experiences around identifying organisational resource constraints and challenges in the transplant network: the implications as such
- Examining social constructions of transplants and “need” for donors in the BMT/SCT (bone marrow and stem cell transplant) context, re-examining “shortage: and “need”
- **Research Plan:** ad hoc interviews via “hanging out” with staff members and also 2-3 in depth interviews with patient and donor related pairs from communities concerned. Will also potentially conduct focus group South African Bone Marrow Registry and Sunflower Fund and ethnography with recruitment drive

##### Research Analysis Approach

- Identifying if ethnically specific cultural and socioeconomic factors contribute significantly to donor attitudes and consent so that we may address these factors effectively from a clinical standpoint, but also for unrelated transplants and recruitment of diversified volunteer donors on the South African Bone Marrow Registry (SABMR).
- South African contextualization and historical grounding of data

##### Agenda for Ethics Focus Group

Introduce myself with background and how I became interested in haematopoietic stem cell transplants and donor registries in relation to minority populations. Situate myself as a student, wanting to learn from this focus group and from “hanging out” with the staff in order to get a sense of everyday work in the unit.

The research that I am doing takes a medical anthropology and diversity studies approach in looking at obstacles to representing donors on the SABMR reflect South Africa’s demographics and furthering an understanding of haematopoietic stem cell donor attitudes and consent.

## **Ethics Brief:**

**I am conducting this focus group for the express purpose of discussing the ethical considerations of this project**

- To help protect informants from potential harms of interview and research
- To ensure better interview experience for all concerned
- Maintains validity of research
- More thorough and thoughtful, richer analysis of data and improved quality of research
- Sensitises researcher to concerns of informants
- *Usage of Data:* The data collected in research will be used for my Masters dissertation to complete an MPhil in Diversity Studies. The data, selectively included by the researcher and incorporated with analysis, may be shared internationally in the bone marrow transplant registry network (possibly SABMR, Sunflower Fund, NMDP, AADP, etc.) and the work may be developed into a piece for publication. As for the raw data, it will be recorded via digital recorder and downloaded onto a computer and backed up on CD by the researcher. The original material will be transcribed and primarily be analysed from the transcripts and included in transcribed form. The original recordings will not be accessible to anyone but the researcher and the identities of the interviewees will be kept anonymous by the researcher in any materials submitted for a readership.

## **ANY QUESTIONS from focus group.**

The focus is, after briefing on research objectives to get a conversation going about ethical considerations in my research. As hospital staff who do the day-to-day work with patients and donors their viewpoints are extremely valuable in guiding me to ensure I formulate plans and conduct research that is ethically sound.

Introductions and roles in the haematology unit.

Will also take notes on responses on a flipchart during focus group session.

**TO (Theory Question) 1: What advice on interviewing patients and donors can the staff offer in order to maintain rapport and elicit responses?**

**FGQ (Focus Group Question) 1: Can you discuss some of your more memorable interactions with patients?**

*Follow up: Any memorable incidents with donors?  
What did you learn from those interactions?*

**FGQ 2:** Do you have any ideas about how patients might respond to interacting with me?

**FGQ 3:** What are appropriate times, and inappropriate times, to talk to patients?

**FGQ 4:** How do you respond to a patient or donor when they are emotionally sensitive?

**FGQ 5:** How do you feel about having a researcher interview patients and donors during the transplant process?

**TQ 2:** How do the staff members feel about participating in an interview regarding the aforementioned subject matter?

**FGQ 1:** Do you have any experience being interviewed for your work or any related issues?

**FGQ 2:** How do you feel about interviews being recorded?

**FGQ 3:** Do you have any reservations about the interview or the research?

**FGQ 4:** Do you have any expectations of the interview or the research?

**FGQ 5:** Any other things you want to say about the forthcoming interview process and development of research?

**Introduction of Consent Forms to be filled out and turned in at the office desk. Last date for submission: Friday 3 August 2007.**

### Appendix III:

#### **Sunflower Fund focus group interview agenda**

Tell my story of interest but also how things have evolved. I have moved from a concern about the causes of donor resistance from certain communities toward simply understanding how organisations involved professionally in the BMT network talk about transplants. As such, I want you all to be aware that I will analyse notes that I take while I am here in the office observing the day to day activities here. And that any interviews/focus groups that we have, like this one will also be recorded and analysed.

I will analyse the recordings and notes using a process called coding where I systematically read the transcripts and typed up notes identifying, linking and organising themes in the texts and then connecting them with existing literature that I have read. I will also use discourse analysis, which is a process of looking at the text and what sorts of linguistic struggles and fixations over meaning reflect larger social processes.

Using this process of analysis I also want to share my own perspective by combining what I have learned in my studies and what I learn from all of you through this research project. And I think that the work that you do is really interesting, which is why I am here and I think I can learn a lot from all of you. So if you later read the research, please keep that in mind. Even if you find agreement or disagreement with it, this research is the beginning of a conversation and engagement with certain issues, not a prescriptive, imposed viewpoint.

I think this focus group is really a part of our conversation together.

#### **ANY QUESTIONS from focus group.**

#### **Central Research Questions:**

- What discourses have arisen in the professional sector of bone marrow stem cell transplants?
- In what sense is the 'need' for donors from specified racial or ethnic groups socially produced?
- What have been the significant impacts of such discourses in organisations studied with regard to donor awareness, recruitment and retention practices, public relations and fundraising, treatment and advice provided, and the actual process of transplantation as it is experienced by donor, patient and family members?
- What do these discourses, as embedded in fields of power, reveal about contemporary South Africa?

**TQ 1: How do the staff members feel about participating in my research and my presence as a researcher?**

**FGQ 1:** Do you have any experience being interviewed for your work or any related issues?

**FGQ 2:** How do you feel about things being recorded or written down?

**FGQ 3:** Do you have any reservations about the research?

**FGQ 4:** Do you have any expectations of the interview or the research?

**FGQ 5:** Any other things you want to say about the process thus far and development of research?

**TQ 2: How do the staff at the Sunflower Fund articulate their work and its impacts in a group setting, and with regard to larger organisational objectives?**

**FGQ1:** What is the most important issue facing the Sunflower Fund?

**FGQ 2:** Please describe to me your PR strategy. What are the main themes and goals?

**FGQ 3:** Why did you come to work at the Sunflower Fund?

**FGQ 4:** What is the most important part of your job here?

**FGQ 5:** What is your relationship with the SABMR like? What perspectives do you share and in what ways do your organisations differ?

**FGQ 6:** Are there any things you would change about the Sunflower Fund. If so, what would those things be?

**FGQ 7:** Has the Sunflower Fund changed at all over time? How?

**Follow-up:** Has there been an impact from regional expansion?

## Appendix IV: Sample interview

### Patient Interview schedule

**TQ :** Was there a change in the sense of embodiment in the patient over time?

**IQ:** How do you feel after the transplant?

**IQ:** How did you feel before?

**TQ:** Was there anything in the relationship between recipient and donor that may have affected donor attitudes and consent?

**IQ:** How did you approach people who you asked to be tested as a donor?

**IQ:** Can you give me a specific example?

**IQ:** How did you feel when you found out that Your brother was a match?

**IQ:** How did Your brother respond when he found out he was the donor?

**IQ:** Did you talk to Your brother about the transplant?

**TQ:** What are the recipient's and the recipient's community's notions of body and property culturally, donor's sense of body and self?

**IQ 1:** How do you physically feel after the transplant?

**\*IQ 2:** Do you think your body is different because of the transplant? How?

**IQ 3:** How much control do you think you have over your body and what it does?

**\*IQ 1:** Did you have any other treatment options if Your brother was not a match?

**IQ 2:** Tell me about when you learned that you needed to be treated with a transplant?  
Who explained the transplant procedure to you?

**IQ 3:** Did you have any fears about the transplant?

**\*IQ 4:** What role did the doctors and nurses play throughout the transplant process?

**TSQ 2:** What social factors contribute to patient's experience in transplant process?

**Theory sub-question (TSQ):** Are there socioeconomic concerns that affected the patient?

**Interview Question (IQ) 1: Who made the financial arrangements of the medical procedures?**

**IQ 1: Do you know anyone who has been a donor or gotten a transplant? Has that affected your feelings about the transplant?**

**\*IQ 2: Does family play a big role in your life ?**

**TSQ: How did the recipient's family affect attitudes and understanding of the transplant process?**

**\*IQ 1: What did your friends/family think about the transplant?**

**IQ 2: Did anyone have any fears about transplants?**

**IQ 3: Did your family members also talk to doctors or nurses about the transplant before, during and after? If so, who did and did it help them to talk to the medical workers?**

**TQ: What were the factors responsible for change or constancy in the patient's attitude and their understanding of haematopoietic stem cell donation and transplants change over time?**

**\*IQ 1: Did you know about bone marrow transplants, SABMR, or Sunflower fund before your treatment? Would it be different if the donor were a stranger?**

**IQ 2: Post-transplant, would you still have gone through it?**