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Tentative (Id)entities

On Technopolitical Cultures and the Experiencing of Genetic Testing[1]

Ulrike Felt, Ruth Müller

Introduction

> *Yes, I remember, we all sat there and then she explained the whole thing [the test procedure] to us, one by one. We all sat there – not my sons, they didn't come with us. They just said: "Oh, they should tell you.", but they didn't tell me. Then, on our way home, we talked, like "Oh, I had thought I would have it from daddy, the gene.", or "Why do we all have it? At least one of us could have been spared!"*
>
> *Today it is just the way it is. We have accepted it – well accepted? I don't know how to express that. We just have it and now we just say: Others have the gene for heart attacks, and we just have the gene for breast cancer. And even so, we at least can do something about it. We are in good hands, we say, we really are. My cousin always says to me that nothing better could have happened to all of us than me joining them [the testing programme].*
>
> *(Woman tested positively for a BRCA mutation)*

Breast cancer has become a topic of broader public awareness in the Austrian context for more than a decade. In this growing public debate, breast cancer is mainly framed as a disease related to lifestyle choices, such as diet and exercise. However, about 5-10% of all cases are believed to be due to genetic predispositions such as mutations in the so-called 'breast cancer genes' BRCA1 and BRCA2, which appear to raise the lifetime risk of breast cancer to above 80% (Wagner and Kubista, 2003), frequently with early onset of the disease and an additional elevated risk for ovarian cancer. Since 1994 it is possible to identify such mutations by genetic testing. While in a number of countries the possibility of testing was integrated into institutionalized health care practices and is covered by health insurance schemes, in Austria this hereditary form of breast and ovarian cancer (HBOC) and especially the possibility of genetic testing have remained largely at the very margins of the awareness of both the public and the

[1] The data on which this article is based have been collected within the framework of the European research project "Challenges of Biomedicine – Socio-cultural contexts, European Governance and Bioethics", funded by the European Commission under the 6th framework programme, 'Science and Society', Contract. no. SAS6-CT-2003-510238. The authors would like to thank the interviewees for sharing their experiences with genetic testing as well as numerous intimate parts of their lives. Further this research would not have been possible without the support of the head of the counselling centre. We further acknowledge the valuable help we got from the centre's psychologists present during the interviews. Finally our thanks go to five referees, the editor and our colleague Maximilian Fochler for their constructive criticism and suggestions. Martha Kenney's help in doing the final language editing is also highly appreciated.

health care system. The institutional embeddedness of HBOC testing is unstable as funding structures have been provisional: no official funding2 as a clinical and hence routine procedure existed at the time of the study. Medical centres wanting to offer this service thus had to integrate clinical testing into research agendas. Hence genetic testing for HBOC occupies a rather unique place in the Austrian health care system, where relations and identities of both patients and doctors are yet not fully defined.

Over the past decades a broad body of literature in STS as well as the sociology and anthropology of medicine has emerged offering analysis of the establishment and up-take of genetic testing. While one line of literature addresses policy and structural issues (e.g. Parthasarathy, 2007), the majority of studies have focused on patients' perspectives. They have carefully studied how the 'new genetics' relates to identity work, as well as issues of personhood and subjectivity, family dynamics and the meaning of kinship, and broader socio-political practices such as patient activism. (e.g. Atkinson *et al*, 2007; Featherstone *et al*, 2006; Gibbon, 2007). Attention has been paid to the growing individualisation of health care issues and the potential for genetic discrimination (e.g. Lippman, 1992); however, other authors have focused on the collectivising and empowering potentials of new genetic technologies (e.g. Rabinow, 1996; Novas and Rose, 2000) and on the emergent forms of "biological citizenship" (e.g. Rose and Novas, 2004). Both of the latter perspectives have been critiqued for overstating the newness of the phenomenon and overlooking contiguity with already existing (bio)medical practices and hierarchies; thus they would tend to be overenthusiastic about the libratory potential of the new genetics as they ignore how these new technologies are integrated into already existing cultural, national and local practices, structures and hierarchies (Gibbon and Novas, 2008; Raman and Tutton, 2010).

Recently, a number of studies have paid more attention to these consistencies by considering more closely how specific cultural contexts shape the meaning and practices of genetic testing, such as Kampriani on Greece (2009), zur Nieden on Germany (2007) or Gibbon on the Cuban context (2009). By establishing a comparative perspective, these authors "illustrate aspects of the cultural shaping and the constitutive forms of a variety of patient subjectivities within specific national contexts" and convincingly argue that

> *"BRCA subjectivities are neither stable nor homogenous and are always the consequence of highly specific historical processes, which are themselves the outcome of varying political, cultural and social practices." (Gibbon et al, 2010: 441)*

Our analysis aims at contributing to this debate by drawing attention to how people tested for HBOC continuously work on making sense of this experience within a national – in this case the Austrian – and local context with their very specific master narratives, modes of ordering and epistemologies. The frame of reference for our analysis is thus a specific Austrian "technopolitical culture" (Felt *et al*, 2010), which consists of specific practices, structures and mechanisms through which technologies are interwoven with society. In the medical realm, this also includes entrenched and normalised ways of dealing with issues of health and illness. In this paper, we will study two aspects of these processes in the specific local culture of the testing centre we re-

[2] Genetic testing for HBOC was neither state-funded nor covered by health insurance; though there was some public funding available from 2007-2010, it is unclear if this will continue.

searched, drawing attention to the subtle but meaningful interactions of the national, the local and the personal: First, we will focus on how, through the specific national and local protocols for receiving genetic testing, individuals are transformed into biomedical entities – for example the icons of a medical pedigree. The ways identities are formed and transformed through genetic testing are closely tied to this process of obtaining, negotiating, refusing and accepting the status of "biomedical entity", which carries with it specific ideas about one's place in a family network, in a specific biomedical and social arena. We propose thinking of this process as a co-production of entities and identities, which we attempt to capture using the term (id)entity. Second, challenging common claims about the increased individualisation that comes with new biomedical health care practices, we want to investigate how individual (id)entities emerge within a matrix of multiple forms of collectivities and how processes of individual and collective identity formation are closely intertwined, shaping and reflecting the way people make sense of genetic testing in relation to the national, the local and personal.

Biomedicalizing and Being Biomedicalized

The emergence of genetic testing for HBOC is part of the broader changes currently transforming medical practices through the infusion with bioscientific knowledges and practices from fields like molecular biology, genetics or proteomics. The concept of "biomedicalization" (Clark *et al,* 2010) grasps those recent transformations and their relation to societal changes, pointing at

> *"increasingly complex, multisited, multidirectional processes of medicalization that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine." (Clarke et al, 2003: 162)*

The emergence of genetic testing has become emblematic of the process of biomedicalization: It depends on a complex interplay of advanced technologies from different domains as well as on interdisciplinary teams that consist of medical researchers, technicians, doctors, and psychologists. It entails significant processes of standardization of medical practice (Timmermans and Berg, 2003; Fosket, 2004), but also increasingly a blurring of the border between health and illness, shifting the attention to the *potentiality* of illness and the possibility of seeing otherwise invisible risks. This entails a number of sense and decision making processes for the 'potentially ill' in order to come to terms with this kind of "disembodied knowledge" (Lambert and Rose, 1996).

There are a number of conditions that can be tested for with no treatment for the condition available, such as Huntington's disease (Cox, 2003). However, for the most part biomedicalized health care promises to render illness increasingly avoidable, turning health into an "individual goal, a social and moral responsibility and a site for routine biomedical intervention" (Clarke *et al,* 2003: 171), combining individual and collective meanings of health and illness. Hence, while some authors frame biomedicalization as a process that allows citizens to take their health into their own hands (e.g. Rose, 2006), others point out its oppressive potential. They fear that individuals will be increasingly expected to combine biomedical interventions with lifestyle and behavioural changes in order to address their 'genetic defects' and be considered responsi-

ble citizens. Non-compliance might increasingly be viewed as hazardous behaviour and disciplined, for example through the cancellation of health benefits (Lippman, 1992). Moreover, consistent with traditional forms of biopolitical control (Raman and Tutton, 2010) nation states could inscribe their own agendas into the regulations and restriction of biomedical technologies, such as specific versions of population politics (Greenhalgh, 2009; Nahman, 2008). Hence, biomedical identities emerge in a framework of conditions that are on the one hand highly experimental, fragile and new, and on the other hand highly restrictive, standardized and normative, and potentially loaded with a multitude of different interests. However, individuals engaging in biomedical practices are not just the passive objects of intervention, but agents who are actively negotiating, contesting or enforcing the meanings of biomedicalization. They do so in contextually situated ways, in specific national, local and personal frameworks, experimenting with the new forms of identities these technologies can bring about.

Entities, Identities and (Id)entities

A number of authors have pointed out that a crucial step in the process of genetic testing for HBOC is the creation of a "pathologised representation of family history" (Gibbon, 2007: 31). Being enrolled as an active patient, the potentially at-risk individual needs to gather and report all available information about his or her family's medical history. This version of family is formalized in the medical pedigree constructed in the first counselling session, transforming each family member into an icon within this visual representation of a "narrative trajectory of risk" (Gibbon, 2007: 31). In the process, family bonds are reworked and family history is rewritten (Armstrong *et al*, 1998). Individuals are transformed into "elements of a collective, familial, and thus biosocial body" as well as into potential "objects of medical intervention" (Nukaga and Cambrosio, 1997: 29).

The biomedical identity of the individual patient is constructable only in relation to this representation of family, eventually becoming what Bourret calls a "family patient" – a biomedical phenomenon made out of

> *"clinical data (the disease), biological data (the gene and the mutation) and social data (family links and degrees of relationship)" (Bourret, 2005: 48).*

While we agree with Bourret that the family patient is an important entity emerging in the process of genetic counselling and testing, we argue that this is only a starting point for far more complex processes of identity formation. However, negotiating, contesting, accepting and reformulating the status and meaning of being enrolled as a specific entity within a biomedicalizied version of family is a crucial part of this identity work. Hence we suggest thinking of biomedical entities and identities as co-produced (Jasanoff, 2004), which we try to grasp with the term (id)entity.

Collective and Individual (Id)entities

The emergence of genetic testing has been accompanied by a number of studies that focus on the danger of reducing individuals to their genetic conditions and subjecting them to genetic discrimination (e.g. Lippman, 1992). While these studies have rightly pointed out the risk of being 'singled out' and objectified, scholars like Novas and Rose have attracted our attention to how individuals are also "subjectified through their location in a matrix of networks" (2000: 490), stressing the relation between processes of identity formation and the multiple forms of collectivities that arise in genetic testing, on the level of the family, the clinic and broader social forms.

Studies from the sociology of medicine have shown that most individuals who are inscribed into a geneticized version of family appear to perform themselves not "as individuals per se, but as selves-in-relation, as interconnected to past, present and future generations" (Hallowell, 1999: 616). New forms of responsibility emerge, resulting in the "burden of mutual obligations and caring commitments" (Novas and Rose, 2000: 490). Decisions in the context of risk and illness management, such as obtaining and disseminating risk information, are no longer perceived to be up to the choice of the individual, but are instead influenced and motivated by more collective considerations, such as familial well-being (Hallowell, 1999). How individuals come to terms with these responsibilities seems highly gendered, prominently featuring the image of the nurturing woman taking care of and protecting her family's physical and emotional health (Gibbon, 2007; Hallowell, 1999; d'Agincourt-Canning, 2001), sacrificing individual preferences for the well-being of others (e.g. the option not to know her own risk).

At the level of the clinic, authors such as Novas and Rose have also identified processes of collectivisation, arguing that individuals become "either willingly or unwillingly implicated in a web of professional and lay support networks as part of being identified at genetic risk" (Novas and Rose, 2000: 949). This is consistent with the findings of Featherstone *et al* (2007), who emphasise the moral and emotional work of the clinic, such as providing a space for patients to confide their fears (2007: 113). In an effort to make sense of their new conditions, patients seek and are encouraged to build "ongoing relationship[s] with the clinical genetics team, which are based upon factors other than that of risk assessment." (2007: 114), opening up spaces for new forms of relationships between doctors, patients and their kin. Rabeharisoa and Callon (1998) offer an interesting way of thinking about these emerging collectivities: they invite us to consider such aggregations as "hybrid collectives" – assemblages of biomedical professionals and patients, multiple forms of knowledge (e.g. biomedical and experiential knowledge) and numerous biomedical technologies. These collectives create a forum for exchange, support and experimentation, but also guidelines and norms that play essential roles in forming and transforming patients' self-understanding and identities.

Finally, a broad range of studies that draw on Rabinow's (1996) notion of biosociality have investigated how the new genetics opened up opportunities for the formation of new communities in relation to specific biological conditions, biomedical practices and forms of agency. In our analysis we will use this concept, as others have done before (e.g. Gibbon and Novas, 2008), to capture the more loose visions and imaginations about the social forms that are emerging in the age of genetic testing in particular and biomedicalisation in general. Specifically, we are interested in how these new communities and imaginaries contribute to the shaping of identities. To allow

for a thorough understanding of this process, we consider it vital to include both physically realised collectivities as well as more imagined forms of communities created or reinforced through biomedical technologies (Anderson, 1983; Simpson, 2000; Nahman, 2008) in our analysis.

Technopolitical Cultures: Recontextualising the Genetic Testing Phenomenon

A growing number of STS authors describe the important role that culturally entrenched routines, practices and ways of reasoning play in how people relate to science and technology in general (e.g. Hecht, 2001; Jasanoff, 2005) and biomedicine and genetic testing in particular (e.g. Felt *et al*, 2008, 2010; Gibbon *et al*, 2010): People do not simply embrace or refuse genetic testing; rather, they engage in complex negotiations that include different experiences with science and technology, historically grounded visions of governance and politics, and culturally entrenched ideas of health, illness and the bodily self. In their comparative study of how people come to terms with two different biomedical technologies (organ transplantation and post-natal genetic testing) in France, the Netherlands and Austria, Felt *et al* (2010) have shown that by offering shared discursive resources and broader sociotechnical imaginaries (Jasanoff and Kim, 2009) different national technopolitical cultures matter deeply. Yet these technopolitical cultures are far from being homogeneous (Felt *et al*, 2008) but offer specific sets of discursive references for different technologies, depending on how they are imagined to link up with societal interests, actors and histories.

We argue that technopolitical cultures matter on at least two levels. First on a systemic level: Using Hecht's work on techno-politics as the "strategic practice of designing or using technology to constitute, embody or enact political goals" (2001: 256), we suggest understanding the nationally specific assemblages of genetic testing as shaped by different "technopolitical regimes" (2001: 257) – nationally distinct ways in which technological innovation, political processes, societal values, as well as technopolitical ideologies and myths are intertwined. Thinking in terms of technopolitical regimes alerts us to the prescriptive dimensions of socio-technical systems as well as to the "broader visions of socio-political order" (2001: 258) inscribed into and performed by them. Finally, in Hecht's framework opposition is always an integral part of any regime, rendering forms of dissent and resistance part of the implementation process. Second, technopolitical cultures also matter on an epistemic level: Studying the uptake of biotechnologies from a comparative perspective Jasanoff suggests that

> *"modern technoscientific cultures have developed (distinct) tacit knowledge-ways through which they assess the rationality and robustness of claims that seek to order their lives" (2005: 255).*

Jasanoff calls these knowledge-ways "civic epistemologies", pointing at broad, nationally rooted ways of making sense and assessing the potential of new technologies. How people frame their personal ways of relating to genetic testing has

> *"thus to be understood as shaped by (but also shaping) a larger frame of civic epistemologies which have been constructed over time and are distilled from multiple encounters and experiences with technology" (Felt et al, 2010: 549).*

Thus we can assume that citizens develop fine-grained context-specific understandings of new technologies and their social meaning that are deeply rooted in culture (e.g. Wynne, 1995). It is thus essential to pay attention to the ways in which people imagine and experience the transformation processes between knowledge, practices, potential actions and social orders in a specific local context. Using this framework to analyze our interview data will allow us to understand how cultural context informs the positions our interviewees take towards genetic testing, while remaining sensitive to their personal experiences, knowledge and values.

Research Site, Material and Methods

The data for this article was collected in the wider context of the EU funded project "Challenges of Biomedicine – Socio-cultural Contexts, European Governance and Bioethics" (CoB)[3] and in cooperation with a key counselling centre in the Austrian testing landscape. This cooperation was vital for field access: Prior attempts (bulk mail) to get in touch with individuals with testing experiences had not succeeded in any satisfactory manner. Being approached by a trusted gatekeeper seemed a necessary prerequisite for granting an interview, due to the public silence around both hereditary breast cancer and genetic testing in general in Austria.

The counselling centre had a number of conditions for cooperating with our project: First, the interviews would take place at the counselling centre. Second, the interviews had to be carried out by the principle investigator of the project. Third, one of the centre's psychologists would be present during all interviews to provide psychological support during and directly after the interview. Before the interview, the psychologist gave the interviewers a short account of the patient's counselling history and pointed out potentially sensitive issues. Both the location and the presence of a member of the counselling centre's team have doubtlessly influenced the character of the stories told in our interviews, as well as which stories remained untold. Fourth, our study had to be approved by the hospital's ethics commission.[4]

Data Sample and Analysis

First, we would like to stress that our sample of interviews consists of individuals who have undergone the full counselling and testing procedure. Thus, our fieldwork does not cover the perspectives of those who disapprove of genetic testing, did the test but never came back to get the results or were currently trying to make up their mind. While it would be very interesting to do a follow up study on these groups, the focus of this study was to explore the multitude of experiences and perspectives within the group of those tested. The final sample consisted of nine women and two men. Eight have tested positive for a BRCA mutation; three tested negative. Three of our interview partners had had breast (2) or ovarian cancer (1) prior to testing; another three had a history of breast tissue aberration; all of the latter chose to undergo mastectomy post testing.

[3] 6th Framework Programme: Contract No. SAS6-CT-2003-510238 (Project coordinator and principal investigator for the Austrian team: Ulrike Felt)

[4] Ethics Commission AKH Vienna: 020/2006

The interviews took place between April and September 2006. Before each interview, informed consent was obtained. A semi-structured narrative approach was chosen to allow individuals to recount their experiences with genetic testing as freely as possible (Lamnek, 2005). We started out asking how the interviewees had heard about genetic testing. If the following narrative did not cover these aspects, we suggested focussing on decision making processes for testing and/or subsequent actions, the meaning of the test result within the framework of the interviewees' lives and how they would place their experience in the larger contexts of Austrian society. The interviews were about 30-45 minutes in length; all were taped and transcribed for analysis.

Pre- and post-interview discussions with the attending psychologist were taped, serving as contextual data alongside a 2-hour expert interview conducted with the head psychologist on a separate occasion, as well as participant observation of an information evening. The information evening was open to counselees and their relatives and focussed thematically on risk-communication within families. To analyse the data, we chose a grounded theory (Strauss and Corbin, 1998) approach, which entails an open coding procedure that resulted in the specific research foci presented here.

The Austrian Biomedical Context

The Austrian medical system is often celebrated as one of the world's best in the policy and media arena. In different research projects, we found that this attitude is shared by a significant number of lay people (e.g. Felt *et al*, 2009). Furthermore, there is a common impression of Austria as a caring state, which is produced by a health insurance system that is organised in such a way that patients never see the real costs of health care and seem to get care 'for free'. They thus often perceive their interactions with the medical system as a relationship not based on monetary exchange; we often encountered the feeling of being personally indebted towards the medical professionals for the care they give (e.g. Felt *et al*, 2009). There is also still a clearly discernible hierarchy, where medical doctors hold a largely unquestioned position of expertise and authority. These power structures also leave their traces in the Austrian patients' movement landscape. In the existing Austrian self-help movement, medical doctors often occupy leading roles and many groups are sponsored by pharmaceutical companies. Rarely are these organisations conceptualised as settings where collectively validated forms of counter-expertise can emerge, take shape and develop momentum. (e.g. Felt *et al*, 2003; Fochler, 2003) This combined with a tradition of largely avoiding controversial public debate about technoscientific innovations (with a few outstanding exceptions) leads to a situation where medical authorities often go unquestioned. The counselling centre we investigated was perceived as particularly exceptional: a sphere within the medical system that offered very personalized health care to individuals in particularly challenging situations. Hence it was simultaneously a space where novel modes of interactions and collectivity could emerge and one where the unquestioned doctor-patient hierarchies typical in the Austrian medical system could play out.

Empirical Analysis: (Id)entity Work in the Context of an Austrian Counselling Centre

(1) Individuals Entering the Realm of Genetic testing

When asking our interviewees to reflect on how they got involved with genetic testing for HBOC we collected a wide variety of stories. Some had been approached by a member of the counselling centre when a close relative was dying of breast cancer; others had already fallen ill and learned about the possibility of genetic testing during treatment; still others had actively sought genetic testing or had read one of the rare newspaper articles which made them think about this new possibility. Yet, all the interviewees characterized genetic testing for HBOC as largely unknown territory before getting in touch with the counselling centre, with no public discourse to make sense of its meaning. This explains why virtually all interviewees felt their story was exceptional and that it was linked to this location – the counselling centre – and its staff in very specific ways.

Though genetic testing was initially unknown territory, none of the interviewees recounted engaging in personal research about the test or its genetic basis. In their accounts the test and the genetics behind it was black-boxed. It was a kind of inscription device that produced visible information about their invisible genetic constitution. Upon further questioning, they would mainly associate the test with "an ordinary blood test" – neither pondering the validity or accuracy of its results, nor addressing any epistemic difficulties they might have encountered with grasping its meaning, nor asking the reasons why they had to wait for a minimum of a year to get first results.

In our interviews, there were two dominant groups of accounts about the reasons for getting tested: Beyond the expectation of learning about one's risk status and possibly being relieved of the fear of a hereditary predisposition, a first group of interview partners argued that they primarily had engaged in testing in order to be granted access to specialized tools of prevention in the case risk status was established. Without the promise of prevention, seeking knowledge would have been useless for them. This strong desire for immediate action could be explained in a two-fold way: On the one hand we can read it through their life and family histories characterized by experiences of illness and death of close relatives and fear of suffering the same fate. "I have a familial predisposition for breast cancer", one of our interviewees explained,

> *"My grandma died when I was 12, my mother died when I was 23, also from breast cancer. Both aunts from my mother's side are affected and so is my grand aunt" (P1).*

Hence, the aim of genetic testing is not so much to gain knowledge but to find a means for escaping potential fates. On the other hand, we can argue that this hope is part of a much wider culturally entrenched narrative that links biomedical knowledge to the paradigm of prevention as the only rational course of action for a responsible citizen-patient. In fact even without having been in touch with a counselling centre, lay participants in focus groups on genetic testing also shared the view that knowledge is only useful if preventive action is possible (Felt *et al*, 2008). Without possible action, knowledge is perceived as endangering the subject and increasing his/her fragility.

To a second subset of interview partners their at-risk status seemed all too obvious before testing. Similar to what Gibbon (2007) found, a history of benign breast tissue abnormalities, a resemblance – be it physical or in character – to a deceased relative or a reoccurring pain in the breast can account for a strong conviction that one is at risk. One young woman (P3) explained,

> *"Yes I somehow [had] the feeling that there was something. In particular I felt constant pain in my breasts, indeed precisely at the spot where my mother also had had her pain."*

The test thus becomes a means of validating their prior knowledge. While they had been relatively sure that they were at risk, this kind of personal knowledge is often rejected by society, friends or employers, and does not serve as a basis for access to enhanced preventive care or preventive surgery. Hence, while they have hardly any hope for a negative test result, this group knows that a positive test result will allow them to engage in preventive action legitimately. A very young woman, who has been seeking intensified care for years based on the strong feeling that she was a risk[5] expressed this very explicitly:

> *"It is somehow the only chance for access to these diagnostic tools. Because otherwise you are not taken seriously anyway, and it's not possible to have it checked out to see if it is alright." (P3)*

Hence, most interviewees in our setting clearly related testing to the chance of taking action. Indeed, genetic knowledge for most of them meant access to advanced technologies of biomedical prevention and to specifically skilled medical experts. This interrelation between genetic knowledge and preventive options is at the heart of both groups of narratives about deciding *for* genetic testing: The core incentive for undergoing testing does not seem to be the hope of being tested negatively and being relieved of all fears, but rather the positive connotation given to the ensemble of genetic knowledge *and* biomedical prevention.

What we observed so far already alludes to the significant role that our interviewees attribute to becoming part of a specific setting, where it is the role of the medical experts to hold detailed knowledge about genetics, whereas other roles are attributed to the tested (such as developing personal coping strategies). This exemplifies what Mike Michael framed as "ignorance and the division of labour" (1996: 118), stressing that instances of not engaging with scientific information such as when patients black-box the test, might be understood more as a deliberate choice than a deficiency. Rather than a mere lack of willingness or capacities, it must be understood as the result of an intuitive understanding of the institutional and interpersonal settings genetic knowledge and technologies are embedded in, as well as of the social hierarchies and dependences they are entering into. This understanding is potentially reinforced by the pre-existing hierarchy between medical professionals and patients in the Austrian context and also by the fact that there are hardly any cultural models for collectives of patients to have their own authoritative voice, e.g. through organised self-help groups. Finally, there is a strong feeling that 'the medical system' was being generous towards them, which requires a gesture of trust in return. (Felt *et al*, 2009)

[5] Her feeling was confirmed by the test and at the time of the interview she had already undergone mastectomy.

What becomes apparent here is the multilayered character of our interview partners' accounts: While they are always highly personal and very individual stories, they are also stories about an inextricable interrelatedness of these individuals with a number of collectives that (trans)form in the context of genetic testing. So while each account presents a unique life story, it is in the interplay of individuality and collectivity that genetic testing deploys its meaning.

(2) Becoming Part of Collectives

The Family at Genetic Risk

In the specific setting of our counselling centre, individuals seeking genetic counselling need to have a distinct family history of breast and ovarian cancer showing a pattern of cases that indicates a possible hereditary predisposition in order to be admitted for testing.[6] Hence, thorough investigation of one's family history is the first obligatory step into genetic testing, strongly emphasising the relational character of genetic knowledge. From the beginning it is performed as knowledge not only about the person tested, but also about her/his genetic kinship, figuring the individual as the "family patient" (Bourret, 2005) as we saw above. As a representative of a familial collective, the "family patient" actively collaborates in materializing him/herself in the risk-based, genetically grounded construction of the medical pedigree – a practice most interviewees mentioned as a key moment in the beginning of the process, which will allow him/her access to the system. A pedigree combines different sorts of data (e.g. oral family history, medical records and test results); this allows for individual family members to be translated into "biomedical entities" represented through specific icons on the pedigree chart indicating both genetic and health status. Family structures are thus rewritten, generating a new and potentially unfamiliar vision of family in which members are not necessarily connected any longer through social bonds and collective memories, but through genetic kinship and a potentially shared genetic risk.

> *"… in one part [branch of the family tree] very nearly all women […] were affected. And in our line nobody. And I was interested to know, if this was quasi serendipity, […] living conditions and attitudes or […] if it was really this gene." (P10)*

This genetic version of family is rarely congruent with the counselee's prior vision of her/his family. It might exclude some that are socially near (e.g. step-siblings) while it includes unknown or distant relatives, with whom they share a 'risk of risk' but not much more than that. Some family branches appear affected while others seem to be spared and thus are rendered invisible within this new 'at risk' genetic family.

Virtually all narratives about the genetic testing experience start by explaining one's place in such a reconstructed family. In these stories, the interviewee is hardly ever the sole narrative centre, but more often we meet "selves in relation" (Hallowell, 1999). In the interviews we could observe the work of elaborating complex familial ties:

[6] For the detailed criteria, see http://www.meduniwien.ac.at/brustCC/index.php?id=11#a5 [in German, last accessed Feb 09 2011]

"My mother fell ill with breast cancer in '94 […] and in '99 she died of it. […] We were offered, my sister and I, genetic testing, so that we could find out whether we were having that mutation or not. […] There was my mother's sister, but I don't know for sure whether it was ovarian cancer. […] And what I know is the grandmother of my mother had it, too; by genealogical research they somehow found out that the grandmother of my mother had exactly that gene, too." (P4)

It is out of such relations, out of carefully reconstructed and rewritten pasts, presents and futures, out of how one is rendered a biomedical entity in the familial pedigree that potential identities start to arise – which will be further negotiated within other collective spheres of genetic testing. Through this reconfiguring of family relations, new kinds of responsibilities emerge, concerning obtaining and disseminating knowledge about one's genetic status, engaging in personal risk-management and encouraging others to do so as well. Each of these responsibilities has individual as well as multiple collective dimensions, as members of these genetic families consider themselves and others at least partially responsible for the fates and actions of others:

"My cousin's daughter did the test with me. Then I persuaded my sister to do the test. And she probably did it because she had two daughters and wanted to know if she ran the risk of handing it down to them." (P10)

This quote illustrates the complex chains of responsibilities towards present and future kin that characterize families at genetic risk. It is frequently argued that the ways individuals feel and engage with these responsibilities is highly gendered:[7] As has been found in other studies, our female interview partners for example frequently alluded to the fact that their male relatives did not take genetic risk and risk management sufficiently seriously, as for example some refused to get tested. However, they explained this behaviour mainly by the fact that men were largely not personally at risk and would thus avoid learning about their genetic predisposition, rather than by stereotypical images of male and female roles. The hypothesis that direct affectedness might play a central role in relating to responsibility and risk-management is supported also by accounts from our two male interviewees. By the time of the interview, the elder of the two had already been treated twice for breast cancer:

"It's the genetic guilt, yes. I mean I do not blame my ancestors, it's not their fault, and my son doesn't say: 'Hey, I got this thing from you!' either – I believe he doesn't even think like that – but if you would ask me, I would not father a child anymore now. I would not father a child if there is this 50% probability that he might get that. In order not to be the guilty one, if he does get it." (P8)

Although this is a single case, it might be interesting to look deeper into the question of how affectedness gets combined with gender and how it might have an impact on male risk perception and the way men perform being part of a genetic family.

Finally, it seems interesting to point to the fact that through the ubiquitous framing of HBOC as a family issue right from the start, genetic risk constituted an individual and collective burden for *virtually all* interview partners, including the non-carriers. Affectedness thus becomes a complex and multi-faceted category: it applies

[7] See e.g. Hallowell, 1999; Hallowell et al, 2005, 2006; d'Agincourt-Canning, 2001; Gibbon, 2007.

to individuals as well as to collectives; it comes in different forms and sizes; it can mean being a mutation carrier, but it can also mean being the one sibling of three that is not carrying a mutation, a situation often associated with "survivor's guilt" (Brédart *et al*, 1998; Smith *et al*, 1999).

The Hybrid Collective

Genetic testing not only reconstructs the family collective, but in our case also supports the formation of so-called "hybrid collectives" (Rabeharisoa and Callon, 1998; Rabeharisoa, 2003) between people affected by a family history of HBOC, diverse medical professionals and a number of advanced technologies. The shared goal of this collective is often stated as identifying BRCA-mutation-carriers and decreasing their death rate, mostly through biomedical means. While fighting death and disease could be considered part and parcel of the medical profession, in our case relations between affected people and professionals are often long-lasting and can become very close. This personal involvement might account for the equally personal character of the way that significant numbers of affected people relate to the professionals and how they frame their relation: though there is no official organisation, no self-help or patient group, there is a certain collective of laypeople and professionals they feel part of, some more intensely, some less. The quote given below is part of an interview with an elderly woman, who was the first of her family to get tested – and the first in Austria to be tested positive. To date, most of her extended family has been tested, with a high number of females identified as being positive. Closing her story on how she happened to undergo genetic testing, she says:

> *"And that's how we came here. Today we could not imagine that we are not part of this. I had a lump several times, I was never scared, because I knew, there is someone I can turn to, someone we know. When you are ill, that means so much." (P2)*

This quote brings both collectives together: the familial "we" and the hybrid collective this family has become part of. Within this collective structure, medical professionals and affected people play quite different roles, roles mostly consistent with the classical lay/expert divide, where the medical professionals are framed as possessing important scientific knowledge, while the tested persons rely on their advice. However, to a certain degree the counselees' experiential knowledge is also taken into account in medical decision-making. This openness to engaging with more intimate forms of knowledge is of great importance to some of our interviewees: they need to know that their *specific* life and family history will be taken seriously, and will be taken into account when it comes to advice on medical decisions. For example, although there are no clinical studies yet available on why some families tend to show early onset of HBOC, they know that the medical professionals will take a family history of early onset into account – and might advise them earlier than others to undergo more intensive check-ups or might even suggest preventive surgery. This is perceived to constitute a significant difference from the rest of the medical system. This is how a woman in her early twenties described her experiences with local gynaecologists shortly after her mother's early death from breast cancer:

> *"They laughed at me. One asked me if there was diabetes in the family, the other looked at my breast and laughed at me. And a third said: 'Well, we don't need to exaggerate, right? You are still young.'" (P3)*

This gestures towards a crucial aspect of the hybrid collective: it constitutes a place where the life experiences of HBOC family members are perceived to be taken seriously. Moreover, the social and psychological consequences of such experiences – and of a potential testing experience – are taken into account and are given space. This happens in various ways: on the one hand, it is possible to hold private talks with the doctors and psychologists. On the other hand, there are also more collective forms of engaging with the different aspects of hereditary disease, such as so-called "information evenings", that address specific topics, but also open up a forum for broader debate. These events are used in multiple ways: some come to pose questions; some participate to show the medical professionals their commitment to the cause; some want to see "how others deal with it" (P3); some bring relatives they want to persuade to take the test or a specific preventive action – counting on the convincing character of the collective performance; in one case a woman brought her husband along as he wasn't convinced of her wish to undergo mastectomy.

However, while the hybrid collective indeed opens up a forum for discussion, there is simultaneously a highly normative undertone. Solutions to the problem of HBOC are negotiated mainly in technoscientific terms, rendering other forms of agency rather inadequate. The *non*-hidden agenda of the medical professionals is to encourage individuals to make use of biomedical forms of prevention. Once positively tested, the coping strategies are envisioned as either an early diagnostics routine specifically designed for BRCA-mutation-carriers or prophylactic removal of breasts and/or ovaries. Moreover, the centre offers psychological support services. Yet they are aware – as one of the psychologists said quite explicitly – that genetic testing is self-selecting and that individuals who were sceptical or rejected this approach would not end up at the centre. Thus, although the hybrid collective opens up a sphere of discussion, it does so in an exclusive and excluding way. It gives room and voice only to a specific way of dealing with the risk of HBOC. This leads to an interesting twist: While there is an unusual amount of flexibility and adaptability within the biomedical services offered, voices advocating non-biomedical ways of dealing with genetic risk tend to be relatively (self)excluded. These observations seem to fit with the broader picture of how self-help movements are largely organised in the Austrian context: they are often run by medical professionals active in the field and are rarely conceptualised as a setting for formulating counter-expertise and engaging in open critique of the medical consensus. Given this background we can understand why the status quo is not questioned by any of the present counselees – or at least not in any explicitly visible form.

Rather, attendants of the information evenings seemed to be in line with the medical professionals. Discussion often centred on those absent relatives who dissented. Frequently, psychologists and medical professionals used narratives about maturation to calm those worried about dissident family members: a time will come when they will turn to biomedical help, probably triggered by some change in their lives, such as having a baby. This narrative of maturation implicitly depicts deciding for genetic testing/biomedical prevention as the responsible and rational choice, while other choices are rendered immature and irrational. Moreover, while it is frequently stressed that each and everyone must choose for or against the test for him/herself, relatives are also encouraged to express their worries and suggest to potentially at risk relatives to decide *for* testing and biomedical forms of prevention, something the medical personnel themselves cannot do.

Expanding Biosocialities: Cohesion, Frictions and Ruptures

As outlined above, the hybrid collective emerging in this specific local clinical context has a very specific architecture of aims, values, and practices, founded on obtaining genetic knowledge and engaging in biomedical forms of prevention. How do members of this special community relate their experiences, decisions, actions and values to larger societal contexts?

We find that positioning their experiences of genetic testing within society at large entails significant reference to broader social forms – be they manifest or imagined – that are perceived to share certain values and visions. Thus they imagine new biosocialities in relation to an increasingly geneticized and biomedicalized understanding of health, illness and the bodily self. Using the plural "biosocialities" highlights the multiplicity and the partly temporary character of such formations as well as the tentativeness with which people see themselves as part of such social forms.

At the heart of imagining these broader biosocial forms are processes of extending the values and experiences shared in the hybrid collective. In our interviews, we encountered three main processes of extension. The first is a temporal one, rooted in a specific construction of the future. Especially in the case of a young woman who tested positive, the future is filled with questions, one of them being: "Is it okay if I still have children?" or should I "eradicate the gene with me" (P4*)?* However, there is a specific scenario created within the hybrid collective that aims at resolving that burden:

> *"And then they told me, well, that [the mutation] should not be such a handicap that I abandon my family planning now just because of that. Because in twenty years the medicine will be that far advanced that they will be able to basically take that [the mutation] away." (P4)*

We could also observe such projection work during information events when concerns about passing on genetic risk were dismissed by the professionals by referring to the vision of a possible future cure. However, this vision is grounded on the assumption that these future children will be as willing to obtain genetic knowledge and adhere to biomedical solutions as their parents are right now. Thus knowing about one's genes means anticipating the future in two ways: believing in a steady improvement of medical possibilities and in the fact that genetic knowledge will remain a broadly accepted basis for individual action.

This first expansion is strongly linked to a specific vision of progress that is equated with technoscientific developments: steady advancement will lead to a gradual reframing of many if not all diseases in genetic terms. Having a genetic disease thus becomes normal. The difference between a BRCA-mutation-carrier and any person in society is not that one is genetically affected and the other is not; the difference, so the argument goes, is that the established BRCA-mutation-carriers know their risk, while the others do not (yet).

This idea lies at the heart of the second form of expansion: the universality of genetic risk. A frequently used example in that vein – both by medical professionals and affected people – is that of the gene for heart attack, while other examples include prostate cancer, varicose veins and astigmatism:

"Now we have that, and now we just say others have the gene for heart attacks and we just have that breast cancer gene. And if so, we can do something to fight against it. And in good hands, we say, we are, too." (P2)

Such accounts argue for the omnipresence of genetic risk and hence a sort of universal genetic affectedness that reintegrates the experience of genetic risk of HBOC into the realm of what is considered "normal". Thus it establishes an expanded group as the target of biomedical knowledge and prevention: everyone. This normalisation however is not considered threatening by our interviewees since both health insurance and labour market arrangements still seem robust enough in the Austrian context to accommodate such a vision.

This is already indicative of the third form of expansion: a strong conviction that society at large should adapt to biomedical forms of knowledge and prevention. Rendering the hybrid collective a sort of model enterprise, a number of interview partners envision that fostering individualised forms of risk and responsibility management is the way society at large should increasingly deal with health issues. As medicine advances, rejection of its services is rendered irrational and irresponsible:

"If they offer you the chance and you are so stupid not to take it, then it's your own fault. It's everyone's own fault, if they get something later on as a result of their own carelessness. And the contributions to the health insurance, I'm well aware, that they are exhausted eventually, but then they should just make such patients pay themselves." (P4)

The quote above nicely illustrates how deeply entrenched neoliberal ideas of individual responsibility towards the community are and how the threat towards the collective (the national health system) is used to enforce normative visions of responsible behaviour. Some other interview partners focused their arguments on the personal and emotional costs of illness that could be lessened if more people would engage in biomedical prevention. Considering themselves to be pioneers of that new way of thinking and acting, a number of interview partners portrayed themselves as being actively engaged in "spreading the word". The quote below shows the high level of identification with the values of the hybrid collective underlying that activist stance:

"Well, I work in a rather big company. And wherever I have the opportunity – we have several projects on health – there I already posted our [laughs], the brochures from [name of hospital]. Well, I think that should be done. […] Well, I think it needs to be propagated." (P9)

Yet none of our interviewees fully subscribed to all of these values nor would they see themselves as tied into them in completely unproblematic ways. They point to ruptures and conflicts arising on at least two levels: Firstly, while being strongly confident in the benefits of genetic testing for themselves, a few of our interview partners voiced concerns that

"society at large" might not be that easily convinced; some feel that "a lot of people just can't relate to that [having a genetic defect and taking certain preventive actions]" (P3)

and hence might possibly discriminate against those who chose to be tested.

"That is just my fear, why I don't want to shout it out loud. The fear that I'm perceived as malfunctioning or not fully operational anymore. I know it's not like that – indeed, I feel much fitter than ever or than during the last ten years, but that's something I don't believe that society is capable of understanding, honestly speaking." (P1)

Thus they understand the position they take towards knowing about their genetic predisposition as the result of a process of gradually learning how to deal with genetic risk – which would not be the case for society at large. Given the relative silence about hereditary disease in general and breast cancer in particular in the Austrian public sphere, there is currently no perceived space to negotiate these issues with society at large.

Secondly, the strong commitment to biomedical prevention also at times creates conflicts with other ideas about the self. We found that a number of these conflicts centred around making use of the option of preventive breast removal. While this is a procedure that is believed to reduce the risk of breast cancer by 90%, it is also a drastic act that is frequently perceived to stigmatize the body and threaten 'authentic womanhood', with or without surgical reconstruction of the breast. The quote below is given by a young woman strongly committed to the paradigm of prevention. In her mind, the logical consequence of this commitment would be to undergo breast removal. However, this is not possible for her:

"I mean, the amputation, I push that very far away at the moment, because I, I don't even want to acknowledge it [the option] at all. They would have to remove the nipples, too, and I can't imagine that it will look like having natural breasts again. Of course, there is this possibility, but not for me." (P4)

Throughout the interview it becomes apparent that these opposing commitments create important tensions within her positioning work. She frequently comes back to the issue of breast removal, attributing a certain amount of inconsistency to herself. Similar conflicting images of the self appeared in other interviews.

Hence, while expanding the newly found biosocial forms on the one hand supports the stabilisation of certain ways of relating to HBOC well beyond the concrete setting of the hybrid collective where they were developed and made to work, these expansions also make the seemingly robust collective agreements more fragile, questionable and questioned, as broader societal orders come into play. This points to the importance of considering broader technopolitical cultures when thinking about what genetic testing might mean in a given society.

Discussion and Conclusions

Looking at these moments of articulation between individuality and collectivity in a specific technopolitical culture leads us to reflect on the issue of (id)entity. As we have shown, the processes of identity (trans)formation always also involved being transformed into entities within the multi-layered collective structures described in this paper. Here we should keep in mind Star's (1991) observation that once a network – in our case a collective – is in place, even those who position themselves outside have to live with the fact of its existence. Thus each of these collectivizing moments contributes to reconfiguring what being tested actually means, opens up certain pos-

sibilities while closing down others, and allows for the uptake of certain identities while making others more difficult to adopt. All three layers of collectivity together create a specific blend of modes of ordering (Law, 1994) and open a space for certain categorization and classification practices (Bowker and Star, 1999) that gain power when people are confronted with issues of health and illness in the age of genetic medicine.

Yet, it is essential to regard neither the biomedical entities nor the co-produced identities as stable phenomena but rather to focus on the constant negotiations and reformulations of these (id)entities along individual life trajectories that became observable in the narratives of our interviewees. Along with these processes of doing and undoing (id)entities, tested persons engage with the specific kinds of affectedness that emerge through genetic testing; fit their new genetic understandings into existing societal constellations; and try to integrate the potentially disturbing and disruptive meanings of being tested into their personal biographies and their "cloth of everyday living" (Lambert and Rose, 1996). In that sense (id)entities are to a certain degree always tentative; they can rarely be considered as stable and always demand reworking over and over again.

Against this background, we want to conclude with four observations that both contribute to the current debate on the culturally rooted ways of engaging with novel biomedical technologies and open up new questions:

First, the absence of a broader institutionalisation of genetic testing for HBOC in the public health system, as well as the absence of a broader public debate in Austria, had an impact on patients' ways of dealing with genetic testing and their handling of (id)entity issues. As they could not and did not have to refer to pre-conceptualised ideas of what genetic testing actually meant in the Austrian socio-political context, they seemed to handle both being an entity in biomedical ordering processes, but also the issue of their identity as a person with a genetic predisposition, in rather tentative ways. They experimented with different meanings of being affected, recontextualised their identities continuously and projected them into potential futures. This means that we find traces of elements identified in the broad body of literature on the impact of genetic testing; yet these elements always appear blended and interwoven with more local understandings that are temporary in character and rarely get definitively stabilised. In that sense *not* being tied into standardised practices and ways of conceptualising being at risk seemed to open up certain possibilities for the tested, allowing them to construct their own stories of pioneering a not fully established field – at least locally speaking. This does not mean that our interviewees did not subscribe to the social orderings performed in the testing centre or in the broader societal context. Rather they expressed the strong feeling that it was their choice and other options were potentially open.

Second, our analysis has shown how "the local" gets inscribed into our interviewees' narratives through the different forms of collectives they are a part of. Thus their story is always a specific blend of individual and collective elements. There is always an overlap between becoming entities in the biomedical system and struggling to align these entities with acceptable identitites. That they are part of collectives/biosocialities well beyond the medical system and that they share a civic epistemology (Jasanoff, 2005) is traceable in their specific performance of an Austrian ver-

sion of the "knowledge society" narrative. In general, our interviewees take the supremacy of scientific knowledge for granted, subscribe to the classical expert-lay divide, admit other forms of knowledge only if they do not challenge the medical authority and use a technology-driven rationale to guide their choices. This could be read as a cultural specificity that is also observable in other science-society issues in the Austrian context. (Felt *et al*, 2008)

Third, the interviewees' description of and their relation to genetic testing showed interesting contradictions with the debates we witnessed in the focus groups on genetic testing which were part of our larger project. In those debates people with no personal testing experience conceptualised genetic testing as an opaque technology related to invisible, mainly global actors – the pharma industry, private insurance companies – that are pushing their interests. The actual usefulness for the patient was perceived as limited. Moreover, the state was conceptualised as too weak to really protect citizens against potentially negative consequences of genetic testing (Felt *et al*, 2008). As shown above, our interviewees at the counselling centre expressed a very different view. Hecht's (2001) reflections on "national technologies" or "technologies made national" and the role this plays in the relation of technology, national identity and choice are instructive here. While in the focus groups participants conceptualised genetic testing as a global socio-technical ensemble that is alien and threatening to local culture, the counselling centre managed to render genetic testing recognizably "Austrian". This means that our interviewees perceived the actual local practices of genetic testing for HBOC as having a fit with their broader visions of the societal context they are part of, as largely consistent with 'national' value systems, as compatible with both their "civic epistemologies", and with their individual conceptualisations of their bodies in relation to health issues. This became possible through constructing the counselling centre as a safe space offering individualised approaches that created the feeling that solutions were tailored to specific problem configurations. Genetic testing thus was performed as have to find a fit with the Austrian health care system, its value structures and the individual patient, and not the other way around.

Therefore, using a distinction developed by Mike Michael (1992), we argue that the focus group participants with no personal testing experience were speaking about "genetic-testing-in-general". While focus group participants struggled with their profound uneasiness that this technology was driven by 'outside forces', our interviewees in the counselling centre gave us an account of "genetic-testing-in-particular" and were thus speaking of a local socio-technical assemblage that in their view made sense. This points to the difficulty of simply speaking about the impact of 'a technology' in broad terms or of abstractly conceptualising the power technologies could potentially develop in a specific local context. Instead it is important to work out the diversity of local understandings that emerge through the continuous process of rearranging technopolitical cultures and new technological options, reflecting the multiple opening-ups and closing-downs of possibilities that happen in these processes.

This analysis thus leaves us with the rather puzzling question of what it would mean for citizen-patients if genetic testing for HBOC became institutionalised in the national health care system as a standard test – moving beyond the intimate, experimental context of a flexible and accommodating hybrid collective. It remains an open question if institutionalisation would allow for forms of counterculture to arise, or if it

would leave individuals exposed to the challenges of genetic testing without a community to help them negotiate how to come to terms with this new technology.

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