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## **"IT'S SECURITY, BUT NOT INSURANCE." CORD BLOOD BANKING PRACTICES BETWEEN BIO-COSMOPOLITANISM AND GIFT ECONOMY.**

**Abstract:** During the last two decades, umbilical cord blood (CB) has become increasingly accepted as a stem cell-rich source which can be used in, primarily, leukaemia treatments as an alternative to bone marrow. Since then, there can be observed a worldwide development of public and private CB banks who either store donated CB units for allogeneic non-directed use, or, at a fee, for potential autologous (private) family use. Both public and private banks, however, do not only depend on local politics, legal frameworks, and medical systems, but are also embedded in the respective social environments and societies they act within, which represent divergent public discourses about professional roles and accountability as well as personal attitudes and practices towards healthcare and biomedicine. In the contested field between continuously increasing biomedical knowledge about CB, cognitive uncertainty, different role ascriptions and perceived responsibilities between public donation and private storage, the various social actors (parents, doctors, midwives, CB bank employees etc.) develop specific strategies of (non-)knowledge management and reinvent or transform "traditional" values and practices in this new biomedical context. With Germany and the UK as societies under research because of their contrasting difference in the individual perception and institutional construction of healthcare, it is revealed how the "mobility" of CB has the potential to test and blur the boundaries between putative antipodes on a variety of levels, developing everyday practices and attitudes which can, perhaps, be best described as "bio-cosmopolitanism".

**Keywords:** biological citizenship, cosmopolitanism, (non-)knowledge, gift economy, biosocialities.

### **Introduction: Biomedical Background**

Cord blood (CB) is, like bone marrow, a rich source of haematopoietic, e.g. is blood forming, stem cells, and is collected directly after birth from the

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clamped umbilical cord. Since 1988, there have been conducted worldwide more than 20,000 allogeneic cord blood transplantations (that is when donor and recipient are not the same person), treating in particular leukaemias, and there are approximately 450,000 tissue-typed transplants registered worldwide as non-directed donations to public cord blood banks (Rocha/Broxmeyer 2010). The number of CB samples stored in private banks for autologous use – that is when donor and recipient are identical – or allogeneic-directed family use, is estimated to be at least two to three million. In 2009, for the first time the number of stem cell treatments from CB exceeded the number of stem cell treatments from bone marrow.

But its usage has advantages and disadvantages: A significant advantage of allogeneic CB transplants, over stem cells from bone marrow, is that they are rapidly available, and, due to their immunologic immaturity, allow for an easier tissue matching. On the other side, there is the disadvantage of a potentially lower cell count, given the limited amount of blood available from the respective umbilical cord, and whilst one of the possible – and practiced – solutions for such low cell doses is the application of multiple transplants, this is not only expensive but also associated with an increased risk of Graft versus Host disease (an immunological attack against the transplanted cells).

There have also taken place approximately 350 treatments with private-autologously stored CB – half thereof directed to family members, mostly siblings, and the other half primarily as autologous transplants within clinical trials. But for the most common medical indication, leukaemia, autologous stem cell transplantations are generally not recommended due to the risk that cancerous changes are already present in the stem cells to be used, and a lack of the desired Graft versus Leukaemia effect (that is the attack of transplanted cells against the leukaemia cells). However, as a positive motivation for private autologous storage, it is often referred to the potential in regenerative medicine, which is ascribed to the non-haematopoietic stem cells that are contained in CB as well, particularly for the treatment of myocardial infarction, organ and tissue engineering, diabetes, and neurological disorders.

But these applications have, predominantly, an experimental character or, as yet, only been shown in vitro or on small animal models. Final and unambiguous results from running clinical trials, like e.g. in the treatment of type-1 diabetes, cerebral palsy or infantile brain injury, still remain to be seen.

So, until 2007/2008 there were, principally, two types of banks: public banks (like in the British public healthcare system) and private charities (like in the German dual, that is semi-private / semi-public healthcare system), which collect samples for clinical use or for research purposes, both calling upon altruism and civic duties; on the other side commercial banks for private family storage, calling upon parental responsibilities and healthcare-related foresight. Established treatment of leukaemia on one side – experimental tre-

atment and private usage probabilities that have been calculated between 1:200 and 1:20,000 (Nietfield 2008) on the other side: I have discussed elsewhere these – putative – dichotomies and the related polarisations and politicisations of biomedical knowledge and non-knowledge; but, here, I will concentrate on another aspect:

In 2007/2008, new CB banking models evolved: in the UK a splitting model where the sample is split into a publicly donated and a privately stored portion; in Germany a combination model of private storage with a donation option. These "public-private partnerships", as well as the generally different dynamic of public and private CB banking in Germany and the UK as contrasting locations, represent an interesting entry-point to what I would call a "biomedical assemblage".

### **Biomedical Assemblage**

If individual identification is always, although sometimes imaginatively, embodied, as Richard Jenkins (2008) points out, biomedical identities are even more so: An imaginative identification with biomedical science which is based merely, or at least predominantly, on knowledge rather than physical participation will, thus, be strongly supported by material manifestations – like cord blood. But, there is also an element of collective identification, albeit often at a high level of abstraction which is constituted in certain spaces. Now, given that individual and collective identification processes occur simultaneously, biomedical identities and socialities emerge, consequently, in particular where the individual and the collective occupy the same space and come into interaction – and CB banking – due to the different available options – provides such a physical node.

However, CB is not only physically but, as well, linguistically a "boundary object" (Star/Griesemer 1989), as it is charged with historic as well as contemporary ascriptions referring to blood and stem cells, (partially mystified) natural processes and biomedicalisation alike. Simultaneously, CB is attributed the potential to coordinate these ambivalences – a capacity which may derive, partially, from the materiality-related stabilising visions which have been for example described by Julie Kent (2006) or Linda Hogle (2003) in the context of tissue engineering. But there is more: Curiously, CB shares the ontological values of blood and organs: In spite of its standardisation as a worldwide tradable medicine, it is frequently categorised in nostalgic narratives of altruistic blood donation to fellow citizens as a collective, and, although CB is similar to organs in not being reproducible and could, thus, be similarly seen as a commodified human "spare part", it rather shares their mystification and symbolisation of an individual "new life". By selectively combining these dif-

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ferent effects of its ontological predecessors and components – of blood transfusion, organ transplantation, and tissue engineering – they appear to supersede and merge with the generally assumed destabilising effects of biomedical technologies.

Given these attributed manifold functions, CB banking mediates as what Peter Keating and Alberto Cambrosio (2000) refer to as a biomedical platform between various social actors, discourses and practices in tissue engineering, general regenerative medicine and haematology, which represent a complex assemblage with CB aggregating rather than integrating them. Therefore, I have conducted in the past three years over 80 semi-structured in-depth interviews in Germany and the UK – with parents, patients, midwives, gynaecologists and obstetricians, biomedical scientists, representatives of public and private health insurances, and with employees of public and private CB banks – intending to detangle at least some of the inherent complexities in this field: one of them being a very "classical" topic in cultural anthropology – the gift relationship.

#### **Cord Blood: The Value(s) of the Gift**

To understand whether or not CB is establishing (what forms of) "gift relationships", it may be helpful to detangle some of the numerous aspects and meanings of value, or biovalue, ascribed – or denied: There is a general consent that CB does carry a certain value, because other than for example cancerous tissue which holds simultaneously a positive value (for the biomedical researcher) and a negative value (for the donor), CB represents a positive – or at least neutral – value for donors and recipients (scientists as well as patients) alike.

At first sight, it may appear easiest to elaborate its economic value. Looking at the open market value, i.e. the price a buyer and a seller agree to pay, already reveals a substantial difference between publicly and privately stored CB: Donated samples do have a market price, but only if they can be sold – and this depends on their quality (size / cell count) and tissue type. Thus, the economic value ascribed by public banks can differ significantly, and it is them who will decide whether or not donated cord blood samples are fed into this market system and can acquire such value at all (approximately 70 percent of donated samples are, actually, not stored but immediately discarded as they are deemed to be not marketable).

Privately stored CB units, in contrast, are not publicly tradable, but does that mean that they do not hold any economic value? Parents who chose to store privately with the additional public donation option very decidedly refused to accept any financial compensation in case "their" sample would be nee-

ded by another patient. The economic value (and the agreed price) within the private banking system is foremost generated by the service of information, collection, testing, processing and storage – not by economically evaluating the CB itself. Thus, both private and public CB banks are involved in generating economic value from human tissues –although they do so by substantially different underlying economic mechanisms.

On the other side, there are the moral values which usually refer to the practices around CB rather than to CB itself: Instrumentally, CB is valuable because it could be used to save a human life. This is the underlying value all social actors involved in CB banking build upon. The actual dissent, here, arises rather from the evaluation of knowledge and non-knowledge management, and economic competition or constraints. But CB is also subject to constructions of intrinsic biovalue(s) where healthcare statistics and healthcare economics have very little effect:

It is "good" in itself – for parents not because it provides an instrumental insurance but because, for them, it is security; for the passionate advocates of a "pure" donation system because it symbolises community; for (many) midwives it is a natural part of a healthy baby. Security, community, nature – these competing intrinsic value ascriptions behind the moral biovalue of CB are more constitutive for the controversial discourse than commodification, commercialisation, or the construction of economic-vs.-moral dichotomies.

So, what is, then, the specific value of CB as a "gift"?

Here, value generation is closely related to the risk-profiling of populations, i.e. ethnic minorities and ethnic "mixes". This risk is, however, predominantly not a health risk but a healthcare risk: Finding a matching stem cell donor for patients with rare tissue types can be a comparably costly enterprise for public healthcare systems if these rare transplants have to be imported from outside the country. At this point, ethnic minorities become, in biological terms, simultaneously classified as an economic risk and – if their CB can be collected (and used or sold) – an economic asset for the nation-state. The biocapital, here, is not generated by private CB banks or pharmaceutical companies, but by public authorities.

This specific targeting, however, doesn't have a generally collectivising effect resulting in specific biosocialities, because – although it is known from bone marrow and organ transplantation that ethnic minorities have a significantly lower chance of finding matching donors – it is problematic to call upon all citizens' altruism when the potential of reciprocity is, actually, limited and defined to a large extent by monetary factors. Such entwinement between regimes of moral and economic value is perceived as difficult to communicate to a larger public. But in contrast to exclusions of donor groups who are perceived to "endanger" or even "contaminate" the public sphere, as for example Kylie Valentine (2005) describes in the context of blood donation,

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this "selective" public CB banking represents an exclusion which, as opposed to being driven by assumed health risks, is shaped by health economics: matching probabilities, international pricing strategies, and calculations of quality-adjusted life-years: It represents an aspect of – delimited – biological citizenship through embodied biocapital which doesn't come into play with other commodified human tissues and body parts, due to the general scarcity of organs, the mass-processing and mass demand of blood products, and the comparably less cost-intensive testing and registration of potential bone marrow donors.

Thus, can CB socialities, based on an abstract "gift relationship" between CB donors and potential patients, evolve at all?

The anonymity between donor and recipient as well as the lacking reciprocity may be overcome by drawing upon an imaginary community of care-taking parents – as it is a meaning popularised by many public banks, which often imply in their communication that the donated samples are primarily saved for the health needs of another child. However, the major obstacle remains that the "gifted" CB may, actually, never turn into a gift. Given the high portion of donated CB samples that become destined for scientific research, there is, however, potential for a different form of gift: the "gift of potential scientific knowledge" instead of the "gift of potential life". From my participant observations in the call centre of a public bank, parents who were informed in detail about the specific research projects their donated sample may be used if its quality wasn't sufficient for clinical use, showed less disappointment or were even equally happy with such result.

Therefore, if the "gift to science" is directed to identifiable research projects, a knowledge-based sociality between donors and the scientific community may be in fact easier to imagine in contrast to a purely abstract altruism which only functions well under the – possibly not very sustainable – "waste-turned-into-a-gift" concept. Here, the evolving attitudes and practices within the public realm rather point towards the imagined relation to a patient in need and to biomedical research as complementary accounts.

#### **Conclusion: "It's security, but not insurance."**

Turning to the private banking side, I would like to come back at this point to the quote I used in the title: *"It's security, but not insurance."* This is a quote from a young father I interviewed, and a statement I was given in similar form by almost all of my interview partners. Sociologists like Nik Brown (2006, 2006a) or Catherine Waldby (2002, 2006) have defined private CB banking as a form of "corporeal insurance" or a "novel form of self-possession", and private CB banks themselves have, in the past decade, fuelled such

constructions by repeatedly advertising it as a "biological insurance". However, most banks in Germany and the UK stopped using this term, as it evoked strong criticism.

The idea in using it was, as I was explained, to draw at the general public perception of the insurance industry as an established (and accepted) commercial sector. But this wasn't always so: As the economic sociologist Viviana Zelizer (1979) elaborates, until the mid-19<sup>th</sup> century, life insurance was controversial rather than commonplace and seen by the public as the commodification of human life. The mere "evaluation" of a personal life in monetary terms was perceived as threatening, linking magical beliefs and superstition with the apprehension that any commercial pact dependent on death would, actually, hasten it.

However, this moral debate ceased towards the end of the 19<sup>th</sup> century when, as a result of industrialisation, urbanisation, an increasing reliance on wages rather than family and community ties, life insurance began to receive political support as being crucial to the survival of widows and orphans, ultimately replacing personal immortality by notions of social immortality. Thus, it is seductive to read the controversial discourse about cord blood banking in general as just a more novel form of this moral debate around "insuring" human life. But the shifting focus from health-related insurance to care-related assurance points to more than an increasing general acceptance of private healthcare, and of the acceptance of uncertainties in biomedical science and technologies.

*"I have taken all precautions possible for my baby and let them do all the vaccinations, and, therefore, cord blood donation then just came naturally."* In this statement of a young mother who had just donated her child's CB, perceptions of health as an individual and a collective risk seem to merge. However, the blurring of boundaries between perceptions of individual and collective healthcare responsibilities was not limited to those who chose to donate publicly: Particularly those parents who intensely discussed the different options but, in the end, decided for private banking, considered it as their civic responsibility to share the acquired knowledge: *"When you have thought about it as much as we have, and decided [for private storage] as we have, you do feel the responsibility to spread the word about the different alternatives – also because this may help that there are more donations."* Here private CB banking appears to reconnect biological accountability back to general political responsibility – biomedical ambivalence reinforcing a more general awareness and participation in biomedical knowledge.

To summarise: CB banking represents a complex repertoire of local and translocal biomedical identity and interest. It represents a concept which – other than an idealised altruism – includes also a critical awareness of the entangled mechanisms of bioeconomics and biopolitics, but – in contrast to the "rational" prudent individual who is predominantly occupied with making decisions about

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her or his own body and health – doesn't give up the (abstract) empathy to benefit a larger society. Instead of tying it to para-religious citizenship duties or nostalgic votes for a nation-state's mutual care relationship, it can also represent a biomedical knowledge-based mode of distinction which merges with an embodied practice. Then, it simultaneously embraces the "gift to oneself", the altruism towards anonymous patients, and the "donation" of potential scientific knowledge, integrating, ultimately, a sense of biological global belonging into everyday practices – which I have chosen to describe as "bio-cosmopolitanism".

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**"TO JE SIGURNOST, ALI NE I OSIGURANJE." PRAKSE ČUVANJA  
KRVI IZ PUPČANE VRPCE IZMEĐU BIO-KOSMOPOLITIZMA I  
EKONOMIJE DARA**

Tokom poslednje dve decenije, pupčana krv (PK) postala je sve više prihvaćena kao bogat izvor matičnih ćelija koje se mogu koristiti pre svega u lečenju leukemije kao alternativa koštanoj srži. Od tada se može primetiti svetski razvoj javnih i privatnih banki PK koje ili skladište donirane jedinice PK za alogenu ne-direktnu upotrebu, ili, uz novčanu naknadu, za potencijalnu autolognu (privatnu) porodičnu upotrebu. I javne i privatne banke, međutim, ne zavise samo od lokalnih politika, pravnih okvira i medicinskih sistema, već su ugrađene u odgovarajuće društvene sredine i društva u okviru kojih deluju, a koje predstavljaju različite javne diskurse o profesionalnim ulogama i odgovornosti, kao i o ličnim stavovima i praksama u vezi sa zdravstvenom zaštitom i biomedicinom. U spornom polju između stalnog uvećavanja biomedicinskog znanja o PK, saznajne neizvesnosti, različitog pripisivanja uloga i shvatanja odgovornosti u oblasti javnog doniranja i privatnog čuvanja, različiti društveni akteri (roditelji, lekari, babice, zaposleni u banci PK itd.) razvijaju posebne strategije upravljanja (ne)znanjem i ponovo osmišljavaju ili transformišu "tradicionalne" vrednosti i prakse u ovom novom biomedicinskom kontekstu. Nemačka i Velika Britanija, kao društva koja su obuhvaćena ovim istraživanjem zbog razlika koje ih suprotstavljaju u individualnoj percepciji i institucionalnoj konstrukciji zdravstvene zaštite, otkrivaju kako "pokretljivost" pupčane krvi ima potencijal da ispita i zamagli granice između navodnih antipoda na različitim nivoima, razvijajući svakodnevne prakse i stavove koji se na najbolji način možda mogu opisati kao "bio-kosmopolitizam".

**Ključne reči:** biološko državljanstvo, kosmopolitizam, (ne)znanje, ekonomija dara, biodruštvenost