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CoB

Challenges of Biomedicine

Socio-Cultural Contexts, European Governance, and Bioethics

Specific Targeted Research Project (STReP)

Citizens and Governance in a Knowledge-Based Society

Deliverable No. 3:

Short report on selective interviews

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Contents

The following report was compiled by DE-UBER; however, it includes the thoughts, comments and results of the discussions between all participants involved in work package three, namely Stefan Beck & Katrin Amelang (Berlin, Germany), Violetta Christopidou Anastasiadou & Costas Constantinou (Nicosia, Cyprus), and Susanne Lundin & Anna Johansson (Lund, Sweden). Authors of the sections covering the particular local findings are the respective teams in Berlin, Nicosia, and Lund.

1. Interviews and Ethnographic Work in CoB

The research project *Challenges of Biomedicine – Socio-Cultural Contexts, European Governance, and Bioethics* (CoB) investigates the bio-political relationship – more precisely, the interrelation(s), boundaries, and shifting concepts – between biomedical science & technology and societies in Europe from a comparative perspective. Taking transplantation medicine and genetic diagnostics as an exemplary field of inquiry, the diversity of socio-cultural attitudes of patients and laypersons towards biomedical knowledge and its applications, as well as towards regulation, participation, and governance in bio-scientific and medical issues is examined in six European countries. Central aim is to better understand the mutual shaping and the shifts in meaning of concepts such as body and bodily integrity, health and illness, the reciprocal co-constructions of experts and laypersons, the (re-)actions and criteria of different actors, the perception of and the positions taken in relation to biomedical technologies, and their – often controversial – implementations. In addition, forms of knowledge and practices within these knowledge contexts were explored against the background of specific social and cultural orientations, economic positions, and public discourses in three different European countries. The comparative investigation of these countries aims at revealing both similarities across national and social contexts, as well as differences depending on national specificities in historical developments, socio-economic contexts and legal as well as institutional frameworks. Empirical data of local laypersons' and patients' attitudes in relation to participation and socio-cultural aspects was collected through focus group discussions and – following a preliminary evaluation of results – successive ethnographic interviews.

The following report is based on the research completed in work package three (WP3), covering months 13 to 24 of the project; central activities in the WP consisted in designing, carrying out, transcribing, and analyzing ethnographic interviews and concomitant fieldnotes. Building up on the research inquiring into the different national socio-economic, legal, and political-participatory contexts of biomedicine performed in work package one (WP1) as well as on the focus group research carried out in work package two (WP2), ten interviews were conducted in Cyprus, Germany, and Sweden respectively. After discussions in the wider project context, members of WP3 decided to carry out in-depth interviews with individuals who participated already in the focus groups. On basis of the interview data, the main objective of the work package consisted in the deep-content analysis of attitudes, preferences, and representations of practices of selective individuals in different countries through appliance of grounded theory procedures and methods. In this context, an important aim was to establish comparability across the three respective languages and local socio-cultural contexts of the ethnographic material. As an intermediate phase leading over to the comparative, cross-cultural, integrative analysis of the overall data collected in the project, which will be carried out in the context of work packages five to seven, WP3 was not restricted to accumulating interview-data, but prepared a close investigation and analysis of the individuals' understandings of science and biomedicine by applying grounded theory methods. Central topics of this first analysis and theoretisation of material were issues like "medicalisation" and "geneticisation", visions respondents held regarding regulation and participation in the field of biomedicine, ideas and conceptualisations of body, health and illness, and, finally, “local specificities”, i.e. issues related to the diverse socio-cultural, national contexts and current public debates.

The choice of the three countries Cyprus, Germany, and Sweden for the ethnographic mode of inquiry, pre-decided already in the project contract, was largely informed by the goal of achieving as much variation and breadth in social and cultural contexts and historical experiences as possible (Hannerz 1998). The respective countries and localities of research, that is Cyprus/Nicosia, Germany/Berlin, and Sweden/Lund, differ for example concerning the size of their population, the socio-cultural composition of inhabitants, the socio-political history, the role religion and church play in the respective societies. In addition, each country has different systems of social welfare, of health care organisation, and quite distinct histories of public health implementation. These differences, as was to be expected, have a clear impact on the perceptions held by respondents of the state’s roles, the roles of politicians and experts and of modes of regulation and participation deemed appropriate; they influence concepts of societal and familial solidarity as well as the ways information “travels” within the national communities.

For the Cypriot context, for example, it has to be noted that the research concerned the Greek-Cypriot population alone, focusing on participants from Nicosia and to a limited extent other urban, sub-urban and rural areas in a relatively small island-community. However, the population is characterised by a high level of formal education and is transnationally well connected to its diasporas abroad. In contrast, the municipality of Lund near Malmø and Copenhagen belongs to the transnational Øresund region in the South West of Sweden and is mainly characterised by its renowned university and accordingly by a high student population. Among other industries, medical technology, pharmaceutics and biotechnology play an important role in the local economy. Focusing on the metropolis of Berlin, the German research took place in an urban, socio-culturally highly heterogeneous locality characterised by a population from both former East- and West-Germany, a high proportion of (im-)migrants mainly from Southern and Eastern Europe. In addition, German participants had experiences in two clearly alternative systems of public health, state-centred, egalitarian and socialist vs. a “paritätisches Wohlfahrtssystem”, a consensus-oriented system of society-wide risk management in health care issues. In short, the contrastive analysis of the three local ethnographies has to be read against this background of socio-cultural variety. To do so in a comparative manner, we could rely on previous ethnographic work on biomedical technologies and related topics by the respective groups in Sweden, Germany and Cyprus, serving as additional material and preparation for the deeper analysis comparing collected ethnographic material from Northern, Central, and Southern Europe.

WP3 extended and complemented the project’s qualitative-empirical data collection to deepen insights and focus questions that could only be touched on briefly in the focus group discussions to collect practice-determining, culturally based, individual patterns of argument and perception that are difficult to elicit in the interactively controlled speech situation of a focus group; and to estimate the participants’ reflections on the focus group’s experience itself, and the impact of topics discussed for their positioning and dealing with the topics in everyday life. In that sense, our involvement in the focus group discussions was an essential part of the following ethnographic work performed in WP3. In the framework of the project both methods (focus group and ethnographic interview) were used simultaneously as methods in their own right and as complementary to each other. Thus, the specificities of each method and the material deriving from it have to be considered. Even though in both methods topics and questions are supplied by the researcher, the key feature of focus groups is the interaction between participants; interviews rely on a one-to-one interaction of questions and responses between participant and researcher. Whereas in interviews, individual attitudes, beliefs and feelings are emphasised, in focus groups a multiplicity of perspectives, views and emotional processes within a group context are highlighted. In comparison to the focus groups, which were held in facilities of the respective universities and research institutions, the localities of the interviews were self-chosen by the participants and thus often took place in a more private environment. The multi-vocal focus group material allows gaining insights in shared understandings, degrees of agreement, group dynamics of positioning, and ways in which individuals are influenced by each other. In contrast, the interview material more extensively elicits individual narratives, interpretations, and reflections made in a biographical mode of contextualisation. We will reflect on the outcomes of the linkage between focus groups and interviews within the project at the end of the report.

2. Procedure and Research Design

The working process of WP3 was structured into three successive phases. The first phase, covering spring 2005, focused on designing the interview guidelines and questionnaires and preparing the recruitment of respondents. In the second phase, during summer and fall 2005, the interview data was collected, transcribed and translated into English. The third phase in the time segment of winter 2005/06 consisted of the analysis of data, establishing comparability (see below) and compilation of the D3-report. During all phases WP3 participants collaborated extensively by means of CMW, mainly using email-based exchange and the software tools provided by Atlas.ti; additionally, the project meetings were used for f2f coordination. The subdivision of the following chapter follows these phases and working steps.

2.1. Preparation

As preparation for interviews, classical ethnographic methods were applied, e.g. explorative interviews were conducted with experts in clinical settings, in transplantation medicine and immuno-typing in the fields of lung-transplantation and bone marrow transplantation, or in genetic testing and screening. Additionally, we could rely on previous ethnographic work and research carried out in Cyprus, Germany and Sweden by the respective teams, concerning transplantation medicine and biotechnology (Prof. Dr. Susanne Lundin), genetic testing, bone marrow transplantation and cross-cultural analysis (Prof. Dr. Stefan Beck), and the impact of medical/genetic knowledge and social aspects of health and disease on notions of solidarity and bodily integrity (Dr. MD Violetta Anastasiadou). An additional point of departure was provided by the research conducted in WP1 and WP2. Together, this preparatory work provided the necessary information for the development of a draft interview questionnaire and the successive refinement and “localisation” following a thorough analysis of exploratory interviews. As to the design, recruitment, and implementation of the interviews, the active involvement – in the sense of a truly participant observation – in the focus groups by Anna Johansson, Costas Constantinou, and Katrin Amelang, who conducted the following qualitative interviews, was considered crucial as an indispensable background for the concomitant ethnographic work.

2.1.1. Development of Interview Questions

A guideline of interview questions was developed after intensive discussions on the basis of the preliminary results of the focus groups by members of WP3. As a first intermediate step, problem-zones and complexes of questions that emerged while examining the focus group material were discussed and identified. We agreed on the following themes as major issues to be elaborated on in the interviews:

- Framing of and coping with health and illness,
- Notions and representations (imaginaries) of body and organism,
- Knowing, deciding, acting (choices and decisions; styles of reasoning and legitimising),
- Participation and political regulatory mode, and
- Evaluating of and positioning towards biomedicine.

Successively, after presenting first draft questionnaires to partners involved in the focus groups but not involved in the interviews, their commentaries and wishes for refinements were included if feasible. These commentaries mainly were related to issues like religion, body, and gender as topics of overall interest that could not be covered in the focus groups in a satisfying manner due to the character of the empirical instrument or the evolving group dynamics. In the next step, four guidelines for questions (see Appendix below) were compiled to cover the two technologies of concern (genetic diagnostics and organ transplantation respectively) and the two groups of participants (laypersons and affected people respectively). Using established principles of grounded theory and the process-oriented epistemologies in ethnographic work, DE-UBER designed the interview guidelines as flexible as possible, meaning that questions by necessity should be gradually adapted and modified according to the interview dynamics. This concerned not only the chronological order of questions / topics covered, but also the emphasis given to themes and the actual phrasing of questions. If appropriate, interviewers were encouraged to divert the course of the interviews, following the agendas set by respondents for sufficient time, before returning to the guidelines. While the interview questions in their majority referred to general, cross-national issues, it was deemed necessary to include a section for specific questions concerning “local” public debates or problem constellations that were significant for the particular socio-cultural (i.e. “national”) context. These local specificities were especially touched upon in the questions about participation, regulation and governance, public debates concerning the assessment of biomedicine, and the health care system – especially these questions in the last section of guidelines were thus locally contextualised.

In Cyprus, GT interviewees were specifically asked questions concerning the – in a sense obligatory – Cyprus Thalassemia prevention programme, a population-wide genetic screening programme that was implemented successively since the late 1970s on the island, while in Sweden impacts and meanings of factors like life-style, age and gender were explicitly explored in the context of medical prioritisation. In Germany financial questions were stronger focused, taking up recent debates in the context of a pending health care reform. As opening and introduction to the interview laypersons were asked about possible prior focus group experiences, and patients were asked about their first exposure to the respective medical technologies. As a general result, we, in most cases successfully, addressed a person and his/her experiences directly without problems. In those few cases where this strategy of asking turned out to be difficult – because people didn't answer only briefly or didn't see their experiences as something special and relevant (a common problem in ethnographic, narrative oriented interviews), a more indirect strategy of asking was adopted, namely addressing the person as expert with specific experiences who can give advice to others in these issues.

In general, questions worked fine with all interviewees. However, more often than not respondents seemed to be more engaged in the first part – dealing with the topics of decision-making, health/illness and body – than in the second part of the interviews, addressing the topics of participation and assessment of biomedicine and biomedical institutions. The main reason for this finding might be that the latter topics moved away from the more concrete experiences to a more general level of discussion. As a rule, respondents were much more reluctant to take positions as soon as the domain of "legitimate expertise" of patient or "layperson" was transcended. Another – perhaps complementary – reason could be the chronologically order of the topics, which located these at the end of the interview when people were more exhausted and becoming less concentrated. Furthermore, the guidelines for interviews on organ transplantation worked a little better than the ones on genetic testing. More specifically, within the context of body and framing health/illness, questions concerning the influence of knowledge about a genetic risk/disease e.g. for the meaning of life, or concerning the localisation of a genetic risk or genetic disease posed sometimes difficulties for respondents, and required more concrete examples on part of the interviewers in order to be answered. This quite common difficulty might have derived from participants' difficulty to differentiate between genetic diseases and genetic predispositions as well as from the difficulty to conceptualise and thus "locate" this abstract entity and relate it to held concepts of body and organism.

2.1.2. Recruitment and Selection

The time at the end of the focus groups was used for the introduction of WP3 and the respective interviewers; in addition, this face-to-face was used for a first recruitment of respondents who were interested to participate in the interviews later. This strategy turned out to be quite successful: Almost all interview participants had taken part in the prior focus groups. In Sweden, two interviewees had to be newly recruited due to the lack of directly affected persons and the need to adjust for age and gender biases. The final recruitment and selection of respondents was based on the interest and time of people willing to participate. In general, respondents were preferred who represented different attitudes or expressed interesting or controversial opinions during the focus groups. These individuals were selected to elaborate their preferences more intensively in the interviews. Attention was paid to the selection criteria that were also used in the focus groups, that is age, religion, gender, and educational bias were taken into account and – if possible – corrected for. However, because of local specificities, all Cypriot interviewees share a Christian Orthodox religious orientation and all Swedish respondents are characterised by quite an high educational level. In the German sample, all interviews concerning genetic testing were conducted with women, due to the lack of time or interest of the already few male focus groups' participants and the impossibility to recruit new persons in the time available after some respondents had dropped out. A detailed overview and profile of the particular participants is provided below.

The data sample of WP3 contains thirty interviews, thereof ten conducted in Cyprus, Sweden, and Germany respectively. As to the focus on genetic testing and transplantation medicine, five of the ten local interviews dealt with each topic. For reasons of interest and feasibility we decided to have a little bias in direction of people who have more direct experiences with the medical technologies of concern. In accordance with this agreement six of the ten local interviews were performed with affected people and four interviews with laypersons.

	Organ transplantation	*Genetic testing*	*Total*
Affected people	3 x 3 = 9	3 x 3 = 9	*18*
Laypersons	2 x 3 = 6	2 x 3 = 6	*12*
Total	*15*	*15*	*30*

2.1.3. Profile of Interview Participants

Pseudonyms, that is numbered acronyms in the case of Cyprus and Sweden, and fictive names in the case of Germany, were assigned to all interviewees; these pseudonyms will be used throughout this report. The acronyms used to designate respondents in the focus group transcriptions are given in brackets.

Interview participants Cyprus

TMLM25 (FG TML4): Aged 25, male, unmarried, has a university graduate in electrical engineering, and works for a private company. He indicated that he is neither an active member of the Church nor a religious person. He never had a relation to or experience with transplantation medicine or other kinds of therapies. He criticised both biomedicine and medical research in Cyprus.

TMLF50 (FG TML7): Aged 51, female, married with 4 children; she is a housewife and a university graduate. She did not have any relation with transplantation medicine and genetic testing, and said that she is a religious person. She indicated that she was impressed when she heard that other mothers would receive organs from their children because she would not do so.

TMAF19 (FG TMA8): Aged 19, female, unmarried, currently a high school student, and wants to be trained as a nurse. She received bone marrow a couple of years ago; she described herself as religious, and she had strong arguments about the relationship between physicians and patients.

TMAM50 (FG TMA1): Aged 50, male, married with 2 children; he is a college graduate and works as a forest officer. He did not describe himself as either an active member of the Church or as a religious person. He has been in a waiting list for kidney transplantation for some years now; he has expressed strong arguments about his relatives, especially about his mother who had been identified as his potential donor but she eventually refused to proceed.

TMAM55 (FG TMA3): Aged 63, male, married with 3 children, is a university graduate and works as a mechanical engineer, and he has indicated that he is an active member of the Church. He received a kidney from his wife and he has explained that organ transplantation is a very good solution. Further, he is the president of the Cyprus Association of Transplanted People and he has utilised strong arguments about the importance government's contribution, the law and information campaigns.

GTLF28 (FG GTL1): Aged 28, female, unmarried; she is a high school graduate and works as a secretary officer. She has described herself as religious. She never had any experiences with genetic testing or transplantation medicine, and she expressed interesting arguments about breast cancer and the importance of an attractive female body.

GTLM50 (FG GTL6): Aged 50, male, married with 3 children, works as a taxi driver. He has finished high school and has described himself as a religious person. His main line of argumentation was that people could control their bodies with possessing medical knowledge and through genetic tests.

GTAM40 (FG GTA7): Aged 32, male, married with 2 children, has graduated from college; he has described himself as an active member of the Church. He works as a tree surgeon. He has a genetic condition himself (ear dysplasia) as well as one of his daughters. He stressed the importance of psychological support and physicians' counselling approach.

GTAM45 (FG GTA4): Aged 41, male, married with 2 children; he is a high school graduate and work as a salesman, and has argued that he is a religious person. He has an 11-year-old son with Down's syndrome. He emphasised psychological support and physicians' counselling approach. He, as GTAF45, was one of the least talkative participants in the interviews.

GTAF45 (FG GTA2): Aged 42, female, married with 3 children; she has described herself as a religious person, is a high school graduate and works for the civil service. She has a daughter with a genetic condition. She was not very talkative and she focused on physicians' counselling approach as well.

Interview participants Germany

Marlene Lukaz (32AF/OT A): Female, aged 57, divorced, 2 (grown up) children, O-level, professional training as secretary, white-collar worker, applying for pension due to her transplantation and fibromyalgia (chronic pain), non-religious background. Liver transplantation in summer 2003, polycystic liver (familial, not life-threatening), participated in a clinical trial of immunosuppressives during her first post-transplantation year.

Hasan Çelik (40AM/OT A): Male, aged 47, married, 2 children (17/21 years old), O-level, white-collar worker in administration, “passive” Muslim, non-religious person, Turkish migration background, since 1974 in Berlin/Germany. Liver Transplantation in 1997 (failure of liver, hepatitis type B).

Jürgen Blumberg (36AM/OT A): Male, 48 years, single, O-level, various professional training, at the moment working in public relations as “street worker” for organ donation; he is a “passive” Protestant, non-religious person. Kidney dialysis since 27 years (kidney problems since childhood), once got a damaged kidney transplanted for a couple of days, does presently not want a new kidney, has due to his job many insights into the “transplantation business” in Germany.

Cora Schuster (21LF/OT L): Female, aged 24, single, A-levels, studies economics; she has a protestant background and is a religious person. Has no experiences with transplantation medicine, and generally she approves of organ donation/transplantation; she is member of a political party.

Volker Nickels (30LM/OT L): Male, aged 45, not married, lives in a steady relationship; A-levels, professional training in business and wholesale, white collar worker, non-religious person (familial catholic background); has no experiences with transplantation medicine, is sceptical of organ donation/transplantation.

Isabel Wilke (11AF/GT A): Female, aged 25, single, O-level, professional training as office clerk, white-collar worker at Cystic Fibrosis Association Berlin/Brandenburg, non-religious background. Cystic fibrosis, at age 20 genetic test to clarify which course of disease is to expect, her boyfriend got his carrier status genetically tested.

Silke Drewsen (12AF/GT A): Female, aged 32, married, university degree, white collar worker engaged in wholesale and export trades, non-religious background. Dilated cardiomyopathy (familial heart disease), on her initiative she and her father have been genetically tested; she further enrolled herself in a clinical trial of a kind of blood-dialysis, in general listed for a new heart (on/off the waiting list depending on her state of health), active in the Association for Organ Transplanted Patients. Focus group GT A, interview was a mixture of questions GT A + OT A.

Regine Paulitz (13AF/GT A): Female, aged 53, married, 1 daughter (aged 18), O-level, professional training as goldsmith and dental technician, retired due to her illness; non-religious, familial Catholic background. Marfan syndrome, has been genetically tested, unclear if she passed it onto her daughter; heart transplantation in 1996 as result of Marfan, organised in self-help group of patients with Marfan syndrome; was earlier engaged in the Association for Organ Transplanted Patients. Focus group and interview GT A; interview was followed by a longer (unrecorded) talk about her experiences with organ transplantation.

Ute Kremer (4LF/GT L): Female, aged 30, married, 2 children (aged 2 and 6), A-levels, student (mentioned legal studies as one of her minor subjects), non-religious background; in her second pregnancy she was confronted with the option of using prenatal testing (did not use it), since 1997 diabetes mellitus (type 1).

Gabrielle Albrecht (5LF/GT L): Female, aged 55, married, 1 daughter (aged 24), O-level, professional training as pediatric nurse and speech therapist, since 30 years working with handicapped children; “passive” Protestant, non-religious person. Generally rather approves of genetic testing/research.

Interview participants Sweden

A1 (C3F/OTA): Female, aged 31-45, married, Upper Secondary school, works as a nursing assistant, active Protestant; had a lung transplant in 2003 following from a “very rare lung disease”.

A3 (F3M/OTA): Male, aged 46-60, married, 3 children, supervisor in engineering industry, not religious; had a heart transplant after a heart attack in 1996.

A9 (OTA, did not take part in the focus groups): Male, aged 31-45, unmarried, Upper Secondary school, working at a petrol station, not religious; had a lung transplant in 1998 because of cystic fibrosis.

A2 (D2F/OTL): Female, aged >61, 1 son, University degree, former head librarian at the University Library, now retired/hobby student at the Human Ecology Division, Lund University; not religious.

A 8 (A2F/OTL): Female, divorced, 2 children, University degree as a dentist, now working in pharmaceutical industry, not religious.

A4 (C5F/GTA): Female, aged 31-45, married, 3 children, Upper Secondary school, self-employed, religious Protestant.; had a genetic test when her son was born with haemophilia; she is a genetic carrier and even a haemophiliac herself even though her symptoms are so minor she did not notice until she took the test.

A6 (GTA, did not take part in the focus group, however sister of A5F/GTA): Female, aged 18-30, living with her boyfriend, 1 daughter, currently on maternity leave, has previously worked as a nursing assistant, Upper Secondary school, active Protestant. She took a genetic test as a child showing that she was possibly a carrier of haemophilia. She took another test before she got pregnant to confirm this and also underwent amniocentesis. She still does not know whether her daughter is a genetic carrier or not.

A4F and B4M (GTA, actually one of the focus groups with only 2 participants due to weather conditions, and thus counts as interview)

A4F: Female, aged >61, married, 2 children, University degree, pensioner, former superintendent, religious Protestant. She took a genetic test when she was diagnosed with breast cancer in 1999.
B4M: Male, >61 years, married, 2 children, Upper Secondary school, works as teacher, religious Protestant. Married to A4F and thereby affected; no experience with genetic testing himself.

A5 (G1M/GTL): Male, aged18-30, unmarried but living with his girlfriend, university student (Gender Studies and Biotechnology), not religious.

A7 (A1M/GTL): Male, aged >61, married, 5 children, University degree, pensioner formerly working as a forester, not religious.

2.2. Data Collection

After developing the guidelines of questions the interviews were carried out in the respective countries during summer and fall 2005. Participants could choose the location of the interview themselves. According to the choice made by most respondents, the interviews often took place in a more private setting, for example in the homes or offices of the interviewees, a favoured café, or a quiet room at a public institution, e.g. a university. The interviews were recorded; the duration was between 60 and 90 minutes. Field notes or notes of observations, like impressions and brief characterisation of the interaction during the interview and notes on the frequently quite informative unrecorded talks before and after the actual interview, were afterwards written down from memory to complement the transcription. The interviews were all transcribed by the interviewers themselves, partially as an opportunity to add comments or remarks, partially as a first step in analysis through concomitant notes taking; transcripts were subsequently translated into English, in most cases by contract translators; to ensure a context-sensitive translation, interviewers and translators closely cooperated during translations. These translations were again checked against the original sound-files to annotate the texts if specifics of original language, metaphors, images or graphic language used produced problems for translation; equally so, if local context required a more thorough explanation or clarification, the translations were annotated for the ethnographers in the other two respective countries.

2.3. Analysis

After exchanging the locally produced translated transcripts and additional materials, the last period of WP3 was assigned for the deep-content analysis of the interview material. Generally, the interpretation of data followed a strict bottom-up approach of analysis, in the sense that no pre-defined set of codes was applied to the interviews, but content-related focal points were developed through a step-by-step analysis of the material. In going through the material, concepts and theories from preparing the input-papers for WP5, 6, and 7 were taken into account as well as the preliminary findings from focus group discussions. As such, the analysis followed grounded theory procedures (Strauss/Glaser) and its principles of “constant comparison” between empirical material and theoretical concepts or within and across interviews. “Empirical density”, i.e. the groundedness and density of codes in the data, was gradually achieved. The analysis was characterised by an ongoing interplay between empirical materials, more descriptive codes and more abstract codes or theoretical concepts, between different levels of analysis, and thus between inductive and deductive principles. The software Atlas.ti was used to structure, summarise and analyse the interviews as well as to provide a platform to exchange materials and discuss advancements of interpretation between the WP3 partners. To grant easy exchange and comparability, the English translations of the interviews were used for coding, however, coders regularly went back to the original material during the progress of coding and analysis, adding comments and refining interpretations. Especially this crosschecking and revising of the codes required intensive work; however, since this provided not only the basis, but already the first steps into theorising, this added workload was agreed upon by the three teams.

Setting out from a methodical discussion of predefined codes used in the analysis of the focus groups, WP3 partners agreed upon using grounded theory procedures, and came to an understanding for necessary steps for linking empirical, ethnographic material and theoretical concepts; these were conceptualised as preparatory steps for the following work packages. Against the background of these discussions the German partner provided a work plan, prepared a manual of relevant Atlas.ti functions and a "test coding" of one interview as an example for training to use Atlas.ti. The software was quite helpful in preparing the actual analysis that was subdivided in four working steps:

1) First open coding (summary of content on a mere descriptive level, adding comments and notes),
2) Merging and refining of codes,
3) Linking of codes (to point out relations),
4) Develop code-families (to summarise codes on a more abstract, theoretically advanced level).

Codes developed in the first step were commented on to explicate or specify the name or label of codes in order to ensure a common use by all coders. Additionally, memos were created, e.g. for writing down ideas and thoughts about relations of concepts during the coding process, or commenting on particular parts of interpretation. The second and third step were partly incorporated in the process of coding one interview after another, but mainly building up further analysis on the basis of the first coding. Concerning the linkage of codes, the Swedish partner provided an input for discussion to create new labels of relations, enlarging the options offered by Atlas.ti. In the timeframe of WP3 we could only start the discussion and agree on the use of some basic labels concerning the quite sensitive and complex step of linking, since relations between codes and concepts are often dialogic and two codes could be linked in several different ways depending on the perspective taken by the researcher. The discussion of possible combinations and integration of codes into code families was based on prior exchange about the issue of comparability and representation of our local findings in a common structure. Taking into account emerging topics and themes in our coded materials as well as the problem-zones of our interview guidelines and overall project interests, we agreed on the following focal points for a clustering of codes:

- Assessment of biomedicine (and modes of elaborating),
- Frames of regulation and issues of governmentality,
- Notions of health, disease/illness (e.g. contrasting medical vs. subjective notions),
- Body (e.g. issues of concrete, experiential knowledge vs. abstract, scientific knowledge),
- Gender (as a cross-section indicator),
- Doctor-patient relationships (issues of trust etc.),
- Religion and other values functioning as rationales for decision-making.

Code-families were created in a two-step process combining a deductive perspective from focal points and by means of induction, using our particular codes and code-relations from "below". The local analytical proceedings were complemented by an extensive and continuous email-based exchange related to the implementation of procedures, technical problems, central topics and findings, discussion of preliminary findings, questions of comparability, and possible code-families. The 5th project meeting in Lund was used to draw together our findings and consolidate code-families as a basis for the concluding D3-report.

In the following chapters, the interviews and local findings will be presented for each local / "national" context in a separate chapter. All three reports follow the same structure and provide a summary of the interviews on a more general level. The reports are divided into six subchapters. The first chapter deals with the assessment of biomedicine and its applications, including positions taken by respondents on research and medical developments. In the second chapter, interviewees' opinions regarding the framework of political regulations are discussed with respect to the organization of health care, ideas of regulation, and visions for an adequate participation. Notions of illness and health are investigated in chapter three, which covers coping strategies, social implications of disease and understandings of causes of diseases as well. The fourth chapter focuses on views, concepts and understandings of the body, for example on metaphors used by respondents to refer to their body or the anticipated bodily consequences of genetic testing and organ transplantation. The fifth chapter deals with experiences and judgments of doctor-patient interactions. The sixth chapter describes issues of religion and gender brought up in the interviews. With respect to the three local ethnographic findings, slight changes regarding the structure or varying levels of aggregation concerning the usage of interview quotes or of paraphrasing and interpreting the content have been applied.

3. Local Findings Cyprus

3.1. Assessment of the Applications of Biomedicine[1]

Assessment of biomedicine by the participants has been investigated at three different levels: Assessments of biomedicine in general, assessment of research efforts, and in notions of “medical progress”. Suffice to say here that participants’ evaluation of biomedicine relied on their prior personal experiences and the relevant information they had in mind either from the media or from other sources such as friends and relatives. Let us discuss this general pattern in detail.

3.1.1 Biomedicine in General

The general evaluation of the applications of biomedicine was based upon three interlinked factors. Firstly, all participants focused on their prior contact with physicians. Secondly, some interviewees evaluated biomedicine in Cyprus on the grounds of the comparison of the public with the private sectors. Thirdly, the comparison of Cyprus with other countries has also been a sufficient line for formulating an argument for some participants. Let us further discuss these three main lines of argumentation.

Physicians as the basis of evaluation

Within the context of this subchapter we are presenting the ways through which physicians are addressed as a baseline for evaluating biomedicine. A detailed discussion of participants’ relationship with physicians follows in sub-chapter 3.2.3.

The main line of argumentation observed was that, although the application of biomedicine in Cyprus is sufficient, it still needs improvement in many respects. Some improvements could be the result of employing young specialists and equipping medical institutions with new technology. This general approach aligned with two axes which, at least to some extent, reflected on the category of participants between lay and affected.

Firstly, most of the affected participants (with the exception of TMAM50 who is in a waiting list for a kidney) evaluated biomedicine on the basis of their contact and relationship with physicians. They indicated that physicians in Cyprus are good, but they do not always inform patients adequately. On this basis, participants indicated the corresponding regulatory routes that have to be taken (further discussed in chapter 2).

Secondly, lay participants’ arguments were more diverse. On the one hand TMLM25 and GTLF28 argued that there is no trust in the Cypriot health care system; they grounded their argumentation on comparing the public with the private sector and Cyprus with other countries. The first pair of comparison touched upon issues of celerity and cleanness, indicating that in the public sector there are observed delays in medical treatment and that the General Hospital of Nicosia is dirty and untidy. The issue of long waiting lists in the public sector as compared to the private medical institutions was also raised by TMAM50 (an affected participant). Within the context of the second comparison largely made by TMLM25, Cyprus has fallen far behind other countries in medical treatments and technology, and he suggested that the case of the UK should serve as an exemplar. Interestingly, TMAF50 and GTLM50 focused on the positive points of Cypriot biomedicine. The former stressed that she would not like to think about any negative points because she is an optimistic person and would like to stress the positive side of it. While GTLM50 indicated some negative points which had to do with the lack of research and physicians' workloads, he emphasised that biomedicine in Cyprus is very good; he compared it with health care systems in countries like Georgia where biomedicine is, as he put it, worse than in Cyprus. Below, the two comparative schemes are further elaborated.

Public and private sectors

The three participants (TMLM25, GTLF28, TMAM50) who compared medical institutions in the public and private sectors utilised specific information derived from their personal relation with medical institutions as well as from friends and relatives in order to support their argumentative line. TMLM25 and TMAM50 mentioned the issue of delays in access for medical treatment, indicating that it is a phenomenon only observed in the public sector. However, TMAM50 stressed that medical treatment in the private institutions is expensive and not affordable by many people. Interestingly, TMLM25 also focused on comparing the quality of treatment in institutions in the two sectors. Drawing information from a friend and his personal experience, he indicated that many mistakes happen in institutions in the public sector which might be proven harmful for people, and that medical therapies might not be consistent across individuals. Suffice to say here that his generalised approach was based on one example for each case.

The public and the private sectors were also compared at the level of hospitals. The General Hospital of Nicosia was a referent point for both GTLM28 and TMLM25 who argued that it is very dirty. The former asserted that when visiting this hospital one might be infected with germs. She indicated that while germs might exist in institutions in the private sector, she thought that they were not visible. The latter compared the General Hospital of Nicosia with Newcastle's university hospital in order to show that a university hospital abroad is better than a state hospital in Cyprus.

Other countries as the "good other"

Cyprus has been explicitly compared with other countries by four participants (TMAF19, TMLM25, GTMA32, GTLM50) on several grounds:

(a) Lack of information: TMAF19 has argued that physicians in Cyprus hide information from patients, and they do not adequately explain the nature of health problems and the involved implications. The comparison was made with the UK and TMAF19 indicated that knowing about the nature of a health problem and the therapeutic process makes a patient feel better.

(b) Insufficient hospitals and equipment: This argument has been utilised by TMAF19 and GTMA32. Again the exemplar was the UK.

(c) Biomedicine in Cyprus is static: GTLM50 used this argument to indicate the importance of research which takes place in developed and rich countries rather than in Cyprus. He thought that research and genetics are the moving powers of society and biomedicine.

(d) There are worse cases: GTLM50 stressed that the health care system in Cyprus is very good and compared it with countries where it is worse than in Cyprus such as in Georgia. He also mentioned that access to the health care system is free in Cyprus, and this is not observed in any other country in the world.

(e) Taxes and access to medical treatment: TMLM25 asserted that the British system is the best one because citizens pay taxes, and they are benefited in terms of medical access. This, according to TMALM25, does not happen in Cyprus where citizens pay taxes without having any benefits.

This reveals that some participants utilised a spatial comparative scheme in order to support their argumentation. That is, the United Kingdom (participants used the word "England") as a geographic and imagined location is perceived as the "good other", or as the model that the Cypriots should learn from in order to improve their medical health care system. This observation deserves further scrutiny, and our attempt is to answer specific questions:

Why the UK and not other European countries?

The UK has been a very popular destination for many Cypriots for registering with universities or for receiving medical treatment for serious health problems for many years now. On this basis, the three participants who explicitly mentioned the UK as a good model had visited the UK for the aforementioned reasons. That is, GTAM32 and TMAF19 for medical reasons and TMLM25 for studying. Therefore, the UK is the only foreign country they have been exposed to for a period of time, and it functions as a cognitive tool or a database to evaluate biomedicine in Cyprus and to answer a specific question posed by the interviewer. This exposure to the UK is often coupled with the medial coverage of cases where Cypriots visit institutions for specific therapies, which are not available in Cyprus, or of cases where Cypriot physicians who live and work in the UK have contributed to the discovery of new medicine and therapies.

Why have these participants not mentioned any problems of the British health care system?

In line with the above short explanation, these participants have not encountered any organisational problems within the hospitals and have not heard of any problematic regulatory modes in the UK through the Cypriot media. Arguably, these participants, having gone through a health problem and having had negative experiences with some physicians in Cyprus, have constructed the British system as the ideal model. In other words, their personal experiences functioned as a database and a cognitive chorography in order to make sense of the Cypriot health care system. Since they mentioned the negative points of the Cypriot health care system, they had to draw information from this database so to support their argumentation. Of course this is not a one-way process but a dialectic relationship. That is, their prior experience works as a source of digging out the strong and emotional cases which were embodied (e.g. hiding information and experiencing feelings of insecurity) and elicited negative feelings (the cases in Cyprus). Since these cases or examples were articulated, these three participants utilised the comparative strategy in order to ascribe a reasonable sense to their argumentation. Through this comparative strategy, they selected examples experienced, which had re-established the feelings of security and control that were lost in the Cypriot context. This psycho-social relocation (real or imagined) took place in the UK. The participants did not have any negative points about the British health care system to mention, not because such points do not exist but because they were never experienced.

Is the comparison always against the Cypriot context?
The case of GTLM50, as already mentioned, reveals that this is not the case. Even though he argued that genetics and research are unknown in Cyprus, that biomedicine in Cyprus is static, and that the EU will bring many chances to the Cypriot health care practices, he was the only participant who compared Cyprus with other countries in order to argue that the Cypriot health care system is good (the example of Georgia and Cyprus). He mentioned the example of Georgia, which received media attention in Cyprus when a Cypriot physician visited medical institutions and they did not have the basic equipment. Furthermore, he stressed the Cyprocentric phenomenon of offering free health care. GTLM50 is a lay participant, he did not have any serious health problems; his sister is a physician, and he believes in medical progress, and that genetics can change one's course of destiny. All these characteristics might have contributed to a balanced approach towards biomedicine in Cyprus and in comparison with other countries.

3.1.2. Research

There has been observed a diversity of arguments for evaluating research, and any lines of argumentation are difficult to unpack. More specifically, half of the participants did not express any arguments in regards to medical research. This could be attributed to their lack of information about such a topic and the difficulty to relate medical research to the Cypriot context. Those participants who answered the question aligned with three different directions. Firstly, GTAM32 stated that he does not know about how developed research in Cyprus is and thus could not articulate any negative or positive points. Nevertheless, he indicated for within the context of discussing modes of regulation that any discoveries in the medical field are beneficial for the government. TMAF19 argued that, although there are not many studies conducted within the medical field, things are getting better, and that the number of studies is increasing. She viewed this increased interest positively. However, she rather referred to studies from the social sciences such as her participation in the FG discussion than to medical research.

Secondly, TMAM55, TMLM25, and GTLM50 viewed research as something important and beneficial for both biomedicine and society, but clarified that research in Cyprus is limited. These three participants directed themselves towards different lines of argumentation. That is, TMAM55 implied that there are some studies in Cyprus but the government needs to utilise all EU's programmes for research. GTLM50 stressed the importance of research in general and genetics in particular. He indicated that genetics is the future and longevity of humanity, though he argued that research is conducted in developed and rich countries and not in Cyprus. To further support his argumentation, he drew information from his sister who is a medical doctor, and said that physicians in Cyprus are still students because they learn from studies conducted abroad. Finally, TMLM25 expressed the most negative position towards research. He explained that there is no research in Cyprus due to the lack of financial resources, and he presented the case of the UK as a good model for the Cypriots to learn from.

What deserves further scrutiny here is participants' source of information and how this information functions as a guide to evaluating research. It is important to distinguish affected people with lay ones. The former appeared to express softer arguments about research in Cyprus, whereas the latter appeared to present more negative points and compared Cyprus with other countries from Europe and the US. One would expect affected people to be more critical towards medical research in Cyprus due to their personal experience with health problems and the Cypriot medical institutions. However, it was the participants from the lay group of interviewees who expressed negative arguments. This could be interpreted as lay participants' attempt to answer to a question based on the information they could recall. The information they had in mind did not come from direct experience but from the media, friends, and relatives. Interestingly, it is the negative news that captures media and people's attention, and it is this kind of information that is usually narrated. Therefore, lay participants, without having experienced any health problems and without having been in the position to view physicians or medical institutions as "saving places", recalled the information that was available in their personal learned rather than experienced history.

3.1.3. Medical Progress

The issue of medical progress was discussed within participants' evaluation of biomedicine and research, and therefore this sub-chapter is short in order to avoid repetition. The main line of argumentation, which has been expressed by four participants (TMAF19, TMLF50, GTAF42, and TMLM25), is that biomedicine in Cyprus is getting better. However, three participants lined with different directions. TMAF19 mentioned that more studies are conducted nowadays than ever before. TMLF50, as GTAF42, stressed that physicians are constantly informed and that there is a rapid improvement, whereas TMAM50 argued that some surgeries which used to take place abroad are now performed in Cyprus. Nevertheless, this medical progress on the island should not be viewed as a general improvement of the health care system, but only as a sectoral one. To elaborate further, these participants who talked about medical progress have also discussed the issue of medical stagnation due to the lack of specialists, technology, and research.

Interestingly, participants again used the comparative strategy in order to balance their argumentation between the two aforementioned main lines. This comparative strategy is of temporal philosophy as it compared Cyprus in the past with Cyprus in the present. Time is understood and used as a topographic tool that organises and locates the information people have in mind.

3.2. Frame of Regulation

What the material from the Cy interviews shows is that participants understand regulation on their prior experiences and contact with physicians and medical institutions. In other words, participants' evaluation of biomedicine (presented in the previous chapter) directly relates to what they think should be done in order to regulate health care more effectively.

3.2.1. The Role of the State, Cost, Access and Priorities

The role of the state

The role of the state has been very often associated with the role of physicians (see next sub-chapter for more details). That is, the state and politicians in particular should listen to the experts and should take political decisions such as passing laws. Also, the majority of interviewees have reduced the role of the state to undertaking the cost of therapies (this is further discussed below).

Apart from referring to the state as an impersonal and abstract entity, participants were asked to talk about the role of politicians. While the question referred to politicians in general, participants answered the question on the basis of the politicians who govern.

The main line of argumentation is that politicians have more to offer to the medical domain in Cyprus, and they have to work harder on it. Interestingly, this line links to participants' prior experiences, self interests, and modes of evaluation as discussed earlier in this report. This triadic relationship touches upon participants' mental topography that has been socially constructed and is under constant revision within the context of their daily experiences and the new information they acquire. Here are some examples:

TMAF19 argued that politicians should visit health institutions and see what is missing. She criticised government's past decision to close down the Oncology Department of Makarios Hospital. Suffice to say that she had therapies at this department as she suffered from leukaemia.

TMAM50 stressed that politicians should pass a new law for cadaver donors and provide legal grounds for a presumed consent. The logic of his argument aligns with his personal and embodied experience of looking for a kidney donor.

TMAM55 suggested that politicians should decide on forming a single unit which would be responsible for all aspects of organ transplantation from registering an archive to organising information campaigns. This participant is the president of the Association of Transplanted People and had raised the issue of politicising transplantation through law-making.

Though GTAM41 does not trust politicians, he argued that what has to be done at a political level is to better the conditions in schools and employment. This resonated with his personal experience with a genetic condition as his son has Down's syndrome and thus he is concerned with issues that attend to his son's education and future employment.

GTLM50 indicated that the role of politicians should lie with the attempt to make people's life better. This argument converges with his previous statements about progress and the contribution of genetic and medical research.

Medical cost

All participants had interesting visions of how medical cost should be handled, and who should undertake this. The main line of argumentation was that the state should play the role of paying the expenses that attend to health problems. On this basis, two participants suggested that when the state pays for the cost of therapies and research it is benefited as well because new discoveries may reduce cost in the future. Further, as one participant indicated, if the state offers opportunities for performing many surgeries on the island such as bone marrow transplantation, then the cost decreases because it does not have to pay for travelling, accommodation and medical institutions overseas. Within this general pattern, there were some arguments which focused on different directions. That is, three participants indicated that wealthy citizens should offer some money for therapies, whereas four participants argued that citizens should also undertake part of the cost.

Generally speaking, medical therapies were perceived as expensive and unaffordable and thus the state was viewed as a protecting agency which should take care of its citizens and undertake the cost. This has not only to do with perceptions of regulation and responsibilities but also with ways of reducing stress and anxiety in front of risk management and the fear of future unexpected bodily and social disruptions. Having a disease is a condition that may rearrange people's social surrounding and redefine them at the onset of a disrupted self-image. Thus, if the therapeutic procedure that follows – which is expected to re-establish this bodily and social upheaval - is granted by government's commitment to undertake the cost of such re-establishment, then patients are more likely to experience feelings of security and confidence.

Access

Two interviewees have associated access with cost indicating that cost should not be an obstacle to access and that access should be granted on an equal basis regardless of one's financial means. However, another observation could be viewed as a line of argumentation because the majority of the participants explicitly supported it. That is, access should be granted on the basis of the severity of a health problem. In line with this, there were two different directions in terms of whether age should be a criterion for access. Two participants (TMLF50 and GTAM32) argued that younger people should have priority, whereas three other participants (GTLM50, GTAF42 and GTAM41) disagreed with this approach. Interestingly, GTLM50 suggested that older people should have priority in order for the younger individuals to show respect. He resorted to comparing younger generations in the past who showed respect to the elderly with the younger generations in the present who make fun of older persons.

Apart from these more general lines, there were a few personal statements, which were noteworthy. More specifically, TMAF19 argued that people who must have bone marrow transplantation should have the opportunity to have access to other countries such as the US rather than to limit their choices to the UK and Israel. TMAM50 and TMAM55 indicated that physicians in the public sector should not have so many patients to see on a daily basis, and that access should take place in less crowed institutions. This last point associates with GTLM32's suggestion that access should be fast and effective. Finally, TMLM25 asserted that citizens should have equal access with no restrictions because they pay taxes for such a purpose.

Priorities

Interestingly enough, the priorities that have been suggested by the participants should not be explored in isolation and outside the context of the aforementioned lines of argumentations.

To elaborate, participants' perceptions of priorities directly link to the answers they gave to the previous topics, and to their prior personal experiences. In other words, the course of participants' argumentation has a specific logic or baseline which alludes to cognitive strategies and narrating pathways. These strategies are used by people to make a coherent story that preserves a continuum in their approach which touches upon issues of individual stability and the "politics of opinion". To be more specific, let us discuss some examples:

TMAF19 indicated that the priorities should lie with purchasing new equipment and employing specialists, and that there should be more opportunities in Cyprus for having other types of transplantation such as bone marrow. Finally, she suggested that associations should support people. This participant received bone marrow some years ago and she evaluated biomedicine on the basis of the lack of equipment, specialists, psychological support and correct information.

TMAM55 focused on the deficiencies observed in hospital departments, medications, waiting lists, etc. He was the person who evaluated biomedicine on this basis and asserted that the role of the state should lie with the better organisation of handling issues that attend to organ transplantation.

TMAM50 emphasised that the most important priority is to pass a new law providing for a presumed consent. This was the baseline for perceiving the role of the state and aligns with his personal experience as being registered in a waiting list for a kidney transplant. Since his mother who had been identified as his potential donor and his siblings refused to donate to him, he directed particular attention towards regulating donation from cadaver donors.

GTAF42 stressed the importance of cost and the psychological support of parents. She had some negative experiences with a physician who used ineffective communicative ways to inform her about her child's genetic syndrome, and that she did not have sufficient information about how to raise her child.

GTAF41 had a similar experience as GTAF42 because physicians did not really inform him about the nature of Down's syndrome and how to handle such a child. He suggested that the most important priority is to inform those people who have health problems.

TMLM25 talked about the severity of health problems and that citizens should pay according to their income. This sounds as if it has reasonably derived from his previous arguments about cost and access.

3.2.2. Ideas of Regulation and Collective Decision-Making

What derives from the discussion above is that participants' ideas of regulation envisage the state as the core agency for taking and implementing decisions. Also, regulation does not only lie at a macro level but also at a meso one as medical institutions are expected to renew their equipment and employ specialists in order to improve medical services. However, there is an underpinning force within these two levels: physicians. All interviewees viewed physicians' role as decisive in terms of regulation and governance, and some participants have clarified that politicians should listen to physicians. While a couple of participants have argued that reaching a social consensus would be ideal in the sense that it would make the decision more objective and patients less stigmatised, they argued that specialists should have the final saying.

We do not have enough data to secure any conclusions about why participants put so much trust to physicians but we could at least speculate on it. As discussed earlier, participants did not appear to trust politicians in health issues, and this might also relate to the history of politicians' role in the Cyprus context and in relation to the political problem on the island. In other words, many politicians are not perceived as trustful individuals in Cyprus despite the fact that the majority of the Greek-Cypriots support a political party. Even though physicians have received media attention due to some alleged medical mistakes, they still enjoy public respect. This could be attributed to a highly specialised and modern society and to the observation that the medical profession has been attributed several qualities such as "saving", "making miracles", "God", etc. Furthermore, when people get sick, physicians are viewed as and expected to be the most appropriate source of information about therapies, behaviours, and medical procedures.

Interestingly, participants were nevertheless critical towards physicians' role. While physicians are perceived as the most appropriate group of people for regulating health issues, they are described as not having appropriate skills of communication and approaching the patients. In this manner, the issue of regulating physicians' training has been raised in a less direct way and alluded to the role of the state in the sense that the state should provide for opportunities for further training in communication skills and how sensitive information is transferred to patients.

3.2.3. Doctor-Patient Interactions

As discussed above, the doctor-patient relationship was used by most participants as a baseline for evaluating biomedicine in general and for suggesting ways of regulations. Here it is useful to unpack this relationship. It was the affected interviewees who largely and explicitly talked about this relationship and they presented analytic arguments. The doctor-patient relationship was described at two levels under the theme "phrasing and psychological support".

All participants argued that physicians are the most reliable source for information and they play a decisive factor during people's decision-making process. In other words, physicians are viewed a mediators between people and knowledge, losing control and regaining control, and as conduits for re-establishing social and bodily integration. However, this general view came out of criticism.

Most participants resorted to a comparative scheme in order to argue that there are physicians who are reliable and physicians who are not. This comparison was also used in order to support the logic of their argumentation, namely that physicians are the most appropriate source of information. Put differently, "physicians" is a reliable source of information which needs improvement. The main line of argumentation has to do with phrasing test results and that some physicians do not support patients and parents of patients. To mention some specific arguments: "Physicians hide information from you"; "the room was cold, they gave us cold information. They told us 'find a relative otherwise you will be connected with a machine'"; "some physicians act mechanistically, a physician has to have knowledge in psychology and be socially educated"; "physicians do not talk"; and, "the day when, and the way, this physician told me that my daughter would be able to handle simple things was the worst day in my life". All these negative references towards physicians were discussed within a context of comparing with cases where physicians behaved as expected by the interviewees. That is, “in England, the physicians told me about the chances for successful bone marrow transplantation and the chances for failure. I appreciated that”; “I received excellent information from physician x”, “it is better to talk with physicians rather than with people with prior experience”; “the night our child was dying, physician x stayed with us all night”; “physician x encouraged us and made us succeed”; “we make jokes, our physician plays with my son, I go there and I feel better”.

These positive experiences with physicians have reduced the distance between affected people and doctors, and the health problem became more transparent for the affected people who gained more control over it. Nonetheless, the power relationship that was identified in the negative frame is identified in the positive as well. The power position of physicians is often taken for granted by ordinary people; when a physician reduces the distance between the two parties, i.e. through making jokes, part of the power is shifted towards patients and affected individuals and thus the latter produces positive feelings towards the former. However, power still lies with physicians because they rule the direction and the level of positions. This is not to say that is something negative and that it should be under criticism. Instead, perhaps it is a principle that could be applied to counselling strategies.

Lay participants used a similar comparative strategy to argue that physicians’ skills need further improvement but the comparison was more vague and was not really based on concrete examples. It took a direction like: “From what I hear, things need improvement but there are good physicians as well”. They used examples they heard from friends and relatives and tried to balance the evaluation of physicians, though the emphasis was on the negative aspect.

3.2.4. Visions of Participation

There have been observed some interesting patterns here, and the main line of argumentation is that all interviewees supported public participation. The rationale for public participation was that citizens could influence decision-making through their opinion, decision-makers could influence public opinion, and citizens could support patients and help medical institutions to deal with issues of deficiency.

Having said this, participation has been expressed in active terms and has been largely viewed as a correcting behaviour rather than as an activity without any clear purposes. However, this active participation carried an underlying passive decision towards participation. To be more specific, while some interviewees have expressed a strong interest in participating and contributing, they had not done so because they had never been invited to any discussions. Relevantly, TMAF19 raised an important issue. That is, people who do not have any health problems are not interested in participating in such issues, and she admitted that this was a common practice for her before she got sick.

Moreover, another characteristic identified from this discussion was a difference between lay and affected interviewees. In general terms, the latter argued that citizens could not be helpful in public discussions because they lack knowledge and interest and thus they suggested the participation of patients, whereas the former favoured the participation of citizens as well. This difference could be explained on the grounds of having different bases for forming an argumentation. That is, affected interviewees have used their personal experience as a baseline for viewing patients as more appropriate for participation. On the other hand, laypersons might have used ideological assumptions about public responsibility to express an opinion regardless whether it is right or wrong.

Finally, interviewees considered the participation of self-help organisations as very important but the direction of this participation was perceived differently. More specifically, most participants envisaged self-help organisations' contribution as supporting patients whereas TMLM25 stressed that such organisations could undertake the task of informing, and GTAM32 argued that they should exert pressure to the government in order to implement decisions.

3.3. Notions of Health/Illness

3.3.1. Coping Strategies

Any lines of argumentation or general patterns cannot be identified here but putting all arguments together we could talk about three types of coping strategies: (a) Body related, (b) Information providing and acquisition, and (c) Normalisation of one's health problem.

Body related

This coping strategy has to do with the practical or imagined ways adopted by some of the participants in order to change their physical appearance and thus to get the deviant uniqueness off their body. This strategy was used by TMAF19, GTLM50, and GTAM32, and touched about ways of gaining one's body back. TMAF19 argued that she would like to have hair extensions due to the fact that since bone marrow transplantation her hair grows wilder and dry and that she would like to go to the gym and train her body so to feel as energetic as before. Though, GTLM50 was not an affected interviewee, he had a problem with his fingernails (his fingernails do not grow properly and he is under therapy) and he indicated how he sometimes tries to hide his fingers in order to keep other people's eyes off his hands. GTAM32 did not have any serious problems with stigmatisation due to ear dysplasia but he sometimes stood in such a way as to make visible only the "healthy" side of his head.

Information providing and acquisition

Information is used as way to contextualise an issue or a phenomenon, redefine it, and thus control it. Within the context of coping strategies, information had a two-way direction. Firstly, it was provided or transferred to other people and this links to ways of normalisation discussed below. To illustrate, TMAF19 talks about her experience in open forums and she aims at informing people about such a common problem which might develop in everybody. This information providing aims at the lack of awareness but it also makes a health problem appear normal and frequent. Further, though it does not directly link to normalisation, TMAM50 used to feel ashamed for talking about his mother who refused to donate but now he does not have any problems with discussing his experience. This disclosure of information made this participant express feelings of injustice and disappointment and clarified that this woman who refused to donate to him is not his real mother, redefining the whole situation as normal in the sense that a "non-mother" would not be expected to donate and thus not be criticised for such a refusal.

Secondly, some participants were also information recipients. Receiving information took two directions: (a) It referred to receiving scientific or medical information through genetic or other tests. This was mentioned or implied by all interviewees, and it had to do with gaining control over one's body. In other words, scientific knowledge was a way to cope with uncertainty and resolve a problem, which has emerged or might appear in the future. More specific references or metaphors are discussed in chapter 4.

(b) Another important source of information, which functioned as gaining control over an unfamiliar situation, were people with prior experience in either OT or GT. Six interviewees explicitly mentioned the contact they had with people who had already gone through similar experiences. This contact was proven helpful on several grounds. It gave some interviewees (TMAF19 and GTAM41) correct information which changed the impression that they had in mind about bone marrow and Down's syndrome respectively. For TMAF19 this contact gave her hope about her future therapy because leukaemia may be a fatal disease. Therefore, the "visibility of life" (as she had these people in front of her alive, talking to her) made her gain some control over the uncertainty of the future and transplantation. The idea of visibility also applies to GTAM41's case because he was told that Down's syndrome was a type of severe mental retardation. When he saw another child with Down's syndrome moving and playing around, he overruled this information he had in mind, challenging physicians' knowledge and approaches. Finally, for GTAF42, having contact with people with prior experience made her realise that she was not the only person who went through this experience. This last point untangles the strategy of normalisation, which is further discussed below.

Normalisation of one's health problem

Normalisation is another way of gaining control over uncertainty and a socially deviant situation. This strategy was identified at a twofold level:

(1) The way a health problem becomes normal in daily life or the way it becomes part of daily life: Three participants expressed arguments that indicate that this normalisation strategy was at play. TMAF19 has rearranged her life in such a way as to adopt to the problem. For example, she used to wear a cap when she went out. GTAM32 has learned how to live with it and he grew up in a village where ear dysplasia was not viewed as a problem; it became part of his daily life. Interestingly, GTAF42 stressed that she now feels happy that she had the opportunity to raise a different child. She also proudly mentioned that her daughter is the best student in her class.

(2) The way a health problem is defined or understood in order to make it seem normal or purposive. There was a main line of argumentation observed in three interviewees' statements. That is, there must be a reason why these problems emerge. This was attributed to God and was viewed as a sent sufferance in order to make some people come closer to God (e.g. TMAF19 and TMAM55). However, this type of normalisation took a different direction in the case of GTAM41 who attributed his son's genetic syndrome to luck. He explained that his son may not be able to offer 100% to a society but he will offer 70%. For GTAM41, "offer" had

to do with working and thus normalised a genetic difference through measuring working capabilities and social offer.

3.3.2. Making Sense of Causes of Illness/Disease

Generally speaking, disease has been believed to be caused by heredity and life-style. However, when the question was more explicit about one's personal health problem, the perceived causes were diverse. TMAF19 used eating habits and life-style such as smoking and drinking as a baseline and stated that since she did not make any abuses she could not attribute leukaemia to life-style but to God. TMAM50 understood the dysfunction of his kidney in terms of both life-style and of an accident he had when one of his kidneys was destroyed and he had lived for years without knowing about such a problem. TMAM55 utilised knowledge he had heard from older people according to which if one has a problem with the throat and does not pay attention, then this problem may affect the kidneys. Since he had gone through such a problem in the past, he used this knowledge in order make sense of the course of his health problem. Finally, GTAM41 attributed his son's Down's syndrome to luck since he was told that it is not a hereditary condition.

3.3.3. Social Implications of Illness

The social implications of illness were rigorously discussed by affected interviewees and aligned with several directions.

The consequence of OT-related problems had an impact on the appearance of the body. Since the body had changed in a way that made it distinct and different or socially deviant, there had been observed a distance or a discrepancy between the body and the self. Some instances are:

TMAF19 used to wear a cap some time after bone transplantation in order to hide her wild and dry hair. She also compared – and still does – her body with other bodies which did not have similar problems, and she "devalues" herself (as she put it) all the time and considers other younger people as superior.

TMAM50 describes his life as being around haemodialysis and stated that when he first had haemodialysis he felt like he was finished. In other words, his body was extended to a machine and therefore was at odds with his self:

> *The first times were… the issue is more psychological. You think that you are finished, that you are not capable of living without technical support. Being connected with a machine for 4 hours filtering your blood…. I think that it is not that simple. To someone who just listens to it he/she may think that it is a game. But somebody who experiences it can see that it is not something simple… it is not like having weight to lift… it is something very abhorrent.*

Interestingly, this did not apply to TMAM50 who had a successful transplantation and received a kidney from his wife. Thus, he did not feel as distinctly different and he only confined himself to the house and limited the number of activities in which he used to be engaged.

GT-affected interviewees also talked about changes of the human body and their implications but they focused largely on the social consequences on their family as they were all parents of children with genetic conditions. More specifically, GTAM32 raised the issue of his daughter's appearance as she has ear dysplasia and argued that this difference might influence her social relations later on, especially because she is a female. GTAF42 and GTAM41 indicated that other people have sometimes opted out opportunities of contact with them due to the genetic condition of their children. Moreover, all of the GT-affected interviewees were concerned with the possibility that their genetic condition may be transferred to the next generations within the family. Finally, these three affected GT participants argued that they have come closer to their families; they have shown more love to their children and have spent more time with them. Though we don't have enough data, this alludes to the mechanisms of family solidarity, and that under personal crises the family becomes the basic social unit of conduct and identification.

3.4. Body

3.4.1. Body Metaphors

There were not explicit metaphors on characterising the body by any interviewees. However, through their answers to several questions, some metaphors have been recorded which reveal some useful insights about how the body is perceived. The body is perceived as consisting of several interconnecting parts, and health problems are located in specific body parts. This approach alludes to a mechanistic view of the human body. Specific references by some participants indicate that this is the case:

"Delete the problem": The word "delete" was used by GTLF28 when she argued that in case she had a predisposition she would take preventive measures and have any signs of the predisposition deleted.

"A predisposition or problem as an enemy": This is how a genetic predisposition and a problem were perceived by GTLM50 who stated that the self in collaboration with biomedicine would be in a war with a predisposition.

"Something rotten on one's body": GTLM50 raised the issue whether, in the future, employers might refuse to employ somebody who had something "rotten" on the body. He was not clear whether he supported such a practice but he utilised some historical knowledge about Spartans who used to kill all the sick babies under the claim that such babies could not contribute to society.

"Immuno-suppressants as protecting [weapons]": TMAM55 argued that when a new organ is transplanted, then one's organism fights against it in order to reject it. Therefore, immunosuppressants were understood as protecting the new transplant.

"A genetic condition as anomaly": This was utilised by GTAM32 to argue that ear dysplasia is attributed to mistake or anomaly in the chromosomes. While it has not been stated by this participant, it is very possible that chromosomes are understood as another independent part of the body.

Apart from these specific metaphors that were used, genetic tests were perceived as recording the internal part of one's body and illuminating the areas which need to be improved. This portrays the body as a car or a machine that may be fixed when dysfunctions occur.

Moreover, some metaphors that associated with the body in indirect ways were also used. To further elaborate, some metaphors touched upon the psychological state of the self such as "cut one's wings", "put me down", "lift me up", "the room was cold", "cold information", "teachers stab him" [about GTAM41's son who attends a classroom with children without any genetic condition], and "There are many Judas" [TMAM50 characterised somebody who said that his mother had the right to refuse as "Judas"].

All these aforementioned metaphors function as a map of understanding and organising the information people have in mind. Or, put differently, participants draw phrases with cultural meanings in order to resemble an unfamiliar situation and thus gain control over a phenomenon.

3.4.2. Locations of Genetic Problems/Predispositions

The references to the locations of genetic problems and predispositions directly link to the mechanistic view of the body as discussed above. Three interviewees (GTA32, GTAM41 and GTLM50) argued that genetic problems and predispositions are located in the DNA and in chromosomes. Unfortunately, we do not have any data that shows how the DNA is perceived. Is it understood as spread throughout the body or as located somewhere specifically, and does it function as a micro-chip that gives orders?

GTAF42 and GTLF28 argued that genetic predispositions are located in the organs that are affected or in nearby areas. For example, the former stated that the genetic predisposition for breast cancer is located in the breast, whereas the latter believed that Thalassemia mutation is found in the stomach because it is located near the womb.

3.4.3. Donor-Receiver Relationship and Family Relatedness

Though a donor-receiver relationship may not seem to relate to the body, we have strong grounds to think the opposite. This relationship has been explored in two interconnecting directions: (1) Donor's image and refusal to receive or donate, and (2) Reciprocity.

Donor's image and refusal to receive or donate

This was a general question posed to all OT interviewees and nobody argued that donor's image could play a role. In other words, OT participants would receive an organ from a compatible donor regardless of the donor's social background. However, when the interviewer mentioned specific examples, some participants' argumentation shifted attention to the importance of the donor's background and personal history. For example, TMAF19 argued that she would not like to find out that her donor used to drink or smoke because she never had such habits. TMAM50 would refuse to receive from a homosexual person without articulating any reasons. Interestingly enough, the donor's nationality was a strong factor in the decision-making process. While all participants would not have any problems to donate to or receive from a Turkish-Cypriot, two participants (TMAF19 and TMLM50) would be sceptical to receive from and donate to a Turk; whereas TMLM25 would not accept to proceed due to the hate he feels for the Turks. Suffice to mention here that TMAF19 would prefer to donate to rather than to receive from a Turk.

It seems here that while some social characteristics could be transcended when people are in need in order to survive or improve their health status, those characteristics that are deeply ingrained in a society and well embedded in people's attitudes as unaccepted or problematic could not be overlooked because they would be perceived as preserving the social and bodily disintegration. Drawing from TMAF19's statements, donating to a Turk is preferable because receiving from a Turk touches upon one's identity and the need to establish a relationship in order to reciprocate. Receiving an organ from the "bad other" would jeopardise both one's identity and the gift-exchange relationship.

Reciprocity

Apart from homosexuality and national identity of donors and recipients, there were other situations which were preferable or avoidable. For instance, while all participants argued that they would like to meet their donors and recipients and have a kind of a relationship with them, the majority of them appeared to be more likely to have contact with their donors rather than their recipients. This preference had to do with opportunity for reciprocating. Interestingly, TMLF50 argued that she would like to have a stronger relationship with her recipient rather than her donor because donating rather than receiving would better fulfil her as a person. This alludes to the issue of a protecting mother who is destined to give than to receive.

Furthermore, the issue of reciprocity was also observed in interviewees' arguments about their preferences between strangers and relatives. Three participants argued that they would prefer to receive from relatives but for different reasons. TMLF50 would prefer relatives because strangers are more likely to show disrespect. TMLM25 stressed that one feels better when he/she helps relatives and TMAM55 stated that receiving from a relative is preferable because one feels less obligated. These different approaches have a common baseline which is a dialectical relationship between receiving and giving, and this relationship is taken for granted within the family because individuals feel that they belong to the same group and thus share common elements in the body such as blood, genes, and common ancestors. In other words, the body is perceived as extended to other family members and thus there is no need to gain it back in case of donation within the family. However, the need for reciprocity becomes stronger when strangers are confronted due to the lack of perceived biological and social bonds between the two bodies, and the body is not viewed as extended. So, donation may be understood as extending recipients' body to the donors, and recipients have to gain it back. Arguably, reciprocity serves as a fabricated connection between the two parties, which helps an organ recipient to gain his/her body back though gift-giving.

On the other hand, if a family member refuses to donate then the perceived shared bonds are rearranged in a way that the individual experiences feelings of disappointment and injustice and questions the originality of these bonds. TMAM50's case is illuminating:

> *[I prefer to receive from a stranger] because I have been disappointed in my relatives. My so-called mother ... shall I say that she tricked me, she made a fool of me, she played this bad game with me? I think it is worse than this. And if she comes now and offers her kidney I will say "no, you may take it with you" [when she dies]. Because*

> *all the tests were made and she did not oppose them and actually my wife told her that if she refused it would kill me. My mother replied: "I will not refuse. I will refuse only if they put me in that black box and take me to the church". However, everything was ready for the transplantation and she refused. She told me that she changed her mind because she was afraid that I would die due to the heart problem I had at the time. So, I went to England to have an operation and the heart problem was solved. When I asked her "what do you say now, everything is ok". She replied that she changed her mind since the doctors first took some blood samples from her body in order to make the designated tests. She had to tell me back then. Then I told her that I did not believe that she really meant what she said, that the word "I refuse" is not hers. I asked her to tell me who did guide her to say these things and that if she did I would forgive her. Do you know what she did say? That, "if your kidneys went bad, what should I be blamed for?" And I said: "ok, I want one last thing from you. Please don't say again that you are my mother and I will never say that I am your son". Is this a mother? Since then, we have not talked to each other again.*

3.4.4. Bodily Consequences of OT/GT

The consequences of OT- and GT-related problems on the body produce social implications, which have been discussed earlier in this report. Here, we are discussing the medical or physical consequences and how these are perceived by interviewees. There has been observed a difference between OT- and GT-affected participants. The main bodily consequences of the genetic problems have to do with bodily appearance. That is, GTAM32's ear dysplasia has to do with changing the form of one's ear; GTAF42's daughter's undiagnosed genetic condition is of neurological nature and influences walk, talk, and appearance, and GTAM41's son's Down's syndrome relates to bodily appearance as well. However, only GTAM32 had explicitly talked about the implications of bodily consequences and argued that this problem may influence his daughter's appearance and self-esteem. For the other two interviewees, the bodily consequences were raised when medical treatment was involved. For example, GTAF42's daughter used to suffer from colds and dyspnea; two problems which were thought to derive from the genetic condition.

As far as OT-affected interviewees are concerned, the bodily consequences are immediate and do not only relate to physical appearance. TMAF19's body grows more hair than ever before, her ovaries have been burnt due to radiotherapy and she cannot have children, her hair grows wild and dry, she feels weak, her sexual need has decreased, her appetite has been influenced negatively, and her body is full of marks due to injections and the Hickman line. Though most of these bodily consequences might be attributed to medication, she perceived them as having been derived from bone marrow transplantation per se. TMAM50 argued that he feels dizzy every time he has haemodialysis, though he did not mention any other bodily consequences; he focused on the psychological and social ones discussed in sub-chapter 3.3. TMAM55 briefly mentioned the impact on one's eating habits and that the body needs to be protected from infections for a time-period of three months after transplantation. Nonetheless, he indicated the positive consequences of kidney transplantation because restrictions such as fatigue, eating and drinking prohibitions were believed to cease to exist.

3.5. Gender and Religion

3.5.1. Gender

Gender was viewed as an influential factor in two different stages: Firstly, three participants (TMAM55, GTAF42 and GTAM41) argued that women seek for more information during the initial stages of a diagnosis. The explanations given touched upon women's sensitivity and interest in learning more about such issues and the female temperament. Interestingly, TMAF19, TMAM50 and GTAM32 disagreed with the aforementioned argument asserting that both use similar sources of information.

Secondly, the majority of interviewees (GTAM32 differentiated himself) stressed that women deal with health problems in a better way. The arguments alluded to an essential biological difference between men and women, such as women are stronger and men are afraid to take risks, men are selfish and indifferent, and men retreat from the problem. This last point was raised by GTAF42 who explained that her husband spends much time working outside the household, and this is a way he uses to keep himself away from the problem. This was, at least to some extent, observed in GTAM41's case where he is outside the household for the biggest part of day and responsibilities lie with his wife. He recognised that things are more difficult for women because they spend more time with a child with a genetic syndrome. Interestingly, GTAF42 claimed that women handle a child with a genetic condition in a better way because they spend more time with him/her. Having mentioned these two cases, it seems that lack of extensive experience in GTAM41's case produces preconceptions about unfamiliar cases.

Apart from information acquisition and dealing with health problems, gender was mentioned in other contexts as well. More specifically and in a more general fashion, some interviewees believed that:

- Women pay much more attention to physical appearance than men. This was discussed in the context of a breast cancer scenario and in comparison with intestine cancer.
- Women are more willing to donate organs than men. This issue was raised by TMAM50 and TMAM55.
- TMAM55 argued that successful organ transplantation benefits women more than men because the former have more new opportunities, especially, to have children.

What needs further discussion is the observation that participants' arguments have relied upon personal experiences, and that they generalised in order to give a coherent answer. As it has been discussed in chapters 1 and 2, prior experience functions as map for organizing the information one acquires and for understanding a phenomenon. Explanations of what is observed through experience, i.e. women worry more than men, were drawn from cultural values which portray men and women as biologically different, impinging on an essentialist approach.

3.5.2. Religion

Religion was not perceived as a decisive factor during participants' decision-making. Religious knowledge has been substituted with specialised medical knowledge, and as some participants have argued, what counts is one's health and life and not religious believes about medical practices and the human body. GTAM32 argued that only the uneducated people might be influenced by religious sayings about health. In similar lines, GTLM50 asserted that religion is increasingly isolated in developed countries.

On the other hand, participants acknowledged that if religion supports, for example, organ transplantation, then more people will be willing to donate. TMAM55 used an example from religious history to support his argument that organ transplantation has been a practice since the time of Saint Spyridonas. He also explained that a religious person may be urged to donate a kidney because "since God gave us 2 we may give the one", a statement that reminds of "somebody who has two tunics he/she should give the one".

However, some interviewees used religion as a coping strategy for making sense of their health problem and for hoping for an improve of their health status. In this case, religion has been used for empowering one's self and for gaining some control over a disintegrating situation. Also, some participants (both lay and affected) indicated that health problems may bring people closer to God.

A final indirect reference to religion was made by GTLM50 who thanked God for endowing some people with capabilities of doing research and discovering. He characterised these people as "God's people". He also stressed that physicians are like Gods or act as mediators between people and God.

3.6. Thalassemia

The CY questionnaire included some national-specific questions on Thalassemia for the GT interviewees, focusing on: the perceived causes, information acquisition, attitudes about the mutation, whether the test is obligatory, and participants' relation with their family environment. Within the context of this last topic, we would like to keep the material as raw as possible without reaching any levels of abstraction or interpretation.

Causes

There were diverse arguments about the perceived causes of Thalassemia:

- Hormones abnormality: GTLF28 argued that Thalassemia perhaps develops due to improper production of some hormones.
- GTAM32 understood Thalassemia causes in terms of its perceived outcome. That is, Thalassemia is caused when blood attenuates and the affected individual needs to receive blood once a month.

- GTAF42 and GTAM41 indicated that Thalassemia is caused by the stigma. The word “stigma” refers to Thalassemia mutation and what these two interviewees meant was that when both a man and woman have the mutation and they have children, their children may have Thalassemia.

Information acquisition

None of the participants mentioned physicians or medical books as their source of information about Thalassemia. The sources that were mentioned were: friends, people who had Thalassemia, and the media.

Is the Thalassemia test obligatory?

There had been observed some interesting attitudes about the test for Thalassemia. While all of them argued that the test is obligatory for the Church and not for the state, some participants clarified that the Church does not prohibit people to get married. It asks people to have this test and if both partners carry the mutation then the Church informs the couple about the involved risks.

Relations in the family environment

Carrying the Thalassemia mutation would mean different things to different participants. Firstly, if both partners carried the mutation then interviewees would think hard about proceeding with getting married or having children due to the high probability for having a child with Thalassemia. Secondly, if interviewees carried the mutation and their partners did not, then this would only make GTAF42 think hard and would possibly change her relationship with her husband because she would possibility transfer the mutation to their children. She understands carrying this mutation as a weakness because it decreases haemoglobin and causes fatigue. Carrying the mutation would not influence GTM41 because many people carry the mutation in Cyprus and because transferring it onto one’s child does not have the implications that other health problems have such as AIDS.

Thalassemia in comparison with Down’s syndrome

In order to record participants’ attitudes towards having tests for genetic conditions, we had a question that indirectly compared Down’s syndrome with Thalassemia. GTLF28 argued that Down syndrome scares her more than Thalassemia because is not as common as the latter whereas GTAM32 indicated that he would definitely have a test for Down syndrome because he had contact with families with children with Down’s syndrome and he knows what it involves and thus he would not like to have a problem that would “hold” him for the rest of his life. Interestingly, GTAF42 stressed that children with Down’s syndrome have the fewer weaknesses. She also clarified that carrying the Thalassemia mutation is nothing compared to serious diseases.

Other

GTLM50 raised an important issue that touches upon parents’ responsibility and individual rights. He asserted that if parents knew that they would have a child with Thalassemia and they decided to give birth to this child then they should be “hanged”. This argument relates to

GTLM50's previous lines of argumentation. That is, he is the person who favours genetic tests, views genetics as the future of humanity, raised the issue of "producing" healthy people in a society and thought that if pre-natal tests for Thalassemia were available then such children would not be born.

4. Local Findings Germany

4.1. Assessment of the Applications of Biomedicine

4.1.1 Biomedicine, Genetic Testing and Organ Transplantation

When discussing the blessings and curses of biomedicine in general, or more specifically the options of genetic testing (GT) and organ transplantation (OT), interview participants relied on their personal experiences with medicine, their knowledge as well as their imaginations of the medical possibilities, and their individual benefit-calculation of medical intervention as main explicit assessment resources. Usually the two technologies were framed in a broader context of more general notions of medical development, research, and its limits. In relation to these benefit-calculations and processes of considering options for or against the usage of medical technologies, the finiteness of life was a prominent topic. That is, since both GT and OT were associated with a medical intervention into life and the condition of health, themes as the limits of prolongation of life, death as result of illness, and feelings about the meaning of illness and death for life were brought up. Living a long and healthy life is mentioned as a value here, which is at the same time critically examined, e.g. in reflections about possible medical interventions which might not be reasonable equally for all individuals, e.g. younger or elderly patients.

In their assessment of biomedical technologies the interviewees consistently classify many of their claims as individual positions, accentuating that feelings and preferences as well as decision-making and coping strategies with respect to OT and GT are very personal issues and that these decisions are highly dependent on the type of person and/or the situation that person is in. Moreover, in contrast to affected participants who reviewed their experiences in order to evaluate the direct benefits and dilemmas of GT and OT, interviewed laypersons (especially UK, VN) pointed out the imaginary, virtual frame of the discussion emphasising that they had not yet to deal with the *real* situation to have to decide and thus have only an abstract, rather arbitrary standpoint.

Transplantation medicine was mainly framed as life-saving technology. A liver transplantation saved the live of HÇ and restored the life quality of ML. Because of that both are very positive about OT, but still point out the aspect of suffering; ML stated that she would not want another liver, meaning that she does not want to go through the procedure again. Even though JB – an dialysis patient – thinks of transplantation as an unpersuasive option for himself, he experiences dialysis as positive and biomedicine generally as live-saving technology. CS has no experiences with OT, but evaluates it as positive option to save the life of others. Although VN was the participant who held the strongest oppositions against interventions as OT during focus group discussions, picturing medical technologies as critical interference into nature and the human body, he referred to the live-saving character of OT as factor why other people might be positive about it.

However, when elaborating on their position towards donation and transplantation, OT as possible medical option was described quite differently, e.g. as last chance to survive, last option to consider, problem of a small elite, or something that is no routine matter, and was thus mostly classified as a highly specialised form of therapy and intervention. Genetic testing, in contrast, was mostly framed as positive possibility of diagnosis, albeit in a more hesitant mode. IW, SD, and RP used GT as additional tool for diagnosis to clarify their condition, while UK and GA have no experiences with GT but do not principally oppose it. However, by reason of their experiences with or their ideas of GT, the limits of genetic knowledge concerning its certainty, the sense of genetic probabilities or knowing about risks of illness in advance, and the benefit of diagnosis for preventive measures or therapy were prominent issues discussed in relation to the framing and judgment of GT. Although notions of time, or rather, of present and future were raised in the context of both GT and OT when thinking about medical intervention and the temporal dimension of life, the connection of present and future emerged more often in the interviews on GT, in the sense of evaluating the idea of knowing what lies ahead of you, or engaging in preventive steps as future investment.

Compared to the more or less positive evaluation of biomedicine when assessing the possibilities of OT and GT on a general level, most participants expressed far more ambivalences, mixed feelings, and fears concerning these options and choices when touching on the complex of *personal* decision-making. This is a quite interesting finding since most debates regarding biomedical progress and possible ethical, legal, social, and cultural effects focus on *political processes* in the public domain and *decisions* in expert systems. These processes of everyday decision-making, the differentiation respondents make between underlying socio-cultural rationales in the public and the private domain as well as their theoretical implications clearly deserve a much more thorough exploration in the coming WPs.

4.1.2 Research

In the interviews, respondents often discuss their views of biomedical research and research surveillance using the broader frameworks provided by narratives of medical and technological progress. Often, participants assign different meanings to “research” without specifying the term, using a wide-ranging definition of bio-scientific or medical research. However, when not speaking about research in general, they mostly refer to genetic research and recent debates on cloning and stem-cell research in the German public and the media, or sometimes relate to pharmaceutical research concerning the improvement of drugs. While cloning is rather seen as something obscure and negative, stem-cell research is more often associated with positive aims and possible medical progress. Again, in these statements it is not so much dwelled on the respective forms of research and its specific issues or problems, but rather are cloning and stem-cell research used as broad, generalised examples when discussing research. Although many participants carefully balance positive and negative aspects of research, research is on a general level often associated with a positive meaning of developing and advancing medical possibilities. Predominantly, *affected* interviewees express an attitude of explicitly favoring research in order to be able to tap into its full potential to improve medical tools and procedures of healing diseases. They seem to be more positive and concerned about research, because they experience as patients the benefits but also the limits of current medical developments. What is more, three of the interviewees were actively participating in research: ML took part in a clinical trial testing a new immunosuppressive medicine, and SD in one clinical test of a new treatment procedure.[2] The genetic tests SD and RP made at a research unit were rather relevant to research than clarifying their diagnosis for themselves. All three shared altruistic motives of helping other patients and contributing to a research they might profit from themselves; all stressed the importance of voluntary participation and patient's consent. Even though all interview participants value the positive aims of scientific research, skeptical positions are expressed as well. In the context of trust in science/research, fear of abuse, e.g. as to the certainty of (brain)-death, is articulated. Moreover, the low degree of research transparency is criticised concerning the openness of procedures in the sense that one cannot look behind the scenes (VN, JB, HÇ), or with respect to the communication of results to the public or patients participating in research (SD, RP). Some (especially UK, CS) state that the problem is not research itself, but what is done with the results, viewing results and consequences of research as problematic to handle particularly on a societal or regulatory level. Here, but also in more positive accounts on research, the issue of research surveillance is brought up.

Overall, limiting research (at least to a certain degree) is seen as important to prevent malpractice. At the same time, however, regulatory measures intervening in research are viewed as problematic or difficult to implement. Many statements oscillate between a positive image of research, understood as progress, and the wish that (German) research is more open, and a more negative image of an unrestricted research and fears concerning the results and effects of research. To find the necessary balance between both poles is considered a delicate task, since research surveillance is pictured as complex field were different interests of politics, science, and economy meet. Opposing science and politics, it is either emphasised that the state must control research because scientists only think about their specific, rather limited research goals – aiming, e.g., for the Nobel Prize –, or that politics and the state has to provide a better financial basis for research.

While some interviewees think that science is exploited by economical interests and have reservations about the research programs of pharmaceutical companies, others stress the importance of research also as a crucial economic factor. Although some respondents criticise that profit interests regularly tend to marginalise ethical worries and that lobbyists from pharmaceutical companies have a too strong voice in politics, others prioritise the economic power of research. This antagonistic model where science serves the public good and economy serves partisan interests of a few rich, implies a quite specific position for politics: It has to function as an impartial – however more often than not quite powerless – mediator. On the other hand and contrasting Germany with other countries, concerns are expressed that Germany – due to a, as it is seen, bioethically rather restricted research policy – might "fall behind" and will be disconnected from world-wide medical progress. Furthermore, three interviewees briefly refer to the role of social sciences research, expressing their ideas about how social sciences and the humanities should become involved in these topics or might complement medical research. Again, this implicitly points to a somewhat diffuse discontent with dominant biomedical epistemologies, research prioritisations and policy relevancies; however, criticism is bound to the first-hand experience of clear epistemic limits of biomedicine, meaning that whole areas of illness-experience are not represented appropriately in biomedical etiologies.

4.1.3. Medical Progress

These thoughts on research policies outlined above are often closely related with highly generalised ideas and opinions about a desirable medical development. Contrasting the past with the present, individuals embed advancements in research in a historical perspective of cumulative progress. Referring to earlier times, and pointing at much higher disease frequencies and quite primitive healing procedures, new medical possibilities and improved treatments are clearly identified as progress. However, the mode of reflecting about advancements in medical treatments is more often than not rather subjective, embedded in biographical accounts: interviewees often relate to their own experiences with medical developments, e.g., emphasizing that they owe their life to modern medicine, or highlighting improvements of treatment in their afflictions and significant increases in survival rates. Especially those affected participants who are chronically ill stress that they experience and profit immediately from medical progress. At the same time they also experience the existing limits of medical options and point out problems researchers do not understand or do not have clear answers to yet. In alluding to epistemological problems of dominant paradigms of biomedicine, and even though a linear notion of progress is quite prevalent, the processes of advancements in biomedicine itself and its inherent discontinuities, ambiguities, and asymmetries is drawn attention to in these statements.

That continuity of development as something positive is often implied more indirectly when respondents underline the necessity for basic as well as applied research. Only GA refers more explicitly to the future dimension of progress, when stating that if she would be sick, she hopes that medicine or research will come up with something in the course of time. Noticeable, medical progress is mostly pictured as inescapable: whatever you think of it, research will go on and on, progress cannot be stopped, medicine will proceed further etc. At a first glance, this notion of unavoidability seems to contradict any possibilities of limiting research and medical developments via regulatory interventions, and it might imply a rather pessimistic view on the potential of societal influences on shaping or intervening into science.

Nevertheless, assessing medical progress in a balanced way, the participants weigh up between positive and negative aspects, specifying points were medical progress goes in their opinion beyond the limits, or should be limited. At which level limits are set and seen as imminent, alas, differs widely: ML has no great reservations to further developments, as long as no human being or animal is tortured. HÇ asks: why should progress be stopped? He underlines that research and progress have to go on, but that politics must take care that no misuse is done. Being pro-research and pro-OT, interestingly for him the only example of what goes too far is the exhibition of plasticised dead bodies by Gunther von Hagen in his exibition (which raised public debates in the months preceding the interview in Germany). Also IW considers biomedical progress as positive and necessary, and mentions withdrawn research funding as negative way of limiting medical progress. Restrictions based on debates that disapprove the aims of research she finds difficult to sustain, since "the moral thing" is a controversial issue of balancing *individual* pros and cons. For JB, medical progress is to be assessed affirmatively if it is used for positive ends – what counts as positive, however, is an *individual* assessment according to his opinion. There should be boundaries but he is quite pessimistic about the possibilities to enforce these limits in light of the unsatisfied thirst of research for discoveries and the prevailing economic interests. RP, CS and UK are more ambivalent, although they all evaluate medicine and medical progress as something that makes our lives better or has a great potential. While RP is unsure if a too liberal research policy is good or bad, she prefers not to limit developments too fast, and thinks research will make its way anyhow. In sum, there is a clear tendency in the statements of respondents to avoid generalised assessments informed by ethical certainties but rather to engage in a careful, often highly tentative moral evaluation that emphasises the inevitable *individual*, highly idiosyncratic perspective of these assessments. This readiness not only to accept the moral plurality characteristic for complex societies but – what is much more – the tendency to take for granted a thoroughgoing moral solipsism as an inescapable element of modern *Lebensführung*, clearly deserves a more intense exploration in the coming work packages.

Noting that technological innovations always will have – often unintended – positive and negative side-effects, CS is especially afraid of genetic research, the prospective of interfering into life and of the unclear directions which medicine might take. Despite the positive potential of medicine to improve and prolong life, UK questions if we really want and should live longer, particularly in the face of overpopulation in certain areas of the world and the inability to manage an appropriate care for elders. Additionally, she worries that medical developments always establish new norms which put pressures on deviant individuals to justify themselves. VN thinks progress cannot be avoided and that it is difficult to draw a line because we are already used to all sorts of progressive benefits. However, he strongly objects to interfere in human nature, since physical wear out and death are normal processes of aging and life. Medicine should rather strive for a good primary care than for a fancy research extending life. SD brings in a different point with respect to limiting developments, stating that without or with only little knowledge the public needs to know more to be able to set a limit.

4.2 Frame of Regulation

4.2.1. Organisation of Health Care

Evaluations of the German health care system and its financial aspects have to be read against the background of current public discussions about the costs and re-organisation of the public health insurance system, which in particular took a prominent place on the political agenda during the various election campaigns in 2005. In this context, it seems to be common sense for most participants that there is not enough money available for ensuring the high level of health care benefits. Restrictions in treatments and economisation of medicine seem to be unavoidable due to demographic changes and the dramatically reduced number of young people in stable work contracts that provide the financial input for the health care system catering a growing older majority. Most respondents opine that the German society is just at the starting point of a development where financial aspects will play an ever-increasing role in health care. This becomes apparent, e.g., when ML considers herself as lucky that she *still* received the expensive transplantation because in her opinion OT (for some) cannot be afforded by society in the long run. However, most participants clearly appreciate the model of a public health care system based on collective solidarity, stressing that society has to compensate financial inequalities of its citizens: everybody should have the right to get appropriate health care independent from his or her socio-economic status. There is an all-encompassing consensus that "our" solidarity system, the icon of the German post-war welfare state, should be maintained in its substance. This proprietary notion, the understanding of the health care system as "our" achievement, the understanding of the German "paritätisches Wohlfahrtssystem" as outcome of a collective success-story, lays the foundations for a culturally specific expectation for participatory rights. Here, a central socio-cultural motif and most probably a core concept of German citizenship is brought into play; again, this complex has to be explored more fully in the following work packages, esp. in the work packages five and six.

In general, the German health care model is considered to provide good-quality services, especially in contrast to other countries; frequently, the US-model is referred to as a negative example. Only CS opts to privatise health insurance completely, since she considers such a model more efficient. However, in explaining her combined model of basic and extra insurance, she nevertheless included all life-saving treatments (including OT) in the basic coverage module, and stated that children should be insured for free. In contrast, she sees cosmetic surgeries, visits to health resorts, and treatments for sport injuries as examples that should be covered through a private, complementary insurance. In her opinion, money is mainly wasted in hospitals, through everyday visits of doctors and through general drug prescriptions. At the same time she stresses that life should not be measured in terms of money and that it is hard to draw a line between necessity and luxury in the context of health care.

The issue of "squandering money" is also brought up by other respondents stating that the discussion about costs is necessary and that there should be a better surveillance of where the public insurance money is actually spend (ML, IW, HÇ, GA). Negative examples used by interviewees are the oversised bureaucracy of the health insurance, the sub-optimal organisation in hospitals and high aspiration levels of physicians. Pros and cons of private insurance models are also discussed in detail by HÇ and RP. Whereas RP worries that risk patients as her daughter might have to pay more, HÇ considers first steps of public insurance funds to allow a discount when the insured comply with preventive health measures as a positive option. Following a scheme of benefits granted for preventive individuals, everybody could decide how (un)healthy he/she wants to live and accordingly might influence the tariffs for their health care insurance.

Several interviewees examine the current situation more critically, e.g. pointing out the already existing gap in service options between patients that are privately insured and those who are in a public insurance fund. While IW views the recent health care reforms as problematic, stating that certain important drugs for the chronically ill are no longer paid for by the insurance funds, VN refers to the decreasing number of physicians in the countryside (a prominent topic in media discussions at the time) and to an increasing number of medical graduates starting to work in the economic sector, worrying that in the future there might be problems that primary care cannot be assured any longer in marginal regions of the country.

Despite the estimated necessity of financial discussion about which conditions of health insurance modern society can and should afford, several participants dislike the dominant economic perspective of evaluating cost-benefit-relations, as they are put forward by evidencebased medicine, and the framing of disease mainly as a "cost-factor". Instead, they point to costs of certain procedures and diseases and the political challenge to weigh up between benefits, alleviating individual as well as familial suffering on the one hand, and financial burdens for society and individuals on the other.

Most respondents find it difficult to actually formulate a clear-cut opinion on the question of setting relevancies and priorities for balancing individual and societal benefits. As IW puts it, the main priority should be to save lives. As to the access to treatment, criteria as urgency and medical necessity are viewed as more unproblematic than giving priority to age. UK for example finds it an alarming tendency to introduce age as priority even if it can be economically justified. She thinks of it as morally wrong, since lives should not weighed up against each other and human beings should be considered as more than a sum of processes, diseases and costs. Whereas GA is strictly against age as criteria, ML, SD and RP consider it, but very hesitantly. Referring to the discussion whether every treatment that is possible should be carried out, VN stresses that instead of economic reasons the persons' wish or will (in the sense of a patient testament) should be considered. Taking the wish of the patient into account is also mentioned by SD and RP; they emphasise that if a person wants treatment (e.g. for prolongation of life in the face of a grave health condition), this is not so much a question of age but depends on the person. Further, SD introduces a combination of age and life expectancy, but concludes that she is happy not having to decide about priorities.

Some interviewees specify their positions stating that their opinions are more an expectation or a modelling of an ideal world as it should be, but that they knew, of course, that economic reality pushes for restriction and prioritisation. The hard facts are associated here with economy, the variable facts – interestingly – with biology and the possible interventions that biomedicine provides. Further, the prioritisation and issues of social relevance are brought up by JB, UK and SD, albeit in different contexts. Relating to healthcare statistics, JB claims that only a small minority is affected by transplantation even though donation is represented in public discourse as a society-wide problem. In contrast, he notes that issues like AIDS or breast cancer affect many more individuals and thus have a much greater relevance, but are discussed at a much lesser degree. Referring to risk groups, UK considers the societal and medical relevance of genetic tests as priority if a test should be covered by insurance. SD brings in societal relevance as criteria for research funding. HÇ declares personal responsibility as possible priority (discussing health risks as skiing, football and smoking), but later qualifies personal responsibility as difficult to measure. Similarly, CS refers to the responsibility of treating your body well. On the one hand she approves of giving alcoholics a lower priority on the waiting list for liver transplantation, on the other hand she says that nobody should be left down to die because of life-style mistakes he/she might have made.

In the context of connecting lifestyle and disease, the image of boozer liver (sometimes smoking) is quite prominent, e.g. when ML regards drinking after a liver transplantation as irresponsible behaviour; instead one should handle the new organ with care. Although most interviewees think one should avoid an unhealthy lifestyle, the main opinion is that diseases can nevertheless be avoided; lifestyle thus is viewed as inappropriate criteria for restricting access to medical care.

4.2.2. Ideas of Regulation and Collective Decision-Making

Despite the conceded unavoidability of medical progress and the acknowledged necessity of research, interviewees call for a collective mechanism of decision-making and regulation when outlining their personal positions on biomedical issues. Here, as in the debates on health care and prioritisation of investments, politics in a broad and more often than not quite diffuse sense is addressed as congruous regulatory authority. Politics – understood for the most part as national governments and its institutions, is viewed as *the* central actor to decide on rules and to coordinate diverse concerns and integrate conflicting interests. Many interviewees notice that social issues and normative positions related to OT and GT are controversial; as they see it, it is not easy to account for where on a societal level boundaries lie for the majority of individuals, and they concede that it is (nearly) impossible that these individual standpoints of pros and cons can compromise with each other. Accordingly, chances for a societal consensus as basis for regulation are seen as difficult to achieve. Several respondents emphasise that a consensus would be an ideal to be strived to, but a state of affairs hardly to be reached in the social reality of modern society. The overall majority does not see any viable organisational model to organise consensus, and is of the opinion that this quiet coexistence of diverse, irreconcilable interests and conflicting opinions is what a democratic society is about. Except GA, who brings up regulational initiatives at the EU-level, all interviewees refer primarily to the nation-state level as the “site” were regulation takes place. Equally, stating that every country has different “feelings” regarding biomedical issues, GA rather implies consensual difficulties at the EU-level than within the respective societies/nation-states. As a hypothesis it can be formulated that the level of perceived moral heterogeneity and normative diversity is already considered as “sufficiently problematic” in plural nation-states, meaning that the EU-level is rather *adding* to this heterogeneity and is not figuring as a prominent reconciling actor.

While some respondents favour majority decisions as typical democratic means of conflict resolution, others favour to delegate these rather complex decisions in the biomedical realm to experts. Ideas vary, however, to what extent different actors should become involved as experts, and to what extent specific interest groups or the public are (or should be) included either in the discussion or in the decision-making process. Although all interviewees consider the participation of interest groups (e.g. patient organisations, expert boards, religious groups) in processes of political regulations as important, many point at the particular interest of these groups (JB uses the metaphor of a garden collective to underline their narrow perspective), and stress that in the end “politics” has to decide. Along these lines RP and IW criticise politics or rather politicians for ignoring citizens or for often having no clue about the impact of their decisions on everyday life. Despite a widespread generalised trust in *formal* political regulation and procedures of decision-making, many respondents disapprove a perceived lack of transparency, especially in the grey zone where politics, economy and science entangle – supposedly. JB is pessimistic about the power politicians have in comparison to the economy and the presumed tendency that politicians hide behind a smokescreen of “Sachzwang” arguments (practical constraints) referring to “Brussels” or “globalisation”, whereas GA worries that politics (and its necessary neutrality) is compromised by economic reasoning or direct lobby-interventions. Also, RP and CS mainly have reservations concerning the influence of pharmaceutical lobbyists on political decisions in healthcare issues.

Several interviewees state that in the end people who have intimate knowledge about the matters at hand should decide; however, they remain rather vague as to which experts they exactly refer to. Expertise is often highlighted in the context of political regulation: respondents held the position that "good" – that is *competent* as well as *situationally appropriate* – decisions should be taken. First of all, the list of actors seen as exhibiting *competence* starts with scientists and physicians that are thought of as competent in *issues medical and objective*, some interviewees additionally refer to patients and their specific patient knowledge, that is *issues existential*. Although the role of the Church as representing relevant segments of society is rather questioned, many consider it advantageous to include representatives of various religious groups, implying that these hold an opinion that contrasts with dominant biomedical views and as such would be able to balance the – no less biased – interests of science and medicine. Here, religion is not regarded as holding a superior ethical position, but rather as providing a counterweight for equally partisan, secular interests that otherwise might become overwhelming. Further, some respondents loosely refer to one of the two German national ethic committees as important institutions that combine scientific and moral expertise. However, "details" such as how the ethic committees actually work, what function they have (re. deciding vs. advising), or the procedures of nominating of members are mostly unknown to our interviewees. According to most statements, "good experts" are individuals that are specialists in one field but who are also able and willing to take other perspectives into account (e.g., which go beyond their scientific field of specialisation and are likely to include the level of everyday life).

Overall, skepticism shines through the interviewees' opinions concerning the representativeness of interest groups and experts. While some grant to experts the key-authority to decide, while other respondents prefer "politics" or the majority of citizens' opinion, most respondents regard a balanced triad of politics, diverse experts, and interests groups as the appropriate body for deciding on rules and regulations concerning biomedical issues. In addition, in some cases the issue of political regulation interfering into individual decision-making was addressed in the interviews, namely in contrasting interests of the state and interests of individuals. GA considers individual interests, but refers to necessary political regulations that are a result of the German "heritage" of misuses in the Nazi-time. VN strongly emphasises that politics can only set a framework of conditions but that at the end individuals have to decide for or against the use of medical technologies because it is their life that is concerned. Equally, because it is a personal issue, RP favours that genetic testing should not be restricted too strictly by the state. Prevalent is the topic of state and citizens' interests in statements disapproving of the objection solution as possible model of organ donation (JB, VN, and CS). The objection or presumed consent solution is seen as taking away the decision from the individual/citizen; CS is even shocked that such a possibility actually exists.

4.2.3. Visions of Participation

Altogether, participation of the general public in political regulation and decision-making is valued as positive and important. However, possibilities of public involvement are mainly seen in terms of electoral participation or membership in a party or interest group. This preference given to representational modes of participation comes as no surprise, given the rather anti-enthusiastic discussion of elements of direct democracy in the German (pre-)election campaigns of 2004 and 2005. Analogous to the general but ambivalent trust respondents have in experts, political regulation, politicians and interest groups, participants as well find it rather problematic to simply allocate authority to a rather ill-defined "public".

Accordingly the option to decide issues of OT and GT by the means of a referendum is mostly rejected; only a minority of respondents prefers majority-decisions. Except IW most interviewees consider referenda inappropriate, because, as they see it, the public cannot be trusted to deal with the complexity of the issues adequately, or because the public does not know enough and might vote "wrongly" as a result of manipulation of public opinion. RP rather worries about minority positions (e.g. patients with a rare disease) that might become rejected. VN is generally pessimistic about the public climate and political culture in Germany (consumer society), stating that political regulation might lack transparency and the public might not be involved, but that this will only change on the basis of public pressure. In his opinion, only a small percentage of the German population is interested; there is a lack of public discussion concerning biomedical and other future issues, and the broad public does not mind.

In these statements respondents mention two conditions precedent to participation that were further elaborated in the interviews: information and interest. According to the respondents, the will to participate depends on the interest and personal importance of the discussed matter. Similar to VN, JB also is of the opinion that the public has no major interest in biomedical topics; rather he thinks that people care more about more personal – and for the majority more existential – issues such as unemployment. Similarly, UK and CS state that there are so many relevant topics under discussion that one has to decide carefully what is personally relevant for oneself. UK even considers it as illegitimate to get involved in these debates without being directly concerned. Similarly, CS says that, on the one hand, whether rules concerning biomedicine are strict or loose is an important issue because these decisions concern her life and might affect her directly; on the other hand she declares that she has never been sick and is thus not really concerned; instead, she is by far more interested in economic topics. RP, SD, and HÇ link their own affectedness and the importance of a matter; they stress that they have not cared to think about these issues before they became interested by way of their illness.

Accordingly, a high level of personal (not abstract) information and competence grown out of direct experiences are often seen as important basis for participation or the right to have an influence on decisions. GA would like to participate but thinks it is asked too much of ordinary citizens, since specific knowledge (a much higher level of scientific education than provided by the schooling system) would be necessary. Or as RP puts it: genetic research is a hot potato, a very complicated issue. For the same reason UK favors to delegate decisions to knowledgeable experts, since in her eyes the public lacks knowledge and public discussion is on a "popular" – that is: rather naïve – level. One could sum up these positions with a quote by CS, saying that the public should be involved only on the basis of information and education. CS and RP strongly criticise that there is not enough effort of disseminating information about GT, OT and research results to the public; and if efforts are made, usually expert knowledge is not communicated in an accessible, understandable way. This idea of an "educated participation" is particularly emphasised (SD, ML, HÇ) with respect to the issue of organ donation, implying that the negative or hesitant attitude of the German public towards donation could be overcome if enough information would be provided.

JB also links knowledge and a right to decide; however, he does so in the context of doctor-patient relations. ML, IW and HÇ refer to three "smaller" prerequisites of participation: ML thinks she is not a good speaker, implicitly referring to the ability to speak up in public as condition for involvement in political/public discussions. IW thinks that intensive participation is desirable but that it is a tough job to approach politicians; it would be much more successful to have a big organisation fighting for your interests. HÇ, on the other hand, points out that many active members in patient organisations could afford to invest time to these participatory initiatives since they had to retire from their jobs due to their illness.

The concrete personal involvement or the personal importance given to actual participation varies greatly among respondents. JB underlines that it is a difference if one has an opinion or if one actually gets involved. He considers himself as a politically critical person and thinks not so good of patient organisations that do not contextualise their activities in a wider political perspective. CS suggests that you can become active in a political party if you wish to be involved, what she herself does. While UK feels unsure if she actually has an articulated interest concerning the discussed topics that should be represented, VN sees his worries taken into account and his opinion represented in the political sphere, and thus does not finds it necessary for himself to get involved more concretely. As patients HÇ, RP, SD and IW refer mainly to the participation of patients by reason of a specific patient knowledge and interest. SD joined an association of transplanted people; RP once was active in such an organisation but is today only active in self-help groups, and IW is employed by a regional patient organisation. ML and HÇ state that all they can do is tell their experiences, and what they do if asked as in the interview. Saying that she wants to be involved a little, UK points to her participation in the interview and focus group as sign of her interest and involvement.

4.3. Notions of Health/Illness

4.3.1 Making Sense of Causes of Illness

In the interviews, various explanations are given about causes (or influences leading to an outbreak) of disease, viewing sickness to be caused by multiple, partly entangled, factors. While most people think that in general various factors combine, there is a lesser tendency to interrelate these when interviewees speak concretely about their illness and its cause(s). Overall participants often refer to medical, diagnostic knowledge using phrases as "I heard/read/got attested by the doctor that". Heredity is most frequently mentioned, often not only in a narrow sense of actual hereditary diseases but also in a broader sense of *pre*disposition. For example as HÇ states that everybody carries cancer cells but that it depends on various factors if you actually develop cancer; or as GA refers to diverse incidences of cancer in her family that might also affect her. JB points out that it is unclear if he inherited the kidney-disease or if it is a result of an earlier viral infection. Although it is clear that the heart-syndrome of SD is not a result of an infection but something "inherited", she is puzzled by the limits of current medical knowledge, since it is known that it is not caused by a simple genetic defect but equally unknown as to why or in which ways it "runs in a family". With the exception of IW, who against the background of her cystic fibrosis states that she has never thought about other (non-genetic) explanations, most people also view environmental factors, living conditions and ways of living (Lebensführung), or one's personal situation, as possible reasons causing illness. For example, air pollution is seen as factor causing or enhancing a disposition to sickness. Being of that opinion, RP nevertheless stresses that in case of genetic disorders it is beyond any outside-influences how they develop and become manifest. Frequently, stress or leading a stressful life is mentioned as additional factor causing sickness, referring both to individual choices in the way of living but also as a general condition of life in contemporary society that is beyond individual influence.

Bad nutrition or other unhealthy ways of living are talked about as certain causes of sickness; however, most people consider lifestyle as a rather diffuse factor whose influence on health and illness is difficult to evaluate. CS rather speaks of lifestyle-related *injuries* (e.g., breaking your leg while skiing) than of lifestyle-*diseases*. SD notices that she smoked and partied a lot and sometimes wonders if that perhaps played a role, or if her disease might have become manifest 10 years later if not having done so. Nonetheless, she thinks of *lifestyle* as a rather speculative factor (medicine cannot tell her why she got ill), and she does not regret the way she lived her former life. RP insists that a healthy life-style is also highly dependent of income, and JB is rather insecure about what decisions to take when an all-encompassing concept like *lifestyle* plays a role in disease-development. Despite the prototypical "boozer liver", most interviewees discount a clear-cut link of disease and lifestyle. The "boozer liver" is often brought up and framed as clear case where an abuse of alcohol leads to liver cirrhosis; in these cases the respective individual is viewed as definitely accountable.

The popularity of this illustration also shows in the statements of ML and HÇ who both have had a liver transplantation. While ML declares that her illness (in contrast to an alcoholic) was not her fault because she "inherited" her cyst liver, HÇ says that he has never been drinking much alcohol and that there were other factors for developing the condition of a shrinking liver. Interestingly, he mentions that he had hepatitis B but he does not link this incident to his liver cirrhosis. Frequently, rather ill-defined "psychological factors" or "the mind" are seen as having a crucial influence on the development of disease, especially in the context of GT. Depending on the person's psyche or personality, the knowledge of a disease or a genetic risk provided by genetic diagnosis can make the person either actively facing it or provoke despair, and thus the diagnosis might become a self-fulfilling prophecy (GA, UK). Also, UK and ML see the personal situation of an individual as playing a role in the actual breaking out of disease. UK finds a possible genetic explanation for her diabetes not very plausible and refers to the personal circumstances; that is, her diabetes became manifest during a time characterised by personal stress and strains because her mother had been terminally ill. Similarly, ML states that she had indeed read that fibromyalgia can be grounded in childhood, but believes that rather the shock of her mother's death played a role. Further, she extends the accepted genetic explanation for her problematic liver. Comparing herself with her sister, who as well has a cyst liver but an unproblematic one, she says that she has never really been happy, because her marriage and various relationships broke up and she never found the "right" partner. Thus, in her eyes the (un)happiness of one's life might as well be a reason for her illness.

4.3.2. Coping Strategies

In the interviews, coping strategies are discussed in the wider context of experiences or imaginations of how GT and OT effect and (might) change the life of the respective individuals. In terms of the decision-making, if one uses the means of genetic diagnostics or transplantation medicine, as well as concerning the actual coping with the consequences of doing so, all interviewees emphasise that these are very personal issues and that the choices taken have to depend on the person and his/her situation. The involvement of family members in the decision-making and coping process is seen as problematic. Because they have no direct experiences of the illness they have a different perspective (e.g., they worry too much), or cannot understand one's decisions or ways of dealing with the issue. Overall, relatives and friends are considered as supportive and helpful; their role and contribution in the necessities of coping in everyday contexts, however, is hardly ever mentioned.

While in the context of OT physical consequences and the time after transplantation are stronger focused in the interviews, genetic testing and possible test results are viewed as issues one has to define a position on *before* taking a test. To make up one's mind is seen as difficult process of having to deal with genetic probabilities, possible knowledge of a risk and a possible future that has to be put in relation to the present situation. Interviewees believe it depends on the personality of an individual whether he/she agonises over the decision to take a test (e.g. if you want to know your genetic status or not), or simply try to accept a test result. Although UK worries that one might loose a natural relation to life, GA and UK think that as a consequence of being confronted with the finiteness of life you probably become more relaxed, live more consciously and enjoy what you have. Facing a severe or chronic illness means to know how quickly life can come to an end. Knowing that cystic fibrosis patients die in their 30s on average, IW thinks that she – in contrast with healthy people – lives more intensely, enjoying "simple" moments, e.g. smelling when walking through nature. Having almost died at the age of 30, to SD relations to friends and relatives became more important. She thinks that in general sick people are more polite because of their experiences. Although HÇ believes that you do not change in general due to the experience of a serious illness, he considers certain complaints or the bickering of his healthy colleagues as "peanuts" and irrelevant. Besides these rather positive changes of one's attitude, RP and JB additionally point out secondary effects of coping with a timeframe that is perceived as limited. JB thinks he is more impatient, while RP states you just live from day to day, do not plan anything long-term, and thus loose a certain lightness of being.

As to the actual coping with illness in everyday life, all interviewees remark that you have to accept it, get used to it, and learn to life with it. Overall coping strategies could be summarised with the following slogans: get yourself informed, take up on life's possibilities, do not give up, work on yourself and thus embed illness in your everyday life. One important strategy is to acquire knowledge about the disease, related medical possibilities, or formalities regarding insurance and your status as chronically ill person, as well as to get in contact with other patients to exchange experiences with them, e.g. in a self-help group. IW describes coping practices as balancing act between living *with* an illness and living *for* an illness, meaning that one has to comply with tedious rules and is confronted with many restrictions but that one also should not forget about enjoying life. Against this background of embedding illness in everyday life, medically prescribed routines of treatment and therapy seem to facilitate the integration of illness in everyday practices and routines. The descriptions of the interviewees reveal how regularity of therapy and medical check ups, side effects of drugs, and hygiene practices (performed esp. by transplanted patients) become a part of their daily routines. Even though they frequently invoke contrasts with healthy persons or their own healthy past, they also point to the difficulty of these comparisons in light of chronic illness and resulting restrictions displaying one's own "normality". Through everyday practice and the routinisation required by disease-management, illness-experience and coping becomes normalised and a way of life in itself (Lebensführung), which implies a whole set of necessary normative as well as pragmatic rearrangements in daily (inter-)actions.

4.3.3. Social Implications of Illness/Disease

Overall, illness is associated with restrictions, which are first of all personal restrictions concerning things one cannot do any longer in relation to one's healthy past or compared to healthy persons. Illness is viewed as something that constrains in various ways concerning the quality of life and the way one (can) live life. Typical examples mentioned by affected interviewees are limited possibilities for travel, sports, and work. Social implications of these restrictions resulting from illness seem to be less obvious but are often implied, especially when talking about illness and work, namely social isolation and the loss of social status and economic standing. The decision to continue to work is not only viewed as question of bodily capabilities to do so despite a worsened health status, but is also to a large extent integrated in considerations about changes in income and social status. ML, for example, went back to work as soon as possible after her transplantation; however, she felt continuously exhausted. In addition, she found it very difficult to establish the necessary hygiene precautions for transplanted patients at her workplace. Because of the reduced income she would have received after an early retirement, she refrained from her wish to quit her job for almost two years until she finally applied for early retirement. HÇ had the option to retire after his transplantation, but considered it an unconvincing option because of the lower income; thus, he went back to work. SD, who is working less, and RP, who is retired due to their illness, additionally refer to the (treatment) costs of illness, e.g. as RP weighs up between buying a vitamin compound that is not covered by insurance, and attending a concert. She states that her financial situation is quite settled since her husband has a well-paid position; nevertheless, she feels that her illness sabotaged her plan of returning to work after parental leave, and in a way reduced her.

In contrast, JB quit his position and started several professional trainings and jobs, explaining that as healthy person he perhaps still would work in his old job and would have never tried other things, having an attitude of "you always can do it later". In this context, JB is the only one who considers illness also as beneficial. The hygiene practices, which transplanted persons have to follow because of immunosuppressive medication, are mostly described as having personal implications; however, sometimes social implications are indicated as well. HÇ mentions that the plenty washing of ones hands may appear fussy for outsiders, and that even at his mother's house in Turkey he extra wiped the dishes and was careful with food. Or, RP talks about various invitations of friends she had to refuse because there were people invited to the diner or party who were slightly ill and thus posed an infection risk to her, or she herself could not join by reason of her own condition. Furthermore, ML and UK put to attention social implications concerning the visibility or bodily appearance of illness. ML tells that the time before her transplantation was a strain, because the cysts made her liver and belly growing big, and she heard comments as "look at the old bird, she got pregnant" while walking through the streets. Also UK refers to a "normal" bodily appearance when stating that an insulin pump had never been an issue for her because you could not deal with it discretely in public. To be able to decide whether your environment knows about the illness or not is in her eyes a "good piece of self-determination".

Interestingly, possible implications of illness for relations to family members and friends are hardly mentioned by the interviewees, even though friends and relatives are considered as support in coping with an illness. During the interviews concerning GT as topic, the issue of family planning is often brought up as consequence when knowing about a hereditary risk or disease. However, the decision to get a child despite one's genetic status or risk is considered a personal decision, and not viewed as problematic e.g. for a partnership. There seems to be a tendency to view it as better or even responsible to not have a child that could possibly inherit one's disease.

4.4 Body

4.4.1. Body Metaphors

Overall, (the) body is a prominent but at the same time quite fuzzy point of reference during the interviews. In the context of illness and medical interventions as OT and GT, body-related issues such as changes in bodily functions, in self-perception and understandings of the body are often brought up rather implicitly. Respondents frequently use metaphorical language and rather tentative forms of speech and images. ML represents her sick body using phrases such as "heavy belly", "corpulent as if pregnant", "a belly full of stones", or "sandbag" to describe the bodily effects of her growing cyst liver and her body state before transplantation. Merging her bodily appearance to the outside-world, the experienced physical disturbances as well as feelings of pain and psychological agony: All these images combine to a representation of "embodied suffering". Neither conforming to her own body ideal, nor to societal body norms of slenderness, her body became a burden she was not relieved of until transplantation. The fear of a gradual deterioration of bodily appearance following illness is also inherent in many comments of other interviewees: IW casually states that she looks quite proper for having cystic fibrosis, or JB mentions that most people would not be able to tell from his appearance that he is on dialysis for such a long time. Alike, RP refers to the phenotype or observable symptoms of Marfan syndrome as a central problem to be addressed in social encounters.

Altogether, understandings of the body are more easily to analyse in the interviews concerning OT, while the link between body and genes remains rather diffuse in the course of interviews about GT (see also next subchapter). Even though a mechanistic view of the body is prevalent in most statements, this view is hardly directly articulated but rather shines through the accounts as an underlying, taken-for-granted assumption. This mechanistic concept is perhaps most prominent in the expression of the "useful" organs in the context of organ donation, understanding "body parts" as rather unproblematic natural resource that can and should be utilised. However, VN criticises this dominant view – "dans le vrai" of biomedical discourses – because of his favored concept of a holistic, "natural body". According to this concept, one has no right to interfere with this body. Although CS does not oppose to organ donation, she brings up the image of cannibalism to designate those cases where excessive use is made of body parts of one dead body/person. Further she refers to the special quality or meaning of the heart. A frequent notion is "organ quality", referred to by JB, ML, and HÇ. While JB criticises that criteria of organ selection have been changed, i.e. more "inferior" organs are used in today's transplantation practice, ML is pleased with her "young liver", and HÇ considers his new liver a "good" one, because it fits so well and has not caused any rejection problems for 8 years.

Even though the body is simultaneously referred to as "other" and "self", the body appears to some extent to be disconnected of the speakers, or is suffering the prototypical "Western" nuclear fission when participants talk about bodily consequences and changes in the frame of GT/OT or in the course of illness: It is the *body* that changes to the worse or better, that carries a risk or a manifest threat, that includes organs that fail and one might get angry with, or that sometimes cannot be trusted or controlled. In these accounts it is the body that changes and sends out more or less difficult to read signals one has to "listen" to or has to "take care" of. On the other hand one's self has to cope with a possible body/genetic affliction, one has to undergo regular therapy to help the body keep the germs down (IW), or has to comply with hygiene rules that the new organ is not rejected by one's immune system. Language oscillates between active and passive, between a body as other / a self as an own and integrated psychophysical entity. CS, for example, differentiates between her body, which she inherited and cannot do much about, and her personality, which is more flexible and inter-active. This ambivalence and fuzziness of concepts reflects also a deep-felt gulf between objective (scientific) and subjective (experiential) perspectives. How respondents navigate between highly loaded– and often controversial – notions of self, mind, spirit, personality and body, which implicit and explicit distinctions interviewees draw between body and self, and how they blend both into a kind of "body-self", still needs further examination.

4.4.2. Locating of Genetic Problems

Genes and the location of genetic risks or "defects" are frequently perceived as rather abstract and thus difficult to grasp. If possible, affected interviewees refer to "objective" genetic knowledge; however, they often feel that it is necessary to explain these genes and their "defects" by referring to concrete symptoms. RP states that Marfan syndrome is somewhere "on the 15th gene", but locates her condition in her vessels and the vascular system. Likewise IW explains the symptoms of cystic fibrosis as being "on some 7th chromosome". However, "in the end the defect runs in all genes, sure, but it only affects certain organs". Because such genetic explanations do not exist for SD's case, she states that a genetic test presents only an idea, but she would nevertheless like to get more concrete knowledge; the broad concept of a "hereditary condition" as reason for her dilated cardiomyopathy leaves her unsatisfied. UK mentions that she currently had to explain to her little son what a genetic fingerprint is, noti-

cing that "it" is in your blood, but that it is difficult to make things such as genetic information tangible: All the descriptions in schoolbooks and images of the double helix are a nice theoretical help, but do not facilitate to grasp that in your entirety of being "you are composed of genes". However, she dislikes the idea of describing a person as mere composition of body parts, bones, tendons, and genes, stressing that a human being is more and that a person or his/her soul cannot be described solely via blood types or genetic information. Nevertheless, for the description and location of a genetic defect, she uses the image of mechanics, imagining a genetic defect as dysfunction, which disrupts body mechanics.
GA locates a genetic defect in the female and male germ cells. To explain a genetic defect she would draw a picture of genes as "drops", of which one is not okay, that is different ("quadrangular drop"). Frequently, genes are somehow viewed as imposing threats and entities that have their own life. While this notion is often used in statements, like: "you have simply to accept it", RP explicitly stresses the puzzlement brought about the fact that everybody carries something in his/her body/self that cannot be influenced or controlled. Despite various quite creative attempts of visualizing and representing, interviewees rather think it a complicated task to conceptualise and "locate" genes and genetic defects. This difficulty also becomes apparent in a manifest confusion to distinguish between a genetic risk and a genetic disorder.

4.4.3. Donor-Receiver-Relationship

Although relations between donors and receivers of organs are in most cases imaginary, nonpersonal relations, they are based on the exchange of human tissues and body parts and thus closely related to understandings of the body and social reciprocity. Donation is understood as a helpful, life-saving act of giving, for which organ receivers as ML and HÇ express their gratefulness. While ML states that she often forgets about her operation because her (new) liver is so good and her health was restored to normal, both ML and HÇ frequently refer to the relatives of their respective organ donors. ML would not mind to get in contact with the relatives, but imagines that her wish might be painful for the relatives because they would get reminded of their dead family member. Likewise, HÇ imagines a connection of sorrows: He would like to tell the relatives that a part of their dead family member lives inside of him, but thinks his appearance would renew their painful experiences of loss.

Although some interviewees state that they would like to know more about their donor, e.g. learn the name, all approve of the rules of anonymity, affirming that it is better for the coping process that you do not have any specific information. Especially affected participants take on a rather pragmatic approach to go on with life, tending to view the new organ simply as chance for a new life, a gift one should honor, be thankful for, but regard as your own. Notions of organ ownership were brought up in different ways during the interviews. While VN views organs as individual, untouchable property, others seem to imply that this ownership expires or rather becomes transferred in the course of an organ extraction and transplantation. On the other hand, the process of donation is imagined as a continuation of the life of a crucial part of the donors as in the image of "living on" that is often used in donation campaigns (CS, HÇ). In the fictive case of an organ of his child being donated, HÇ states he would have the feeling that his child is not completely dead, but at least a part would still be alive. In that imagined scenario, he would like to know the person that received the child's organ. Seeing his child through this person, he believes a part of this person belongs indirectly to him because his child is a part of him. Here, kinship relations are imagined through the exchange of body parts that in turn are conceptualised in a proprietary language. However, with respect to his *own* new liver, HÇ later in the interview insists that there is no relationship at all between donor and receiver in the sense of "you owe your life to someone, but that is all." While HÇ, ML, and SD think there exists no relationship between donor and receiver, VN thinks that a strong relationship exists by reason of the bodily exchange, but does not believe a real (spiritual) affiliation could emerge. In his eyes, nobody would become an organ donor if he or she would have a problem with a person of, e.g., another sex or lifestyle, who is receiving the organs.

In general, all interviewees are of the opinion that characteristics of the donor – be it sex, ethnic group, etc. – do not (and should not) play a role; yet, imaginations and limited information one might know about the donor is regularly mentioned. CS considers it a strange feeling and not an easy process to cope with an organ one received from a stranger. She would dislike it if a "mass-murderer" would receive her donated organs, conversely she would prefer to receive an organ from a child or at least from a person "who led a flawless life". Although she thinks that donor-/receiver characteristics do not play a role, she implicitly connects characteristic traits of a person with the one of an organ. SD has read about patients who wonder if they have received a male heart, or imagine that certain characteristics can be transferred via the organ. She regards these imaginations rather as a result of your psyche playing tricks with you or of the bodily changes and side effects of the drugs one has to take. Therefore, the sex or donor background is irrelevant in her eyes. Because of a mistake of the medical staff, ML was able to glimpse in her file, and thus knows that she received her liver from a 41-year-old man. She does not care about the different sex, rather she finds it wonderful that she received "a young liver" (she was 56 at that time) and, according to the doctors, "a beautiful liver". Young is in her eyes better, because the liver is not "worn out". She says the sex of the donor does not matter, but also states that men drink more alcohol than women, implying that a "female liver" is better because it is probably less affected by liver damages. Even though the donor background is considered as unimportant, she still looked up the given name of her donor in the Internet, wondering if it might be Swedish.

HÇ stresses that the sex or personality of the donor does and will not play a role in a situation where you are facing death: "Name me any person, the worst you can think of, I would have accepted even from this person. You have the choice, it's either you take or you die". At the same time he twice mentions that he was told that "his liver is from Czech", adding that he is not a racist. In statements where living donation is brought up, e.g. as VN ponders that he might donate in case a family member would be affected, or as JB states a possible kidney donation of his sister was not an option for him, it is also referred to the circumstance that decisions and relations are in a way more complicated. Altogether, participants rather think about dead donors than possible living donors, which seems to facilitate the application of a mechanistic body view, the value of anonymity and the wish to better not know (too much) about the donor as a person.

4.4.4. Interpreting the Body

The question of how chronically sick persons perceive or interpret their bodies in the context of illness and medical intervention is – of course – a central topic in the interviews with patients and affected respondents. While UK and GA also mention the image of "listening" to the body as possible consequence of the knowledge acquired after a genetic test result is received, the issue of paying attention to body signals frequently arises in the context of the question of how to cope with illness on an everyday basis. Concerning their well-being, OT- and GT-affected individuals rely to different degrees on a combination of auto-perception (i.e., close "listening" to body signals) and subjective experiences with "their" illness on the one hand, and an ultimate reliance on medical surveillance on the other. This shift from *Selbstbeobachtung* to *Fremdbeobachtung* (self-perception vs. observing through externalised techniques, be they simple, self-applied diagnostic tools like hypertensiometers, or complex platforms such as immunodiagnostics) creates a fundamental insecurity: Chronically sick persons regularly have to undergo medical check-ups where their body functions, their blood parameters, the enzyme levels etc. become measured and quantified applying a complex medical, diagnostic apparatus (knowledge and technologies). While they are not in command of these systems, they nevertheless gradually become experts in their own right, juggling competently with output-data of diagnostic test procedures, diagrams, and figures. During the interviews this parametrisation of self-perception and the implied transformation of bodily experience played a crucial role. In a way, as RP puts it, one is obliged to let medicine look at oneself, because auto-perception is an insufficient mode of self-perception; without the help of medicine, the chronically sick cannot really perceive or develop a "feeling" for states such as a bad blood count, an enlargement of the abdominal aorta or a possible rejection risk.

Although the interviewees describe how they tend to "listen" more closely to their "inner selves" or refer to bodily experiences, e.g. that the heart beats very fast (SD), phrases such as "you don't *notice* anything" are often used when pointing out the limits of auto-perception. These fundamental limits in the case of organ transplantation relate also to the impossibility to "perceive" of the new organ. HÇ emphasises that one cannot notice any difference: you just wake up after the surgery and are told that you have a new organ, but you cannot feel it. The same applies to the rejection of her new organ ML experienced: she states that she did not notice anything until she had to vomit and was told that this was a beginning rejection. Similarly, RP tells she is often not sure whether her problems with circulation are the result of the weather or a problem with her cardiovascular system caused by her disease.

However, with the partial exception of being a necessary substitute for auto-perception, medical tools of observation are viewed as rather limited: Not all modes of (well-)being can be measured objectively and test results cannot fully represent how one feels or perceives his/her bodily condition. Since undergoing transplantation, HÇ has a problem with forgetfulness, which is a highly subjective and circumstantial experience. He criticises that doctors do not take his problem seriously enough or consider it as possibly related to his transplantation: during check-ups doctors only care about his blood values and his liver parameters. Since there is no established "mechanism" linking transplantation and cognitive performance, his forgetfulness cannot be interpreted as "symptom" and is thus being dismissed. IW mentions that in contrast to a physician, for her test results are immediately related to her experience of well-being. It becomes apparent that medical measurements ambiguously mirror her experiences of illness. In general, most interviewees are very hesitant to claim that one really can "learn" what your body signals; the possibility of getting the right message is very restricted. For example, IW first states that you learn to listen to your body and interpret indications over the years but she later brings up a more complicated example, imagining that it can become really strange when your knees hurt, you think about rheumatism but the test reveals your rheumatic status is fine. Only JB states that he knows his body really well and would feel if something is not all right. He does not undergo the specific procedures of weighing and having the blood pressure taken before every dialysis, saying that he has it "under control".

Another aspect of misreading the signals sent by the body is brought up by UK, a mechanism that could be labeled as "intentionally generating a false negative diagnosis". She states that she anticipated that something was wrong with her before she was diagnosed by her physician as suffering from diabetes, but that she misinterpreted signs. Describing the symptoms and her soothing misinterpretation, her narration has the punch line that the quite obvious "correct medical diagnosis" was not acceptable for her in this moment in her life when she had to take care of her dying mother. In all these interview accounts of interpreting the body and its "signals", a specific vernacular knowledge of illness emerges that comprises the individual bodily perception and everyday experiences of living with illness as well as other patients' accounts, values of medical monitoring. However, this vernacular knowledge is highly "contaminated" and deeply influenced by a diverse range of knowledges (popular, popularised and scientific; taken from the general media, specialised literature, the internet, f2f discussions with other patients or medical counselling). How these heterogeneous and quite often incompatible knowledges are reconciled in illness-practices or accounts of suffering clearly deserves to be explored in more detail.

4.4.5. Bodily Consequences of GT/OT

When participants outline their thoughts on GT/OT, considerations of the body are prevalent in all interviews. However, laypersons rather refer to imagined bodily consequences in a more general frame of reference, discussing the body as being an "object" of medical intervention. In the context of transplantation, CS and VS stress that because self-healing capacities of the body fail and instead death and the body parts of another person are prerequisites of transplantation, one definitely will consider and reflect on the body differently. Similarly, UK and GA suppose that if one learns about a possible genetic risk one will form a different relationship to the body, involving present as well as future perceptions and appearances of the body. While GA especially fears direct bodily restrictions, UK worries more about bodily appearance.

In contrast, affected participants closely refer to experienced changes of their body and attitude towards their bodies after having made use of GT/OT. Particularly the "decline" of one's body is a prominent topic. In the OT narratives of ML and HÇ, bodily decline – expressed in the motif of organ failure – is a frequent issue before transplantation. OT helped them to re-establish a certain degree of normality: to live with a normal functioning body and liver (HÇ), to get rid of restrictions concerning the movement and appearance of one's body (ML), and concerning the level of energy to go back to work or do sports. Above and beyond these positive bodily consequences, the pervasive negative side effects of taking immunosuppressive drugs are described as a “price” one has to accept. Severe consequences for body-practices encompass regular medical and daily individual surveillance of body functions, rigid hygiene rules, personal as well as social restrictions; HÇ experiences declining body functions by reason of taking strong medication since 8 years.

The non-OT-affected interviewees picture bodily decline rather as process with respect to the course of their illness. Although she is better at the moment and experienced how therapy could stop her body’s decline, SD knows that she will need a heart-transplant in the long run. Transplantation is for SD and was for RP one crucial consequence of their hereditary diseases. Concerning the decline and vulnerability of their bodies, all interviewees emphasise the importance to take good care of one’s body. IW made the genetic test to know if she has the light, medium or hard course of cystic fibrosis and thus to be better prepared what lies ahead of her. Overall, to take care of the body means to live a healthy life, act in accordance with the rules and guidelines that are set by doctors, and closely observe and “listen” to your body. More concretely, this meant for IW to take therapy more seriously, that is to inhale regularly, do all the exercises, etc., in particular since the test revealed that she has not, as she thought, the light course but the medium-course of cystic fibrosis. JB stresses the significance of being physically fit when your body declines that easily. He points out that he always did sports, even though doctors prohibited sports in the earlier days of dialysis, an attitude that changes at the moment.

As noticed in the subchapter on social implications of illness, bodily consequences of illness as implications and circumstances of being chronically ill become incorporated in the everyday practices and routines of affected individuals, and thus gradually become a “normal”, integral, non-focal part of life.

4.5. Doctor-Patient Interactions

4.5.1. Doctor-Patient Relation

As skilled patients, the affected interviewees interact frequently with a variety of physicians and medical professionals – in RP’s words, “you have to deal with doctors constantly”. IW even states that she somehow grew up with doctors, and RP declares that she is so frequently a visitor at the Heart Institute that her presence there is virtually taken as a given as is the furniture. Against the background of their experiences with physicians and ideas of how doctor-patient relations should be, participants (including laypersons) bring up different roles or functions of physicians. First of all, physicians are mentioned in their function as healers one turns to trustfully for diagnosis, check-ups, surgery, therapy and general advice. Further, physicians are considered as important advisors for clarifying questions, providing and explaining all sorts of information concerning disease and its treatment. In addition, doctors are pictured as researchers, as part of the health care system, or even as experts in political or ethical discussions. Being professionals, they are further viewed as representing a distinctive perspective that is often helpful but can be conflicting with one’s own perspective as well. ML, for example, states that her doctor was in the beginning not convinced that the transplantation she longed for would be necessary at all. Not until the doctor came to the conclusion that liver punctuation, which for ML was straining and only a small relief, did not make any sense any longer, she was assigned to a transplantation centre. Here, not only different judgments of doctor and patient are brought up, but also the aspect of patients depending on their physicians' evaluation. The difference of perspectives and the fundamental dependency is also stressed by other patients, for example when criticizing that doctors know about diseases, treatments and surgeries only in an abstracted mode, but do not have experienced suffering themselves. As to coping and clarifying what it "really means", many patients turn to other patients' experiences via self-help groups or internet-reports. At these forums names and addresses of more perceptive physicians are often exchanged as well.

During the interviews physicians are regularly evaluated by means of comparing them with other physicians one had to deal with at another place or time. As an exception, HÇ even referred to an international statistic of transplant surgeons and survival rates of patients they operated to prove that his surgeon performs really well. The crucial issue of evaluation is also brought up by JB: You either have to inform yourself beforehand about a clinic (try to gather objective data) or you have to go there to get an impression and guess if it is a good or bad clinic (a subjective, and therefore questionable, substitute). He thinks that many patients still assign a higher and somehow superior status to physicians and criticises that most individuals are more suspicious and careful when turning their car into a repair shop than when turning themselves into the hands of medicine. He stresses that one should have a healthy mistrust in physicians and be cautious in relation to the medical system. Concerning the issue of trust, the interviews (especially those with patients) reveal a strong differentiation between a general trust in physicians and medicine and a specific trust in a particular physician: most interviewees tend to be much more skeptical and cautious with the former, and more trustful in the latter.

However, in the interviews also a notion of a kind of "trust imperative" appears as pervasive motif: The necessity of trust as a basic element of social interaction with experts and when one moves into the realm of medical care. The evaluation of a physician and his performance as well as the necessary trust in a doctor more often than not relies on a – more or less – educated judgment of the *social* interaction with a doctor, i.e. to what extent the patient has the feeling to be understood and informed properly by the doctor.

4.5.2. Knowledge Practices & Power/Knowledge

In general, there is a strong belief in and a positive evaluation of professional medical knowledge. When positioning themselves as patients with a specific disease, patients often rely on medical categories; e.g., explaining things by paraphrasing their doctor's comments and using "official" expressions. In an overall tendency it is apparent that to have information symbolises having – and to some extent creating – security. Yet, patients mobilise the temporal depth of knowledge created on the basis of their more or less long experiences with medicine and the health care system to relativise the "truth-values" of medical knowledge. Particularly genetic knowledge is seen as of rather limited importance with respect to representing tentative, statistical information and not hard facts. In this context, especially genetic or risk probabilities are viewed as rather unsatisfying information that is difficult to handle. Although participants stress the importance of individual decision-making, probabilities provided by physicians are considered more mystifying than helpful. Furthermore, patients raise the issue of individual doctors having only a certain amount of knowledge and information, either being general physicians (too general knowledge) or specialists (too detailed knowledge). While IW who has the same doctor since childhood states that her doctor often knows better than she herself does what is going on, indicating that her doctor incorporates not only medical information but also patient experiences in his overall knowledge, JB describes situations with young physicians or specialists in dialysis centres he visited in his holidays, stating that it was essential that he did exactly know what was going on. He refers to both, the knowledge he holds due to living with dialysis since 27 years, and the knowledge he acquired through educating himself on various disease related issues: especially chronically ill respondents show a thorough-going level of self-education that afford them with the ability of a critical evaluation of physicians and the competence and stamina to actually choose their doctors. Here, the experienced pervasive dependency on expert knowledge is – at least to some extent – assuaged.

Overall, most interviewees are critical concerning doctor-patient interactions. While they clearly prefer a dialogic model of reciprocal learning and exchange, actual doctor-patient interactions are often criticised with respect to what information is given and how it is communicated to the patient. Thus, many patients consider it important to get additional information, not only with respect to their individual coping strategies with illness, but also to have a better standing when communicating with doctors. At the same time some respondents refer to the limited latitude of the health care system or the working conditions of doctors that do not provide doctors with sufficient options for explaining issues to patients in detail. In this context, especially RP and SD stress that one more often than not has to urge doctors to provide more information or the information one wants to have. RP thinks if you have good or rather relevant questions and do not just want to small-talk, doctors will take time to explain things to you. Whereas SD claims she always had to take care of it herself, e.g. asking doctors about their opinion of her participation in a clinical trial testing a new procedure, that is asking them “you [doctors] know this, I know from this medical congress about clinical research that you know this method – can I [SD] do it?”.

JB explicitly refers to the German concept of a “mündiger Patient”, which refers to a well-informed and self-determined patient as a crucial element in a functioning doctor-patient relation, a patient that decides and judges autonomously and whose judgments and decisions are respected. This concept includes the patient’s right of say and assigns to the patient an independent role. However, JB notices that despite the increasing discussion of this concept in the medical sphere, most medical professionals do not know how to actually handle a “mündiger” patient. While JB is the interviewee who puts the strongest emphasis on notions of “taking things into one’s own hands” and being independent, notions of an “active” patient appear frequently in most affected participants’ accounts. To become an active patient comprises various things for the respondents: It means to be willing to learn, to invest time to get information and self-education, in order to be able to handle such different information as medical diagnostics, figures, professional articles, dealing with forms provided by the insurance bureaucracy, and individual inferences of other patients. It also stands for not simply conforming to the doctors’ prescriptions but to participate in crucial decisions regarding therapy, e.g. suggesting new treatments, urging for a certain therapy, a different drug etc. In addition, it can mean to participate in research or clinical trials or to become a member of a self-help group or patient organisation. The figure of the active patient reveals not only aspects of expanding or re-gaining independence but also quite demanding aspects to the patients' capacities to learn, to be reflexive and to speak up for oneself.

4.6. Gender and Religion

4.6.1. Gender

Issues of gender/sex are not mentioned very often in the interviews but if this is the case, gender and sex as categories are employed or referred to in a rather broad sense. The topic is brought up in very different contexts in a rather implicit or incidental way. Overall, gender/sex is not viewed as an important rationale for decision-making and coping. Interviewees rather stress that it is rather the personality of the individual patient that is important, meaning that every person – regardless of his/her sex/gender – thinks differently. This individualistic approach might to be expected from patients that deal with a medical system that sails under the banner of individualised medicine. Although IW states laughingly that men think differently, she thinks one cannot differentiate between specific attitudes because, e.g., all (male and female) cystic fibrosis patients have different perceptions and perspectives. Only RP thinks that men handle illness differently, either suffering extremely or resisting. Referring to other patients with Marfan syndrome, she says that there are hardly any men who accept a diagnosis and deal with its consequences, but that most men do not want to have anything do to with it. Life-style and sex are only linked by ML when she notices that women drink less alcohol than men, indicating that a liver of a woman thus might be less risky in terms of liver damages.

As mentioned earlier, the sex of a donor or any other characteristic is not considered to be a relevant factor in the context of organ donation and transplantation by the respondents. Issues of bodily appearance or visibility of illness are mainly brought up by female interviewees. Related statements seem to indicate that visual questions are more relevant to women than to men. This understanding is present as UK associates breast cancer and breast removal in the context of societal body norms, or as ML describes her bodily situation before transplantation, but is also implied in smaller statements as SD articulates that the information that you gain weight after transplantation because of the cortisone is “very interesting for a woman”.

An additioinal aspect is the association of women with a more “caring” attitude. This notion especially appears in female interviewees' accounts arguing from a perspective of a woman or mother in the context of caring for or worrying about children, other relatives, or family planning. In a way this notion also appears in all the small references HÇ makes concerning the involvement of his wife in the coping process. In total, gender/sex seems to play no great role or seems not to be considered as important factor in the issues discussed during the interviews. Nevertheless, this “invisibility” or “black-boxing” of gender should be further scrutinised, as well as the question of how mentioned ideas of sex/gender could be put in a more coherent perspective in the context of biomedicine and its related issues.

4.6.2. Religion

Overall, interviewees express that in general, or specifically in terms of their illness, religious beliefs do not have any influence on their personal decision-making. Nevertheless, they think that religious beliefs can function as rationale for decision-making and coping. Religious beliefs are mainly assigned to "others": "really" religious people as Catholics or Muslims. It is often assumed that religious beliefs oppose scientific matters and a positive valuation of biomedicine, and that religious persons are more likely to disapprove of organ donation, transplantation, genetic testing and genetic research. Yet, usually they do not know what the position of the respective religion or church actually is. Except CS who considers herself as rooted in church and religion, interviewees describe themselves mostly as being not religious. However, most grew up with a religious family background or socialisation, and loosely assign themselves to a religion. Further, most participants think that religion and church play a great role in society. UK, for example, views Christian values as closely linked to our culture. Although VN thinks there is a strong link between ethics, morals and religion, he dislikes the Church and would rather refuse something because of ethical or moral reasons than because of religious reason.

In general, religious beliefs are understood as a system of values that have an influence in our society, and some refer to the positive presence of religious representatives concerning public discussions and political regulation of biomedical issues. ML and RP refer to friends or other patients to whom religion seems to help in coping, but for themselves they both consider religion as irrelevant. RP actually states that she became non-religious through her disease, explaining that she found out that only she herself could make things happen. She considers the idea that someone (God) is leading you as "gibberish" and church as "just a big fuss, a spectacle for people, that's nothing but a big show in the end". Although she disapproves of religious ideas as predestination, her statements on genetic defects as non-controllable threat include a certain idea of predestination. JB claims that religion plays no role for him concerning the dealing with his illness, yet against the background of his life's journey he believes that "there is a certain destiny", or rather "a certain path carved out for us". HÇ says in the same breath that he is not religious; he is a German citizen, and a Muslim; however, he has nothing to do with religion, meaning that he is for example not going to the mosque. His linkage of religion and citizenship might appear a bit unusual at first glance, but might be explained by the situation that in Germany Turkish migrants are often automatically thought of as being very religious Muslims and no German citizens. Muslim means here more a cultural affiliation, similarly to the linkage of Christian values and German culture UK employs. Further, HÇ remarks that he believes more in the human being itself and the idea of people living together in harmony than in religion.

Altogether, it seems that during the interviews ideas of human life, death, dignity and human nature are more discussed in a frame of individual beliefs than in a frame of religious ones.

5. Local Findings Sweden

5.1. Evaluation of the applications of biomedicine

5.1.1. Biomedicine in General

The interviews on GT and OT as specific technologies often evolve around a wider complex of biomedicine (in terms of e.g. medical progress, medical research, and one's experiences of medical service in general – especially for those interviewees with no personal experience of OT or GT). Overall there is a tendency to put great trust in modern medicine, and as a result biomedical techniques are often highly valued. People are willing to use the means available to improve their health – as long as the benefit of the treatment outweighs the risks or the suffering it causes. Thus, the valuation of biomedicine is – amongst other things – based on a relation between the estimated risks/harm and benefits. A medical procedure has to be considered worth undergoing in order to be justified, and this means that medical interventions used for less urgent or non-medical conditions (e.g. for cosmetic purposes) are often criticised. New medical techniques make it possible for us to improve not only our health but also our lifestyle and our appearance, through e.g. diet pills and medication for increased potency. These non-medical measures are not condemned but generally given lower priority. Thus, two categories of biomedical interventions are produced: On the one hand cosmetic/enhancing measures, and on the other hand urgent/illness-related measures. Whereas the first one is not always seen as a human right and a property of public organisation, the latter is unanimously perceived to be a public concern as medical care is a fundamental right for every individual.

The right to care is nonetheless understood as an option rather than as an obligation. Recurrent rationales in general discussions on biomedicine and medical treatment are the patient's/the individual's right to integrity and self-determination, in most cases materialised as some kind of informed consent. This means that no person should be subjected to treatment against his/her will – an argumentation frequently brought up in the interviews, last but not least with regard to old age care and life sustenance. The increasing possibilities to prolong our lives through medical technologies generate new questions about human dignity and life quality. Several interviewees refer to experiences from care of elderly parents and acquaintances and strongly reject the idea of sustaining life at any price.

5.1.2. Research

The interviewees' use of the concept "research" is often vague and undefined. It sometimes refers to personal experiences of being subject of research (for GT patients such as A4F, B4M, and A6) but mostly describes the idea of new medications and medical techniques being developed by a similarly undefined group of "experts" (including doctors). Research activity is also attributed to pharmaceutical companies, which are perceived to be financially driven (unlike doctors). Discussions on research and medical progress are often intertwined with notions of economy, financial limits in medical service sector, and the profit interests of the pharmaceutical industry.

Although rather imprecise and sometimes criticised for being financially driven, the understanding of research is generally positive and research is perceived as valuable in itself. There is, however, a distinction made by several interviewees between research as such and the application of research, whereas the latter gives rise to a more critical approach. Thus, research as such might be good and necessary for medical progress, but the precarious matter is which findings to bring out in public.

In order for research to be acceptable, one could impose certain restrictions or rules.[3] In the interviews there are two main standpoints: The first emphasises the need for some kind of restrictions according to ethical rules and the second claims that research itself should/could not be limited but that the application of research should be somewhat regulated (see discussion in subchapter 5.2).

According to the first point, there is a more or less clear line which cannot be crossed in order for research to be acceptable. The distinction is much the same as was shown in the approach to biomedicine in general (risks vs. benefit) and is mainly based on the perceived usefulness (life-saving/life-enhancing potential, medical vs. non-medical interventions) of the research in question. Cloning is here a frequently used example of a technology which is generally not justified; its medical value is clearly doubted at the same time as the societal risks in producing identical individuals are seen as fairly high. But the rejection of research on technologies such as cloning is not only caused by lack of medical usefulness. It is also a consequence of its inherent “unnaturalness” – the technology is perceived as opposed to “natural” modifications of the human body. This perspective could be identified with several interviewees, but is mainly emphasised by A6. To her, naturalness is a strong rationale for what is to be seen as tolerable: The human being has to be the way it is and it should not be modified by e.g. altering genes. (However A6’s understanding of cloning is blurred with perceptions of other medical technologies, mainly reproduction technologies such as artificial insemination, which makes her argumentation somewhat mixed up).

The second standpoint refers to research as much of an automatic process happening irrespectively of human agency. Research could not be restricted as it “wants to continue” (A2), and what could possibly be limited is the application of research findings.

Interviewees of both approaches share the same idea of us all the time being gradually used to new (medical) technologies. For this reason it is important that research/development is not being rushed, but that we manage to accommodate. From this point of view restrictions and regulations are merely flexible constructions providing us with time to adapt to new discoveries and techniques.

5.1.3. Medical Progress

Medical progress is a continuous process and a direct consequence of successful research. Discussions on biomedicine presuppose a linear and chronological medical development where knowledge about diseases and thus therapies are regarded as being constantly improved. An historical perspective is inherent in some of the argumentations (medical care is better and more adequate today, and more things have been given medical explanations) and a future perspective is perhaps even more frequent when discussing development and medical progress.

The historical perspective is especially present in A7's discussions from an evolutionary biologist's point of view. Today's advanced medical technologies make it possible for us to save many lives and thus the natural selection of former days is eliminated. Since we now can make people survive for so long, A7 claims that we need to invent categories for social selection, e.g. classes, and that genetics might form a basis for this social selection as well.

Future prospects are dominated by the idea of a continual development, which means that medical technologies are believed to become even better as time goes on.[4] Perfecting the human being or creating an ideal person is depicted as the ultimate objective of medical progress. This applies especially to progress in genetics and genetic technology and it is not only a good thing. Even though great faith is put in the continuous development of certain medical technologies, there is a simultaneous concern that they could be misused on a societal level or that medical discoveries will be used for purposes we cannot even imagine today.

5.2 Frame of Regulation

5.2.1. Organisation of Health Care

The overall impression from the interviews is that most interviewees are content with the Swedish health care system as an organisational whole. This applies to affected as well as laypersons; whilst lacking direct experience of OT/GT, lay interviewees often draw on personal experiences from other encounters with medical service.

Images and ideas of the organisation of health care mainly rely on a perceived opposition between financial interests and the values underlying medical care. Medicine should ideally stand free from profit interest and financial involvement at all, as it is seen as incompatible with its foundational principles of altruism, everyone's equal rights and the benefit of mankind. One clear example of this is organ trade, which is categorically rejected. Organ trade, especially when organs are removed from people – mainly children – without their consent contests the autonomy value as well as the principle of medicine as isolated from financial interests.

All interviewees tend to condemn organisational models, which distinguish rich people from poor by offering better medical service for those who can afford it. Everyone's equal right to treatment and care was previously mentioned as a fundament in perceptions of biomedicine, and this should be irrespective of each person's financial situation. Most interviewees agree that not even people who caused harm by themselves (e.g. smokers) should pay for their own treatment. Arguments in favour of this approach point to the impossibility of drawing a line between a harmful and a non-harmful lifestyle but also to the fact that smokers have been paying their taxes, too.

The separation of medical values and profit interest results in the favoring of a public health care system instead of privatised health care. A system where everyone shares the costs (by paying taxes) is believed to offer equal opportunities as well. The Swedish organisation of health care is highly valued in this respect. Several affected interviewees claim that they would never be able to afford their treatment or even their medication if it had not been governmentally subsidised and most of them adopt a collective approach: We are all in this together and we should all contribute some money – we might even need it ourselves in the end. The collective approach could on the other hand be seen as a compelling imperative as well; for example, A3 describes his feelings of being a burden for society as a patient. The need to go back to work in order to pay taxes again is underlined in a few of the interviewees' statements.

The high valuation of a publicly financed health care further means that private health care is often discussed in negative terms. The US is sometimes mentioned as a frightening example. A system in which people pay for their own health insurances is believed to be very unjust, as only rich people can afford adequate treatment. This additionally means that poor patients will end up as burdens for society anyway since they have no opportunity to recover. The only situations wherein private financing might be regarded as a good option is when you receive medical care in a country where you have not been paying any taxes (A7) or when you subject yourself to cosmetic or non-medical interventions (A4). On the whole there is a vague fear that public health service will decline even more in the future (as it already has), and that a privatisation will result in e.g. medicines becoming more expensive.

The distinction between medicine and economy and the perceived incompatibility between ethics and financial interest are further depicted in the relation between pharmaceutical industry and public health care. Private pharmaceutical companies are financially driven and their profit interest is somewhat criticised (they exploit people's worries about health) but they are nevertheless described as important agents that we cannot do without. However, a clear line is drawn between this financially driven industry and the public health care, which is perceived to be altogether good and neutral. Once again it is argued that medicine and economy are two categories ideally kept apart – e.g. doctors should never "be bought" by the pharmaceutical industry (A4).

In reality, though, even public health care is dependent on financial means, and costs are taken into account when evaluating different treatment methods and research. How resources are/should be allocated (prioritisations within society and the medical service sector) was one of the local-specific questions posed in the interviews, and thus prioritisations became a prominent topic for discussion. These could mainly be outlined as socio-economic, medical, and GT/OT specific prioritisations, whereas the first category is an overarching classification stating how resources should be distributed to e.g. health care, educational system, and infrastructure. On this level several interviewees call for more money to medical service; only A2 actually holds an opposite position as she requests more money to be invested in young people and less in medical service.

Medical prioritisations in general should, according to most interviewees, be based on a principle of urgency – i.e. the one most in need should be given priority over the others. This further entails a distinction between medical and non-medical conditions or interventions as described in subchapter 1, and conditions which are not perceived as immediately medical should be given the lowest priority – if dealt with at all in medical service. The prioritisation of certain treatments above others is also a matter of costs in relation to rates of succeeding and life expectancy. E.g. A2 questions the legitimacy of transplant surgery as it is a very expensive operation, and the money might instead be used to increase the life quality of a large number of patients suffering from less severe diseases. What is mainly doubted, however, is so-called life-maintaining or life-sustaining care. Even if the main arguments here concern human dignity and self-determination, the financial limits and thus medical prioritisations are also part of the motives.

The OT-specific prioritisations primarily regard decisions on the allocation of organs (which is not only dependent on the amount of financial means but also on the number of organs available and thus nevertheless on the societal organisation and regulation of medical issues). The OT-affected interviewees tend to stress the hardships of coping after the transplant and the need to be able to “look after oneself” as regards e.g. the handling of medication and taking care of oneself and one’s body. Thus, the ability to cope after the transplant is seen as the major rationale for allocation of organs and thorough investigations are performed prior to the transplant in order to find the persons most likely to have a successful treatment. The coping ability as a criterion means that some people might automatically be sorted out, such as drug addicts, alcoholics or even smokers. The attitude towards diseases caused by these kinds of lifestyles varies between the interviewees. Although all of them agree that people suffering from lifestyle diseases should have the same right to treatment as anyone else, several interviewees claim that they would give lower priority to these people (and doctors are often believed to make this decision as well).

GT-specific prioritisations are not explicitly discussed in the same way as OT or more general medical prioritisations. However, A5 presents a specific standpoint here, as he strongly argues that testing for diseases where no treatment is available should not be prioritised and preferably not handled at all in public health care, as it should only deal with curing diseases.

Age is frequently mentioned when discussing medical prioritisations as well as the allocation of organs in OT cases. Age is by all interviewees seen as one of several grounds for giving priorities; however, they position themselves differently in this issue. The most common standpoint is that the urgency of the disease, the physical shape of the body or one’s ability to cope after e.g. a transplant do not always coincide with one’s chronological age which consequently should be of lesser importance when giving priorities. A contesting approach is that age as a rationale for transplant prioritisations also links back to socio-economic prioritisations: from a socio-economic point of view it is more beneficial to treat a younger patient. Thus, according to this approach, research as well as medical resources should principally focus on young people (this approach is notably held by two of the oldest interviewees).

5.2.2. Ideas of Regulation and Collective Decision-Making

As discussed in subchapter 5.1, research is generally perceived as valuable and beneficial as long as it (or its applications) is subject to some sort of restrictions and regulation. Such restrictions should be based on ethical rules for what is acceptable or not acceptable in a specific historical and cultural context. Inherent in several interviewees’ argumentations is science as innately opposed to ethics (i.e. people’s ideas of what is right and wrong) and therefore limits should be set by e.g. politicians. The line between the ethically acceptable and the ethically unacceptable often corresponds with the line between what is perceived as natural and unnatural or between medical and non-medical/cosmetic interventions, but also between medicine and economy. An even stronger rationale for acceptance might be respect for personal autonomy – e.g. research such as during the Nazi regime is condemned. However, it is difficult to outline the exact underlying rationales, as the interviewees in most cases simply call for "ethics" and "ethical rules" without further specification. One of the main reasons for imposing restrictions is also the fact that we all need time to accommodate to the thoughts of new technologies and new medical discoveries; thus, the regulation has to be flexible to allow for changes in time.

Ideas of regulation regarding research as well as the organisation of health care mainly range between two different approaches: Partly there are interviewees stressing political regulation as the only strategy; partly there are those seeing expert governance as a favorable solution.

Political regulation and supervision is by many interviewees argued as the only way of actually imposing laws and reaching agreements on restrictions. Decision-making and legislation are seen as part of politicians' responsibility. Elected politicians are described as representatives of the people and interviewees holding this approach tend to have confidence in politicians and in the Swedish political system. Politicians are assumed to have the ability to acquaint themselves with the issues necessary in order to make the right decisions, and they should work on regulations mainly on a broad level. This attitude of trust in politicians comes along with skepticism towards experts, based on a perceived opposition between science and ethics. Experts such as scientists are believed to go at any length in order to come up with new discoveries, and political government is therefore needed to impose a proper regulation.

The opposite of political regulation is expert governance, which is strongly argued by the GT-affected interviewees A4F and B4M. The "expert" concept links together with a broad sense of the concept of "research" and involves mainly researchers and doctors. Doctors work close to the patients and are therefore likely to be seen as active in the organisation of health care issues on a practical level. Significant for this approach is that politicians are distrusted and not believed to have anything to do with health care, neither financially or legislative. Political distrust emerges partly from cutbacks and a subsequent decline in Swedish health care and, unlike experts, politicians are described as isolated from reality and real life.

Between these two opposite poles there is a range of argumentations on how regulation should be organised. The most common approach is one that emphasises political legislation as necessary, but that it should be based on consultations with groups of experts knowledgeable in the field. Questions having to do with practical care situations (e.g. the allocation of organs) could be handled exclusively by medical professionals. However, it is important that in such situations decisions are always collectively made in teams so that no single doctor has to take on this responsibility alone. This is also believed to make the decision-making less arbitrary (especially argued by A2 and A8).

A specific form of research governance is ethics committees, mainly brought up by A8 who works herself in the medical field. Ethics reviews are here described as the favourable way of supervising and regulating research in general. However, globalisation is by some interviewees presented as a problem in the sense that it would take an international agreement for the legislation to have any effect, and it is considered quite impossible to reach such a settlement.

The regulation of GT and OT as specific medical technologies is discussed from a more detailed perspective. GT regulation would mainly serve to prevent misuse of the test results. There is a fear that society will develop in unexpected directions, thus allowing new applications of GT of which we cannot yet conceive. Notions of the risks inherent in GT mainly refer to a perceived correlation between eugenics and GT and thereby its potential to become an instrument for controlling and designing populations. More current risks of GT are linked to the contexts of employment and insurances (e.g. A4 herself has experience from difficulties in having an adequate insurance for her haemophiliac son). This calls for political regulation to prevent genetic discrimination – genetic information should not have to be transferred to e.g. insurance companies.

Discussions on OT regulation, on the other hand, are more concerned with the different ways of organizing and regulating transplantations and donations. The main part of the interviewees does not recognise the presumptive consent model (i.e. they do not know exactly what the law says about who can become a donor). However, when explained, it is a solution approved of by all interviewees, as it is believed to produce more organs than a solution for which an explicit consent would be needed. The main objective of OT regulation is to facilitate the taking of organs and thus to increase the number of donors. However, there are some alternative suggestions made by the interviewees: A2 would like to see a conditional solution where you have to approve of donation in order to be able to receive an organ (an argumentation based on ideas of reciprocity and fairness). A3 would like to make donation compulsory – the individual should have no choice after his/her death. A8 emphasises euthanasia as a way of getting hold of more organs and, similarly to A9, she also slightly questions the family right of veto as it is in most cases thought to be a hindrance to donation.

5.2.3. Visions of Participation

The visions and understandings of public participation are quite varied. The interviewees emphasizing the need for political regulation consequently point out electoral participation and political activism as the main strategies for public participation. Participation is often described in quite passive terms, which means that it presupposes an invitation or a request in order for someone to participate in other than elections (statements such as “if they would ask me I would do it” are quite common even though it is unclear who “they” are in this context). There are also ambiguous perspectives on whether public participation is really beneficial; here, A2 stresses the need for the public to obtain a lot of information in order to be able to have an opinion.

What is striking is that participation in most cases is understood as participation on a more direct and personal level. In the context of OT participation is thus understood as taking up a position regarding donation and to register for it. Patients’ participation is actually interpreted in much the same way and is seen as part of the interactions between doctor and patient. Patients’ participation could be, for example, when the doctor listens carefully to what his patient has to say about his experiences of a specific treatment. Taking part in genetic research like A6 and A4F do is also described as a strategy for participation and a contribution to science, at the same time as it is an essential part of their patient-doctor-narratives. Patients’ participation is moreover often understood in terms of autonomy and self-determination as regards medical care – from this perspective, decision-making on the undergoing of a specific therapy is part of the patients’ participation. Even other forms of participation, such as telling one’s experience, rely on voluntariness. One should only take part and engage in participation if one really wants to and participation should never be an obligation just because one is a patient.

Those interviewees who understand patients' participation in terms of lobbying and telling one's experience describe it as highly valuable, as patients hold experiential knowledge which is seen as a supplement to expert knowledge. One strategy for patients' participation could be to engage in a patient association working on moulding the public opinion as well as lobbying politicians (three of the interviewees are members in such associations, although one of them does not refer to this as a manner of participation). Especially OT patients' participation is seen as a strategy for publicity aiming at recruitment of donors.

Taking part in the CoB project is only a few times referred to as a strategy for personal participation. In those cases it is first and foremost considered to be a way of increasing OT/GT publicity and to bring out these issues to people in order to make them more well-informed.

5.3. Notions of Health/Illness

5.3.1. Coping Strategies

Strategies for coping with a disease, or for coping after OT/GT, could be roughly divided into two subcategories: physical/practical measures and mental strategies. The first category includes preventive measures and general lifestyle changes. For GT patients this could involve breast removal and frequent check-ups, whilst for OT patients it concerns e.g. learning how to handle medication and hygiene practices – body-related routines to be further discussed in subchapter 5.4. Also physical rehabilitation through e.g. physiotherapy and exercise plays an important part in coping after a transplant.

Being able to go back to work is by several interviewees described as crucial for coping after a severe disease, e.g. after a transplantion. This point is most heavily underlined by A3. He sees this as the primary way of readjustment to society and thus necessary for recovery and for leaving the illness-related identity behind. Here, A3 tells a story about a friend who was never able to return to work after his transplantion, and who is consequently stuck with the identity of an ill and transplanted person. But at the same time as emphasizing the importance of working A3 also claims that his disease made him realise that there is more to life than work and thus he does not work full-time anymore.

Mental coping strategies are much more implicitly present in the interviews. One way of coping could be not to think about the disease/the test result/the transplanted organ – a frequent approach with affected OT as well as GT interviewees. Or one could build life on the basis of a new "philosophy". Several interviewees claim that their mentality has changed after the undergoing of OT/GT – suddenly one appreciates the small things in life and takes on a "carpe diem approach", thus one starts to live here and now more than to plan one's future life, which is perceived as rather insecure. Interesting to note is that lay interviewees imagine that a positive GT result would bring about much fear and worries, whilst GT-affected people (and especially A4F) stress the test result as a relief as it actually makes it easier to cope with life.

Further strategies for coping are seeing the disease as simply meant to be (especially as regards the passing on of genetic defects) and to adopt an optimistic attitude based on the idea that you will learn something from enduring hardships. Another strategy could be the normalisation of one's illness and its implications. This is especially evident with the OT interviewees, as they describe their adjustment to new conditions (e.g. large amounts of medication, rejection experiences, and hygiene rules). Normalisation/naturalisation of illness happens as the new lifestyle becomes everyday practice. Even the bodily state while waiting for an organ could be normalised; A9 describes himself getting so used to being ill that he did not realise his health was severely declining.

5.3.2. Making Sense of Causes of Illness

Disease is believed to be caused either by hereditary or by environmental factors. In most cases heredity and environment/lifestyle is thought to co-operate; however, the interviewees picture their interrelatedness in different ways.

When making sense of the origin of their personal disease, the OT interviewees often refer to a combination of factors. Heredity might be seen as the foundation or the precondition for a disease to break out, but in the end the course of the disease could be hurried or triggered by environment or lifestyle. This is often contradictory, as people on the one hand state that their disease is hereditary and thus impossible to do anything about; and on the other hand that their way of life (stress, fast food, smoking) might have caused the disease to develop. While hereditary explanations tend to be based on legitimate medical knowledge, environmental accounts mostly emanate from personal reflections. Heredity frees the individual from responsibility, but it is perceived as practically random. Thus, questioning one's lifestyle could be a way of trying to explain why the disease happened at this very moment and to this specific person.

The only interviewee explicitly rejecting the idea of lifestyle causing disease is A6. She claims that one cannot worry too much about one's health, as whatever might be supposed to happen will happen anyway – no matter the precautions taken. This approach is nonetheless inconsistent with her blaming smokers and alcoholics for causing themselves damage through a destructive lifestyle – which once again shows the complexities in perceptions of genes and environment. The ambiguous relation also reflects in the interviewees' approach to GT. Genetic tests are not always considered reliable; they simply show a probable risk which could develop in any direction according to external circumstances (and, as A5 points out, you might die from something other than this genetic disease anyway).

The GT-affected interviewees spend a great deal of time on describing their family history as regards genetics. This could be seen as one strategy for making sense of hereditariness by tracing the origin of the disease. A4F is rather well-acquainted with medical concepts of her different genes and proportional risks, while the others refer more vaguely to older relatives and statements such as "it was meant to be" (A4).

"Healthy" and "ill" are concepts working as categorisations and self-presentations in the interviews. E.g. A5 who never suffered from any serious disease describes himself as sickly and even imagines that he will die young because of that. His opposite is A7, who identifies as an extremely healthy person even though he has heart problems and also, "had some accidents and broken some things but, cut myself when I –. Other than that I've almost never been sick. Had the child diseases. […] And my back, I slipped in the forest of course."

Apart from these two categories there is a third one as well: the genetic carrier, being on the verge of health and illness. Being a carrier means, in this context, that one has the genetic disposition for a specific disease, but at the same time one is healthy at the moment. E.g. A6 sometimes refers to herself as a haemophilia carrier, sometimes as a healthy person – and she finds it paradoxical that she might transfer a genetic disease to her future son without being ill herself.

5.3.3. Social Implications of Illness

The social implications of illness/disease are not always evident. Social stigmatisation because of disease was hardly an issue at all in the interviews – with an exception for discussions about a possible genetic discrimination as regards insurances and employment. Personal relations are generally not described as affected by the disease (even though support from friends and family members might be important for coping with illness). One of the few things mentioned concerns breast removal/prostate surgery and its negative impact on the patient's sex life. Whether this becomes a problem or not is, however, seen as an outcome of the relationship in question and what it used to be like before the onset of the disease.

A lowered immune system resulting from OT medication has direct implications for social relations, as the patient must not see a lot of people during the first months after the surgery. This carefulness has to be taken into account for the rest of one's life as well, and e.g. A1 states that she chooses not to meet people with infections or small children for this reason.

As regards GT, the decision on whether to inform people about one's test result could definitely have social implications. The GT interviewees agree that family members should always be informed – it would feel awkward to hide such a secret from the closest ones. Honesty is an important rationale for informing but also the potential to help others as this kind of information is depicted as a life insurance or a warning. Informing family members is also necessary for receiving their support.

Whether to inform people outside of one's family is a more difficult decision. Whilst several interviewees are quite reluctant to this, A4F and B4M would be more inclined to inform e.g. employers. Especially for A4F informing others is seen as a way of attracting attention to the GT possibility (which is still unknown to a lot of people) more than as a way of revealing personal information. Not telling employers about a genetic disease (which has broken out) is seen as dishonest – but then again you should not tell something unless you are explicitly asked. However, according to A4F and B4M, people who are reluctant to talk about their test results are considered to be ashamed of their genetic defects.

Diseases might further influence reproduction and decisions on having children. This is a frequent topic mainly in the GT interviews; being a genetic carrier is always taken into account when one decides on having children or not. It is not desirable to pass on a defective gene, but neither is an abortion an obvious choice. In fact, it is only the lay interviewee A7 who strongly argues that a person with a genetic defect ought to choose not to give birth to make sure the gene is not transferred to future generations.

5.4. Body

5.4.1. Body Metaphors

The body is implicitly present throughout the interviews, but as it is often quite abstract it could be difficult to grasp the complexities in body view and body perception. Therefore, in this section, we will examine at a more detailed level some of the body metaphors and images quoted in the interviews as they might point to underlying ideas of the body.

Several metaphors evoke thoughts on a mechanistic understanding of the body as they are more or less representations of the body as a machine. The term "spare-part-human-being" (Swedish term: reservdelsmänniska) critically describes the product of continuous organ replacement. The spare-part-human-being functions as an image for artificial life sustenance and it is probably an implicit reference to the replacement scenario presented in the focus group discussion. Moreover, medical check-ups are referred to as "safety inspections" (Swedish term: kontrollbesiktning), which involves the image of the body as a car, and the pieces removed during breast cancer surgery – and subsequently used for genetic testing – are described as "remainders" (Swedish term: restprodukter). Whilst the two former images in a very explicit manner refer to the body as a machine with exchangeable parts and need for surveillance and maintenance, the latter approach implies the same but on a more implicit level – here is a distance between self and body where the pieces removed and tested are actually described as waste and no longer body.

The differentiation between body and self is also highly present in metaphors of the body as a threat or an agent. Being "disappointed in one's body" is used to describe the imagined feeling of being unable to have children. The "body playing tricks" is a way to visualise the experience of suddenly realizing one is a carrier of a genetic predisposition – in this case haemophilia. It seems as if the body has been keeping a secret for 30 years, which is suddenly revealed. Further images of the body as being autonomous and as acting on the self include "body as enemy" – describing the body as somewhat threatening and in need of surveillance and control. This image is also linked to the metaphor of "distrust in one's body" – when having a genetic risk inside – which also implies that the relationship between self and body is quite complex and complicated and that one's body could let one down at any time. To this group of metaphors could also be added notions of "listening to oneself" and "hearing your own signals", which indicate that we have to pay close attention to the signals mediated by our bodies in order to be able to maintain our health.

Genes and genetic problems are also represented by several metaphors. The genetic defect as "uncleanness" (Swedish term: smutsighet) is used by a lay interviewee when trying to describe what it would feel like to have a certain genetic disposition. You might be totally healthy (i.e. without physical symptoms) but the knowledge of you carrying this disposition for a genetic disease would make you feel unclean and somewhat ill all the time. The general uncleanness of a genetic defect further implies that the gene itself becomes part of one's person instead of being located in a specific part in one's body. The image of "the gene as one's soul" describes this relation and negotiates the distinctions between body and self/personality/soul.

The organ as object of transplant gives rise to a number of metaphors and imagery. First and foremost it is described as a gift – and the idea of organs as commodities is strongly rejected. The donated organ is further linked to a natural resource, which means that it would be a waste not to use it when possible (here, a mechanistic view of the body shines through, which fits well with the "remainders"-image). At the same time, however, donating an organ could also be seen as a way of prolonging the life of the donor, who gets to live on in the shape of the recipient. Even though this is explicitly said to be a "romantic" thought, it nevertheless attributes a certain meaning to the organ (i.e. it is not just a physical/mechanical part which can be exchanged – it still is an actual part of its former "owner", the donor).

Symbolic meanings of different organs (mainly the heart) are also expressed using various metaphors. One interviewee is e.g. critical towards politicians using the expression "Thinking with the heart instead of your brain" as it implies heart as the locus of emotions and brain as the locus of rationality. If this would be true the interviewee would not be the same anymore after his heart transplant. The thinking (i.e. the self) is assumed to take place in one's brain and the heart is simply exchangeable according to a mechanistic model of the body.

Another interviewee describes a donated heart as potentially "good" and thus attributes characteristics to it even though she is consciously aware that this is not reasonable. However, she claims that one could perhaps turn e.g. a murderer's heart into a good heart once it is incorporated into one's body. Here, too, is an expression of the need for opportunity of control and domestication of the body: We have to keep our bodies – even our organs – under continual surveillance.

5.4.2. Locations of Genetic Problems

The images of genes mentioned above refer to genes being part of one's soul rather than of one's body. In fact, the perceived abstractness of genes makes it difficult to localise them in a certain spot. However, when asking the interviewees where their genetic problems are located, they tend to localise the consequences of the gene rather than the gene itself. This means that A4, as a haemophiliac, points to her liver since there are defects affecting her blood coagulation ability, and A6, as a haemophilia carrier, points to her belly as for her the gene represents the risk of transferring the disease to her child during pregnancy (at a second thought she also mentions her blood as the location of the defect).

A slightly different view is introduced by A5 who, in accordance with his image of the gene as equivalent to the person, states that a genetic defect is in every cell of your body – and here he uses the image of Lego pieces to describe the way the body is composed and kept in order by our genes. An interesting difference is the disparity between A5's view on genes as being *us*, and A6's view of genes as separate or alien objects existing within her body rather than being an integrated part of it. Her approach could possibly be a consequence of her carrier status and the fact that she is neither ill nor completely healthy – the haemophilia gene is inside her simply waiting to be passed on to a child.

5.4.3. Donor-Receiver-Relationship

The major part of the interviewees considers the relation between donor and receiver to be merely imaginary. However, this does not prevent some of them from describing this bond. A2 speculates on donation as a chance for the donor to live on in the shape of the recipient (much like a parent living on through his/her child). This strong symbolic and physical connection between donor and recipient is based on the idea that the transplanted organ does not become fully incorporated into the recipient's body, which is opposed to the most frequent argumentation among the interviewees. For most of them the donated organ is strongly conceived of as a gift, and once the organ has been given it is (practically and symbolically) integrated into the identity of the recipient. This is especially so for the affected interviewees who claim they do not think much about the organ coming from another person – however, when reflecting more closely on it some of them have ideas about the donor and the donor's family. E.g. A3 describes the connection he nowadays feels to Finland, the Finnish language and Finnish people following from his knowing that the donor was a Finn. A3 has been travelling in Finland after the transplant and he even lit a candle in a Finnish church in memory of the donor.

Nonetheless, the bond between donor and recipient is mostly understood as pure imagination, whilst the bond between recipient and the donor's family is strong and more explicitly emphasised in OT narratives. None of the interviewees have actually met any relatives of their donor, but they expect this to be highly emotional; and the bond is thought to be recognised by both parties. This might be an argument for wanting to meet the donor's family, but it might as well be a reason for not wanting to. The feelings towards the donor's family are strongly dominated by gratefulness – perhaps even more towards the family than towards the donor himself as the nearest of kin often is the one who consents to donation.

The relation between donor and recipient is moreover imagined to depend on whether the donor is a dead or still lives. A living donor implies a much closer connection and a concrete bond between donor and receiver. This is partly because the living donor is often a family member of the recipient but also since the living donor makes a different kind of contribution as s/he deprives himself of an organ in a somewhat altruistic act. This further entails the potential debt of gratitude, which would much more come to the fore when the donor was a living one: in that case s/he might even come and ask to have his/her organ back – which would definitely not happen if the donor was dead. Thus, receiving an organ from a dead donor is considered safer as it does not directly affect another person.

The most important aspect concerning the donor is obviously the quality of the organ. Otherwise the donor matters only insofar as characteristics are believed to be transferred through the transplant – and insofar as the recipient obtains some kind of information about the donor; otherwise s/he would not know about potential characteristics anyway. The anonymity regulation (which is approved of and respected by the interviewees) thus could be seen as some sort of protection against being affected too much by the donor's personality.

Even though on a practical and pragmatic level the donor does not matter as long as the organ holds a certain quality, this is still object to some speculations negotiating between a rationalistic and a romantic approach – e.g. it would be "pretty cool" to have an African heart even if one simultaneously states that this is of no real importance (A2). The interviewees who have actually received an organ deny that their personalities should have been affected by traits brought along with the organ – but they are still fond of reflecting upon this. A3 jokes around about how he hoped to be able to speak Finnish after receiving a Finnish heart. He is also curious about the donor and tries to invent an image from knowledge of body size and assumed gender (male) – thus constructing an image of a person quite easy to identify with. In somewhat the same way does A2 invent an image of a person to whom she would *not* like to donate (a criminal, a vain or a bourgeois person). Even though the interviewees agree that it is of minor importance in reality, identification appears to be crucial when picturing the relation between donor and recipient.

None of the interviewees sees a problem in removing organs from a dead person. People not having any use of organs when they are dead is rather the main argument in favour of donation. This approach tells us something about how the body is perceived: when a person is dead s/he definitely does not need a body anymore. Not taking care of the organs available is, from that perspective, a waste of resources and donation could be one way of actually making death valuable. The view on the body after death is, however, believed to differ according to religion, and some interviewees claim that people with religious beliefs might refuse donation because of bodily integrity matters and the will to be buried as an intact body.

The general approach does not make any symbolic distinction between organs. Apart from certain medical differences where larger organs are believed to cause more technically complicated surgeries, no differences are recognised between different organs – as long as it does not concern one's brain. As personhood is perceived to be located in the brain one could not exchange one's brain and still be the same person. Thus, there is a divide between the brain (person) and the rest of the body, and once we (our brains) are dead we have no use of the other organs.

5.4.4. Interpreting the Body

Interpretations of one's body function as grounds for perception of health and illness, and thereby as rationales for decision-making. This is particularly present in OT narratives. The decision to undergo a transplant is often a result from interpretations of one's physical condition (although sometimes in consultation with doctors). One frequent description of the body state prior to the transplant is "not having energy" (Swedish term: inte orka) to e.g. walk stairs, to move at all or to do ordinary everyday things, which is interpreted as a signal that one's body is in a bad condition. Bodily risk estimations are also part of the decision-making concerning OT. On the one hand, risks could refer to medical-physical risks always inherent in surgical operations; on the other hand, they mainly refer to the risks of being affected by cancer as a side-effect of the medication after a transplant. Knowing that one has cancer running in the family could make one consider this risk even more – however, as transplantation in the end was the only option for survival all interviewees regarded it as worth trying.

Bodily rationales are not as evident in decision-making concerning GT. However, the argumentations point to preventability/curability of the disease as crucial when deciding on taking a pre-symptomatic genetic test. Testing a disease for which there is no cure or treatment is believed to induce so much worries that the anxiety in itself could cause the disease to break out.

Interpretations of the body relate to the image that one could actually listen to one's body or pay attention to certain signals of disease. The interviewees often describe themselves as neglecting their bodies in this respect, and this model is used for explanations of why one did not take precautions in time or why the disease got so bad that a transplant was necessary. Neglect is mostly explained by the fact that one is unlikely to believe that one will actually be affected by a serious disease (recurrent in many interviews on OT as well as GT), and this is generally seen as more of a male feature than a female one. It is also a question of likelihood with regard to e.g. heredity and previous experiences: A1's lung disease is rare and she had never heard of it before she was diagnosed; thus it is more difficult to interpret the symptoms. A3 did not think he suffered from a heart attack but simply thought it was the same kind of back ache he got from his work (and which he, when looking back now, actually interprets as early bodily signals of something being wrong).

Interpretations of bodily symptoms might also change after certain operations. A4F claims that she used to worry a lot about her body, sensing cancer everywhere, before she removed her ovaries. Now that the risk for developing genital cancer is gone, she interprets her body in other ways and does not pay attention to pains or bulges anymore. Her story further points to a discrepancy between medical conclusions and bodily perceptions, which is particularly brought to the fore in the context of GT. A4F was advised by a doctor to remove her ovaries, based on the risks of her developing cancer. However, as she did not interpret her body as an ill body (apart from her worries), at first she did not want to go through the surgery. This could be compared with A1's removal of her uterus once she was affected by cancer. Although this meant that A1 would never be able to have children, she does not mention any doubts concerning this operation. Thus, while the bodily perception of illness might be a rationale for going through a surgery, the urgency of preventive surgery is unclear, as the patient does not sense illness in his/her body.

5.4.5. Bodily Consequences of OT/GT

Going through an extensive transplant surgery or taking a genetic test results in mental and social changes but also bodily consequences come out of it. The medical or physical consequences of OT are undoubtedly stronger and more present in the interviews than are the medical or physical consequences of GT. Linked together with OT are experiences from the surgery such as waking up in the hospital and the physical pain following afterwards. In fact, narratives of the first time after the transplant surgery mainly centre on bodily changes and bodily sensations. For some it was a real hardship and the bodily suffering overshadowed the joy to be alive or the thoughts of the donor. For others it was more of a positive bodily change, having one's energy back and – as described by A3 – waking up with warm feet; however, the body is still the focal point.

The surgical operation had durable effects on the patients' bodies in the form of scars and wounds. This might also affect body perception: E.g. A1 suffers from bad perception of touch on her chest after the transplant, but she is nevertheless very much aware of this part of the body which is described as feeling different from before. Several lay interviewees also discuss changes in body perception and especially GT is generally believed to complicate a person's relationship to his/her body.

On the other hand, GT itself does not involve any direct medical or physical consequences as long as preventive measures are not taken. Preventive measures, however, could be quite extensive and are highly body-related, e.g. when removing ovaries or breasts. Breast removal for preventive purposes is generally rejected and is considered too drastic to go through. As it is clearly linked to female identity, breast removal will be further discussed in subchapter 6.

Many of the bodily consequences after OT stem from the intense medication. In order to cope with the new organ the patient has to take large amounts of medicines, and this medication weakens the immune system. Thus, to be able to take care of one's body after a transplantation one must first learn to handle all the medicine, and thereafter one has to learn how to handle the bodily consequences of the medication. The OT-affected interviewees are aware that their bodies are much more sensitive to infections, and they need to pay attention to certain hygienic rules as well as to their bodies. The medication also causes changes in appearance, such as growing hair all over the body, which is perceived as stigmatizing – A3 claims that he looked like a monkey and it took a lot of shaving and cutting not to scare people.

However, there are also positive bodily changes after the transplant. Above all, in the long run it is primarily a way of gaining energy and bodily strength, thus opening up opportunities to do things that were unthinkable before the transplant. This bodily enhancement has a direct impact on social and everyday life as one could e.g. take a shower, wash the dishes, tie one's shoes and meet with friends without problems, which produces a sense of independence and autonomy.

5.5. Doctor-Patient Interactions

5.5.1. Doctor-Patient Relationship

Although the heading of this subchapter indicates that it only concerns interactions between patient and doctor, the latter category also includes nurses or other medical professionals. In the interviewees' stories, patient-doctor-interactions are often described more in terms of information exchange and discussions rather than specific medical interventions. The social and counselling dimension of the patient-doctor-relationship seems to be of great importance. Informing the patient about treatment options and their consequences appears to be one of the main tasks of a doctor, and information is more understood as an interactive process than as the patient being a passive receiver. Thus, the counselling function makes the doctor the person being most influential on decision-making concerning the undergoing of a specific therapy. In the end, though, the patient should have the final say on how to proceed, and the role of doctors is mainly to inform about risks and benefits of different treatment suggestions. The patient's self-determination is called for as guiding principle in patient-doctor-interactions and consent should always be required in order to perform treatment. Patient's autonomy as rationale also implies a patient's responsibility, which on the one hand may include patients actively requesting certain forms of therapy but on the other hand it also entails the responsibility to take good care of yourself after receiving a costly operation like OT.

The most personal relationship between patient and doctor is presented by the GT-affected interviewees. They seem to have more or less one family doctor doing research on their cases who is consequently specialised in their family relations and history of disease. This kind of contact between patient and doctor is perceived as quite intimate, and seeing a doctor who knows much about one's familial and hereditary background is highly valued as a security. Particularly, A4F has an exceptional relation to her doctors. When telling her story and how she got in contact with GT, she introduces a number of doctors by name and formal title (which is rather unusual in Sweden) – she actually takes out her diary and reads their names out loud (did she write them down especially for the interview situation?). Her self-presentation in this context refers a lot to herself as being a very interesting case for the doctors to do research on. Taking part in research is for her a contribution to medical (genetic) progress of which she is rather proud. A reciprocal relationship is outlined in which doctors could not do without patients' involvement.

The valuation of doctors is generally appreciative. Trust is emphasised and direct personal experiences from health care are often positive. With some exceptions doctors and medical professionals have proved to be caretaking and reliable in interactions with patients. The lack of an explicit decision-making process points to this unreserved trust in doctors knowing what is best – patients rarely describe taking actions against their doctors' advice. However, even the best doctor can make a mistake and some of the interviewees have experienced this (e.g. miscalculating a dosage of medicine). It does not, however, necessarily affect the way the interviewees relate to medical service in general, since "doctors are humans too" (A3) and you cannot expect them to be flawless.

A7 is the only interviewee taking up an entirely critical position toward doctors as well as towards people consulting doctors for every little complaint. To him, the role of doctors is merely to ease worries and provide illusory relief by prescribing useless (placebo) medication. Doctors providing support and easing worries is an inherent aspect of other interviewee's doctor-patient-narratives as well – but to them it is a comforting security rather than a delusion. A7's approach towards doctors could be seen in the light of his general approach to health and medicine – he understands himself as a very healthy person with some experiences of doctors making mistakes; further, he considers himself too old to undergo any extensive treatment at all.

5.5.2. Knowledge-Practices

As mentioned above, informing about treatment options and explaining medical conditions are some of the primary tasks for a doctor. Information acquisition is mainly understood as an interactive process involving both doctor and patient. This often leads to the patient making a decision on how to proceed with the treatment.

Regarding information acquisition in the specific contexts of OT/GT, OT patients are informed about the option to undergo a transplant, what it practically means (including surgical risks), and what life will be like afterwards, e.g. what kind of restrictions will there be. GT patients, on the other hand, are informed about the estimated risks of them having a disease, the test taking procedure, possible preventive measures and medical risks, e.g. concerning miscarriage in case of prenatal testing.

The information obtained from doctors is communicated orally as well as in written form. On the whole the information one has received is seen as sufficient – i.e. the interviewees do not require any additional information and even though they are not always well-informed they do not experience their lack of knowledge as a problem. Transplant patients are generally more knowledgeable than GT patients and more often claim that they have received enough information. (Other possible ways to collect information are mentioned, e.g. going to the library or search the Internet – but the interviewees in general are content and happy with the information they have received from their doctors.)

The only interviewee having specific opinions on the way information is provided is A4F. She claims that she always receives information from doctors when seeing them, and afterwards she is given a written summary of what has been said. However, she explicitly prefers oral information. Written information is perceived as much more frightening: it is difficult to grasp and there is no room for dialogue or clarifications. Once again the interaction model of information is emphasised.

In one sense, medical knowledge and information from doctors mean comfort and security. Getting to know the reasons for why one feels a certain way and whether the symptoms are going to disappear or not could calm the patient. Even the confirmation of one's worries and suspicions could be perceived as comforting: by naming the problem it is made legitimate and a therapy or medication might be provided. One obvious example is A4F: To her, the genetic test result itself was an important confirmation of her previous health worries. Although she had always known that a large number of her relatives had died from cancer, this was never a sufficient motive for her to take precautions until she found out that she really carried the cancer disposition herself. Medical knowledge legitimised her fears as it is seen as superior to non-scientific knowledge (e.g. body interpretation, lay perceptions).

Medical knowledge often serves as a rationale for agency and decision-making. Regarding OT this could concern information/knowledge on the medical risks of the surgery in relation to the benefits of the transplantation. For GT it might involve the estimated risks of having a predisposition (on the basis of family history) and the preventability of the disease in question. Whilst GT interviewees agree that it is good to know about a hereditary disposition for a curable or preventable disease, there is a strong tendency to reject genetic information about diseases for which there is no treatment available (or, to some interviewees, even diseases which have not yet developed are better to not know about). The issue of GT decision-making is, however, complex, as it is also an outcome of the perceived reliability of the test and whether one is inclined to believe in environmental factors above genes.

The preference for diagnostic GT rather than pre-symptomatic testing corresponds with the argumentations on therapeutic interventions vs. preventive measures. Whilst the first ones are regarded as acceptable and necessary, extensive preventive measures (such as breast removal) are strongly questioned as it is considered a too radical operation on one's body. However, medical knowledge could cause this standpoint to change. For instance, in subchapter 4 we discussed A4F's reaction to the doctor's suggestion of preventively removing her ovaries. She did not want to at first, but after consulting with the doctor and receiving medical facts on risks and benefits she agreed to it.

The impact of medical knowledge on everyday life is obviously greater for the affected than for the lay interviewees. OT patients in particular often refer to medicine when discussing their daily lives – last but not least is knowledge about the increased susceptibility for infections incorporated into everyday life and everyday hygiene practices.

5.5.3. Power/Knowledge

Here, we will discuss some techniques for discipline and self-surveillance stemming from medical knowledge. Most interviewees agree on environmental or lifestyle factors being of great importance for one's health. They clearly share the same notions of what is an healthy (or – more explicitly– what is an unhealthy) way of life. Stress, smoking, alcohol, and "wrong" food such as too much sugar, fat or fast food are frequently brought up as the major threats to a healthy lifestyle. However, this discourse on a healthy living refers to an ideal rather than a practice; the interviewees are quite careful with holding people responsible for leading unhealthy lives, since it is often impossible to draw a sharp line between harmful and non-harmful activities. Nonetheless, the knowledge/discourse on what is good and bad for our health underlies the implicit self-critique of what might have hurried the course of one's disease: smoking, eating habits and a too hectic way of life.

This knowledge further imposes a certain degree of self-surveillance, particularly in life after OT/GT. The OT patients often state that it is essential to be able to "look after oneself" (Swedish term: sköta sig) after going through the transplantation. This expression is somewhat summoning, and it points to a high degree of self-surveillance and discipline. To look after oneself means to handle the medication correctly; to do exercise and physiotherapy and not expose oneself to health risks as mentioned above. The body's increased susceptibility for infections further necessitates certain hygiene practices, such as being careful with what one eats, how one eats and what people one sees. In fact, looking after yourself means that you have to pay much attention to your body and you have to be observant all the time not to expose yourself to bodily threats. The "look after oneself" -concept is referred to as one of the main criteria to undergo transplantation (see subchapter 2). Thus it could be seen as an imperative from the medical service sector on how to lead one's life, and the interviewees much like to attribute to themselves the characteristics of an ideal patient in this respect. It is interesting to note that the OT patients look after themselves not primarily for their own sake but more because it is seen as a responsibility towards others: the donor's family (who provided the organ), society and medical service (which offered resources for the transplantation) and other patients on the waiting list (due to the scarcity of organs).

Also, for GT patients discipline touches on the health discourse discussed above, but self-surveillance is moreover brought into play when thinking about having children. One is supposed to use the means available in order to give birth to a healthy child, and as a person carrying a genetic disease one is expected to be careful not to transmit one's defective gene to future generations. This results in a way of self-surveillance concerning reproduction, which is implicitly expressed by several interviewees. It is often described as a personal/parental responsibility not to give birth to disabled children, but it could nevertheless be regarded as a technique aiming at the control of populations.

5.6. Gender and Religion

5.6.1. Gender

The interviewees all agree that gender should be unimportant as rationale for medical prioritisations. Neither should the donor's gender matter, as characteristics are not perceived to be transferred with the organ – A3 exemplifies this referring to a male friend who received a heart from a young girl; he did not become female at all.

When asking about gender differences concerning coping strategies, body view, etc., the interviewees generally claim that it is the outcome of individual differences (what you are like as a person) or medical differences (according to disease) rather than gender-related characteristics. However, in the argumentation this approach is often mixed with statements on essential gender differences. Concerning e.g. decision-making, ways of coping, and body view, most interviewees would agree that this has more to do with individual than gender-specific characteristics. But at the same time women are described as generally introspective and sensitive in coping with illness, whilst men are depicted as fact-oriented, tougher than women and ignorant to their body and health – they would rather not admit that they are ill and are therefore less willing to consult doctors.

The GT interviews touch on issues such as preventive removal of breasts and genitals. Breast removal is referred to as a very drastic intervention, even a mutilation, and A4F describes the awkward feeling the first time she saw her mother without breasts after a cancer surgery. Breasts should only be removed – "peeled off" – if necessary for survival; thus, to have them removed preventively is not an option for any interviewee. However, in the interviews breasts and breast removal are not as intertwined with femininity, sexuality and age as it was in the focus groups. It is mainly A4F and B4M who refer to these issues, emphasizing the need for a good (heterosexual) relationship in order to cope with such bodily changes.

The removal of genitals (ovaries and uterus) also touches on the issues above. It is not visible in the same way as breast removal and thus it does not affect one's appearance, but it is nevertheless an extensive operation. Particularly for a woman in reproductive age removing genitals could be devastating. A4 claims that she would feel less feminine if she were unable to give birth after removing her uterus; inherent in this quotation is reproduction as constituent of femininity. This topic is also touched upon by A7; however, in a completely different context: A female friend of his cannot have children and A7 claims this is because she has too much testosterone after playing football. By performing a practice that is considered masculine she is in other words disqualified from being a real woman.

5.6.2. Religion

A few of the interviewees define themselves as believers, but A1 is the only one who claims that her faith has mattered in dealing with biomedicine. A1 belongs to a mission church, and this religious community has been important for her coping before and after the transplantation. She describes her faith as strengthening, but in fact the social support offered by the reverend and other church members (e.g. their prayers for a new pair of lungs) seems to be equally important as her faith itself.

The majority of the interviewees only discuss other people’s religious convictions and their consequences in relation to biomedicine. Swedish people in general are not believed to be affected by religious values when evaluating medical issues; the only one touching on this is A8 who claims that we all have a common outlook on things where fairness and helpfulness are important elements.

Even though several interviewees claim that they are unsure of how different religions are positioned towards certain biomedical technologies, most argumentations automatically presuppose a conflict between religion on the one hand and science, biomedicine, and progress on the other. The only interviewee practising religion, A1, sees no trouble in combining her faith with trust in medical science – she believes that God uses doctors to heal people. But with the non-religious interviewees there is a strong inclination to describe religion (above all certain religious groups, such as Jehovah’s Witnesses) in opposition to science in general and OT/GT in particular. However, even Christians believing in resurrection are described as opposed to donation and transplantation because of bodily integrity. Religious people in general are also believed to disapprove of genetic technology, as God to them is almighty and we should not interfere with our destiny (his creation). Reducing the body to entities such as genes could thus be provocative from a religious point of view.

However, religion is also understood as positive in some respects; e.g. A5 argues that coping with illness is probably easier for a religious person than for an atheist who can hardly find a meaning in suffering.

Note: The tendency in the focus groups to link together religiousness with other ethnicities is not at all present in the interviews.

6. Concluding Remarks

6.1. Reflections on Procedure

According to the project description, work package three aimed at complementing and expanding the empirical data of focus group discussions by means of qualitative, ethnographic interviews. The prior participation of most interviewees in the focus groups provided an ideal basis for (re-) introducing the project and topics under investigation to the respondents. What is more, the focus group discussions and the experiences of participants provided a crucial point of reference during the interviews. This not only made “rapport” much easier but also allowed participants to refer to examples or sequences of the exchanges from the focus groups to support their arguments and contextualise their views. Also, interviewers could ask participants to clarify their positions taken in the group discussion in those cases where the preliminary assessment of transcripts showed ambiguities or vagueness. The ethnographers’ motto “meeting people a second time” was further profitable for the researchers conducting the interviews with respect to deepen insights gained in the focus groups and by extending the general frame of ethnographic work.

Overall, the interviews were not so much about introducing completely new topics to the respondents but rather about elaborating on and deepening issues, topics and subject matters already brought up. However, the more intimate setting of the ethnographic interviews made it possible for thoughts and argumentations to evolve in a more biographical mode: respondents were able to use the one-to-one interaction of the interview to discern in a much more detailed way individual patterns of perception and reflection. Therefore, underlying rationales (styles of reasoning) and values (culturally patterned moral practices) as well as narratives and representations of individual practices and coping strategies became more apparent during the interviews. As such, conflicts and rationales related to decision-making were further elucidated. As well, topics taken up briefly in the focus groups such as concepts and understandings of body, health/illness, doctor-patient-relationships and subjective religious and/or moral orientations could be elaborated on much more thoroughly. The interviews also provided a good opportunity to focus more closely on established ideas of participation and regulation; similarly, insights of how people relate themselves to current public debates, the health care system in general and political discussions relevant for the topics discussed could be brought up in an individualized way.

An important – and simultaneously challenging and experimental – feature of WP3 consisted in the organisation of a collective process of ethnographic work in the three participating countries. The procedural, methodological and theoretical integration of three independent local research teams and the “doing” of ethnographies in highly diverse socio-cultural contexts in order to produce comparable data required intensive exchanges between researchers. Since ethnography is characterized by a highly individualised epistemic style – as it is conventionalised in classic ethnographies – and since slightly different “national” schools of doing ethnography exist, to develop a research methodology required to venture into partially uncharted terrain. To ensure comparability of case studies and findings on the one hand and to preserve an explorative mode research that takes emerging puzzlements and perplexities as lead for further inquiry on the other, the research teams decided to follow grounded theory principles. Accordingly, close collaboration and exchange between individual researchers and teams was established during all phases, beginning with developing the research design, explorative interviews, research and well into the analysis, to guarantee a coordinated mode of interviewing and a synergetic definition of analytic categories as well ass their application and integration into higher-order concepts and hypotheses. The software Atlas.ti provided an ideal virtual common workbench for this integration across research sites. Also the further analysis and comparison of cases in the following work packages will be much easier on the basis of this intense preparatory work.

6.2. General Tendencies

The interviews and the additional ethnographic data produced a rich empirical material that reveals surprising similarities between but also unforeseen specificities in the “local” findings in Cyprus, Sweden and Germany. As a general tendency, the material from the three countries shows more similarities than differences, somehow revealing a “European” or even “pan-human” perspective on the topics discussed. At a second glance, however, the views and perceptions of respondents in Sweden and Germany seem to have more in common than those of Cypriots compared to Swedish and German interviewees. However, there are significant divergences between the diverse topics discussed, complicating the picture and preventing a simple explanation referring to notorious “cultural areas”. The question of similarities and differences and their potential background in socio-cultural contexts clearly needs closer examination for the different topics explored.

The most significant differences between findings in the three involved “localities” concern evaluations of the political framework or judgements of role the state or “politics” fulfils or should fulfil. A major dissimilarity consisted in the views respondents held regarding the organization of an appropriate health care system. Although positions and critiques clearly refer to the respective national frameworks of the (bio-)medical system and subjective experiences with health care delivery and the problems related to individual illness-trajectories, it is quite amazing how similar expectations of respondents are: the criteria for the appropriateness of a well functioning health care system are to a large extent shared by all interviewees. In part this may be related to the significant fraction of affected respondents in the sample.

Also, important similarities have to be noticed concerning the evaluation of biomedicine: positions, ambivalences, worries and hopes respondents hold regarding the benefits and risks of biomedical innovation and the implementation of innovations are highly comparable. Most likely, the influence of media coverage and increasingly “globalised” narratives of scientific progress may play a crucial role here. However, positions held concerning coping practices, concepts of illness (subjective experiences) and disease (‘objective’ description), or the conceptualisation of bodily function are clearly impregnated by cultural practices. Quite surprisingly, religious differences seem to play a rather marginal role in the *explicit* accounts given by the respondents, perhaps indicating a slight tendency of reduced direct influence of religion in the national contexts observed. However, this “universal” tendency requires specific explanations for all research sites since the respective socio-cultural settings are highly diverse in all three countries and – even more significant – in the local contexts that were chosen as a basis for recruitment of respondents deviate significantly.

A pervasive issue in all interviews with affected participants was the problematic of normalisation of health problems and illness experiences. In the narratives of participants, illness emerges as a highly distinct "lifestyle" (Lebensweise) imbued by biomedicine and scientific epistemes. All of the respondents in the sub-groups of GT- and OT-affected are characterised by "chronicity" understood as a particular state or mode of being ill / being different / being a sufferer. As such, this mode has pervasive repercussions for subjectivities, self-management and *governmentaliy* and it defines social relations of participants on the micro- and meso-level in a very specific way. In contrast to disease, illness has to be conceptualised accordingly as personal as well as social, as an objective and subjective issue at the same time, where conflicting and to a large extent incompatible knowledges have to be continually synthesised and integrated.

Interestingly, a frequent strategy chosen by respondents in all three countries was to organise their arguments and narratives using a comparative mode: References to the "other" (meaning members of other religions, other societies or other nations) were frequently used to specify the *individual* position and the *subjective* views held. Whether this can be interpreted appropriately as a vernacular cultural relativism, taking irreconcilable ethical and moral differences for granted in pluralized, modern societies, or whether this has to be interpreted as 'ethnographic effect', a cautionary style of arguing in the specific situation of the interview will have to be explored further.

6.3. Outlook

Members of WP three came to the understanding that the ethnographic material based on interviews and observations clearly deserves more close inquiry and that – although CY-MMC and SE-ULUND/IE have no further person-months at their disposal for WP's 5 and 6 – they will cooperate in further comparative analyses and publications. These will be organized around three topics / broad themes:

- Normalization of illness experience
- Imaginary Links in Donor – Recipient Relations and Social Refractions of Anonymous Reciprocity
- Forms of governmentality (i.e. expertise, knowledge, reflection) and modes of participation in patient-groups and clinical trials

7. Appendix

Interview Guidelines and Questions for the four groups of respondents

[A] Transplantation Medicine – Affected Participants

1. Knowing – Deciding - Acting

When did you first learn about the option that organ transplantation might help you?

What sources of important/relevant information did you use for your decision regarding the usage of organ transplantation? Could you rely of former experiences / experienced people to help to understand the issues involved?

Who was involved or rather whom did you involve in that decision-making process?

What were the main factors that played a role in your decision-making process?

Concerning relevant information and factors in the decision-making process – do you think this is different for men/women? – If so, in which ways?

From the patients' point of view: What are the most difficult points in making a decision concerning both organ transplantation and organ donation? [This question refers to decision-making concerning organ transplantation and organ donation respectively.]

Did religion play a role in the decision-making process? What do you think is the role of religion for others/generally in deciding about the usage of organ transplantation and organ donation?

2. Health/Illness

After the transplantation, how did you experience that you had a "new organ"? After some time to accommodate, what does it mean now for you to have a new organ in everyday-life?

More concretely, what are consequences for everyday-life and how does one cope with it?

What consequences does organ transplantation have for how you live your life? Did/does it have any impact for your life style and in which ways?

Do you think consequences of organ transplantation regarding everyday-life and the way one lives his/her life is different for men/women – if so, in what ways?

How does (knowledge about the possibility of) an organ transplantation influence the view on the personal meaning of life/the quality of life?

There are people who say that most diseases which make organ transplantation necessary are "life-style diseases". This places the "moral" responsibility for the disease on the shoulders of ill people / people needing a new organ. What do you think about this opinion?

How do you explain the malfunctioning of your "old organ"?

With your knowledge now, do you think you could have avoided transplantation through life-style changes?

3. Body

Did the process of organ transplantation influence the experience of your own body? In which ways?

Did you experience an immuno-rejection? How did you perceive it?

Regarding organ donation as prerequisite for transplantation: Do you sometimes think about this other person [the organ donor]? How would you characterize your relation to the donor? Does the sex [lifestyle, class, cultural background] of the organ donor play a role for you – if so, in which ways?

4. Participation

Concerning the regulation of decision-making in transplantation medicine (organ donation, organ allocation) – Is participation and having influence as a patient and a citizen desirable at all – why/why not?
[Follow-ups depending on previous answer - medical system, political framework, state-level]:
What role - if any - should transplanted patients/citizen take in public discussions?
Do you want to get involved yourself? Where do you see possibilities to actively participate/make your point of view heard?
Regarding how the regulation of biomedicine is dealt with: As a patient, is trust in the medical system / the political system / politicians warrantable?
What role should doctors, self-help organizations, politics or the state have in regulation?

5. Evaluation/Positioning

Which positive and negative points come to your mind when evaluating progress in the medical domain and the debates about limiting medical research and development?
Should one reach a societal consensus regarding these limits? [in the sense whether it is desirable that society/all citizen agree on certain limits]
How can a consensus be agreed upon given that a growing plurality of values and norms is held by citizens that might have different cultural orientations?
As in any other field, there are limited resources and high costs in transplantation medicine. And of course there are discussions about financing. How should access to medical treatment and technologies be granted? Who should pay for it? What should be priorities?
There are different principles concerning the consent to organ donation: [shortly explain objection solution (“presumed consent”) and (extended) consensual solution)]. Which model do you prefer – why?

[B] Genetic Testing – Affected Participants

1. Knowing – Deciding - Acting

When did you first learn about the option that genetic testing might be relevant for you?
What source of important/relevant information did you use for your decision regarding the usage of genetic testing? Could you rely of former experiences / experienced people to help understand the issues involved?
Who was involved or rather whom did you involve in that decision-making process?
What were the main factors that played a role in your decision-making process?
Concerning relevant information and factors in the decision-making process – do you think this is different for men/women – if so, in which ways?
From the patients' point of view: What are the most difficult points in making a decision concerning genetic testing?
Did religion play a role in the decision-making process? What do you think is the role of religion for others/generally in deciding about the usage of genetic testing?

2. Health/Illness

After getting the test result, how did you experience that you have a certain genetic risk/a genetic disease?
After some time to accommodate, what does it mean now for you to have a certain genetic risk/disease in everyday-life?
More concretely, what are consequences for everyday-life and how does one cope with it?
What consequences does the result of a genetic test / a genetic disease have for how you live your life? Did/does it have any impact for your life style and in which ways?
Do you think consequences of genetic testing regarding everyday-life and the way one lives his/her life is different for men/women – if so, in which ways?
How does (knowledge about the possibility of) a genetic disease/a certain test result/ a certain risk influence the view on the personal meaning of life/the quality of life?
[One could ask here if people see any other reasons for explaining a manifestation of a genetic risk besides the genetic cause? Here it would be interesting to explore how deterministically people see genes or how they think the relation between genes and environment.]

3. Body

Did genetic testing (the dealing with probabilities concerning a certain risk) influence the experience of your own body? In which ways?
In which way is it difference for the body perception whether the test result concerns a certain percentage of probability, a hereditary risk, a defect or an expression of a defect?
Do you think bodily experiences concerning genetic knowledge/disease are different for women/men – in which ways?
Where would you locate a genetic defect/risk in your body? How would you explain this to other people?

4. Participation

Concerning the regulation of decision-making regarding genetic testing/research – Is participation and having influence as a patient and a citizen desirable at all – why/why not?
[Follow-ups depending on answer of previous question - medical system, political framework, state-level]:

What role - if any - should patients with experiences in genetic testing /citizens take in public discussions?
Do you want to get involved yourself? Where do you see possibilities to actively participate/make your point of view heard?
Regarding how the regulation of biomedicine is dealt with: As a patient, can one trust the medical system / the political system / politicians?
What role should doctors, self-help organizations, politics or the state have in regulation?

5. Evaluation/Positioning

Which positive and negative points come to your mind when evaluating progress in the medical domain and the debates about limiting medical research and development?
Should one reach a societal consensus regarding these limits? [in the sense whether it is desirable that society/all citizen agree on certain limits]
How can a consensus be agreed upon given that a growing plurality of values and norms is held by citizens that might have different cultural orientations?
As in any other field, there are limited resources and high costs in genetic testing and genetic research. And of course there are discussions about financing. How should access to medical treatment and technologies be granted? Who should pay for it? What should be priorities?

[C] Transplantation medicine – Laypeople

1. Knowing – Deciding - Acting

When you applied for participation in the focus group discussion, what was your main interest in transplantation medicine – and in the discussion?

Regarding the focus group discussion you have attended: what were new points and/or import points for you concerning the discussion? Did you discuss this "experience" in your social environment? If so – with whom?

Are you registered as organ donor - why/why not? Did you (re-)think about / change your donor status after the discussion?

If you registered –did you discuss this decision with friends / family?

Given the discussions you had and your experience: Why do people donate their organs – or: why don't they? (i.e.: What are main factors that play a role in your decision-making process regarding respectively organ donation and organ transplantation?)

How do you feel about the possibility to help a stranger by donating your organs?

What role has religion for you personally in the decision-making process about organ donation and organ transplantation? What do you think is the role of religion for others/generally in deciding about the usage of organ transplantation and organ donation?

2. Health/Illness

Organ transplantation is regarded as a very advanced therapy. From your point of view: how does transplantation differ from other, "classical" forms of therapy?

There are people who say that most diseases which make organ transplantation necessary are "life-style diseases". This places the "moral" responsibility for the disease on the shoulders of ill people. What do you think about this opinion? What should follow regarding the financial cost of organ transplants?

3. Body

Do you think that the possibility of organ transplantation and organ donation influences the way people think about their body? Did it make a difference for you personally?

The term "organ donation" encompasses many things from heart transplants to skin transplants. Do you think that the *kind* of organ transplanted makes a difference?

Do you think that the personality of the donor – e.g. his or her gender / sex, his or her life-style or his/her ethnicity plays a role? How so?

How would you characterize the relation / the bond between donors and recipients of organs?

4. Participation

Concerning the regulation of decision-making in transplantation medicine (organ donation, organ allocation) – Is participation and having influence as a citizen desirable at all – why/why not?

[Follow-ups depending on answer of previous question - medical system, political framework, state-level]:

What role - if any - should citizens take in public discussions about transplantation / donation?

Do you want to get involved yourself? Where do you see possibilities to actively participate/make your point of view heard?

Regarding how the regulation of biomedicine is dealt with: As a citizen/patient, do you think that trust the medical system / the political system / politicians is warrantable?
What role should doctors, self-help organizations, politics or the state have in the regulation of OT / OD?

5. Evaluation/Positioning

Which positive and negative points come to your mind when evaluating progress in the medical domain and the debates about limiting medical research and development?
Do you think it is important to reach a societal consensus regarding these limits? [in the sense whether it is desirable that society/all citizen agree on certain limits]
How can a consensus be agreed upon given that a growing plurality of values and norms is held by citizens that might have different cultural orientations?
As in any other field, there are limited resources and high costs in transplantation medicine. And of course there are discussions about financing. How should access to medical treatment and technologies be granted? Who should pay for it? What should be priorities?
There are different principles concerning the consent to organ donation: [shortly explain objection solution ("presumed consent") and (extended) consensual solution)]. Which model do you prefer – why?

[D] Genetic Testing - Laypeople

1. Knowing – Deciding - Acting

When you applied for participation in the focus group discussion, what was your main interest in genetic testing – and in the discussion?

Regarding the focus group discussion you have attended: what were new points and/or import points for you concerning the discussion? Did you discuss this "experience" in your social environment? If so – with whom?

After the discussion – did you (re-)think about / change your position re. genetic testing?

If you will ever be in the position to decide whether you should test your genetic status – do you think this decision should be discussed with your friends or your family?

Does religion play a role in the decision-making process? What do you think is the role of religion for others/generally in deciding about the usage of genetic testing?

2. Health/Illness [* refresh the breast cancer scenario of the focus groups *]

What does a test for breast cancer mean for the tested person and her family and friends?

What will a genetic test result tell you? (re. the relevance given to a genetic test result; probabilities, hereditary risk)

What might the consequences be of a genetic test which established that you are carrier of a mutation?

How does the knowledge about the possibility of a genetic disease/a certain risk influence the view on the meaning of life/health?

[One might ask if people see any other reasons for explaining a manifestation of a genetic risk besides the genetic cause? Here it would be interesting to explore how deterministically people see genes or how they think the relation between genes and environment.]

3. Body

How would you explain to other people a genetic defect/risk in your body? Where would you locate it?

In most cases, a "positive genetic test result" means that a healthy person might get ill in the future. How do you think will this kind of "conditioned prediction" influence how people experience their body? How will it influence their everyday practices?

4. Participation

Concerning the regulation of decision-making regarding genetic testing/research – Is participation and having influence as a patient and a citizen desirable at all – why/why not?

[Follow-ups depending on answer of previous question - medical system, political framework, state-level]:

What role - if any - should citizens take in public discussions about genetic testing?

Do you want to get involved yourself? Where do you see possibilities to actively participate/make your point of view heard?

Regarding how the regulation of biomedicine is dealt with: As a citizen/patient, do you think that trust the medical system / the political system / politicians is warrantable?

What role should doctors, self-help organizations, politics or the state have in regulation of genetic testing?

5. Evaluation/Positioning

Which positive and negative points come to your mind when evaluating progress in the medical domain and the debates about limiting medical research and development?
Do you think it is important to reach a societal consensus regarding these limits? [in the sense whether it is desirable that society/all citizen agree on certain limits]
How can a consensus be agreed upon given that a growing plurality of values and norms is held by citizens that might have different cultural orientations?
As in any other field, there are limited resources and high costs in genetic testing and genetic research. And of course there are discussions about financing. How should access to medical treatment and technologies be granted? Who should pay for it? What should be priorities?

[E] Locally Specific Questions

Cyprus:
Interviews on genetic testing, added questions with respect to thalassemia
Interviews on transplantation medicine, concerning question about donation and donor-receiver relationship stronger focus on aspects of donation between strangers/family members

Germany:
In interview questions concerning financial aspects of health/care medicine, linkage to current debate on re-organization of health-care in Germany

Sweden:
Concerning interview questions about prioritization (access to medical treatment), stronger focus on gender/sex, life-style, age

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Notes

[1] Throughout this report the word “biomedicine” refers not so much to the epistemological, methodological and institutional transformations due to an ever increasing integration of (molecular) biology and medicine since the 1980s but rather to the clinical and diagnostic *applications* of this kind of medicine since the 1990s as they are perceived by the respondents; cf. for an etymological as well as institutional sketch of these developments Keating/Cambrosio 2000.

[2] The high proportion of participants in clinical trials among the affected respondents is clearly an effect of the recruiting mechanisms used for the focus groups; however, the motifs relevant for their participation in clinical trials as well as in the CoB-study are analogous an throw a light on their active altruistic orientation.

[3] Specific regulations on GT and OT and the different processes of regulation will be discussed in subchapter 2.

[4] However – as stated above – development could rush too fast and we sometimes have to wait for people to accommodate before introducing a certain technology.