

# LEARNING TO EAT STRAWBERRIES IN A DISCIPLINED WAY

## Normalization Practices Following Organ Transplantation

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This article addresses everyday strategies of coming to terms with organ transplantation that we term normalization practices. The analysis is based on focus group discussions and ethnographic interviews with transplant recipients, their relatives and waiting list patients in Sweden, Cyprus and Germany. Exploring our respondents' narratives we analytically differentiate between three levels of practices normalizing the post-transplantation experience: (1) a personal level, (2) a level of the intimate, and (3) a level of anonymous sociality. Our comparative perspective shows that sociocultural differences play a much greater role in interactive normalization practices (levels 2 and 3) than on the personal level (1), where universalized medical knowledge provides a framework that supersedes the role of cultural or social differences.

*Keywords:* normalization practices, chronic illness, Sweden, Cyprus, Germany

*Well, from time to time I think about it [the transplantation] and I'm very grateful. But most of the time I forget about it, most likely because my liver is doing so well. Everything has become so normal already, just like before, it's hard to believe actually. I had not imagined it would turn out this good ... Of course I am still careful with my meals. (Marlene Lukaz)<sup>1</sup>*

Marlene Lukaz is 57 years old, lives in Berlin and received a liver transplant in 2003. To capture the meaning organ transplantation has had for her one has to go farther back in her story, beyond early 2002, when she was put on the waiting list for a new organ. At that time, she suffered from a tremendous-

ly enlarged liver full of cysts, which had developed over more than a decade and for which she had undergone painful liver punctures for many years, each puncture relieving her for a short while only. Although her polycystic liver was not life-threatening, transplantation improved her life significantly, relieving her from various burdens associated with her "heavy belly", which reduced her mobility, caused chronic pain and was a visual reminder of her obvious exceptionality: "Just imagine: I appeared to be highly pregnant all the time. I couldn't even bend down to close my shoes – I never bought shoelaces. And of course my appearance stressed me psychologically. People said: look at the old bird, she is pregnant. I couldn't take it."

Considering all her experiences, Marlene Lukaz sees organ transplantation as a favourable medical intervention and as a success: Transplantation relieved her of suffering, considerably enhanced the way she experiences her state of health, and enabled her to look back on her chronic liver problems as a temporary, exceptional episode in her life. However, she did not return to normality in a simple, straightforward way. Instead, her everyday life is intricately shaped by the many *chronic* side-effects of transplantation: among them forced adherence to strict hygienic rules, the permanent, worrying risk of organ rejection, adverse consequences of immunosuppressive drugs, regular medical check-ups, limited capacity to work, and, as a result, her pending application for early retirement. Yet, she claims to “*forget*” about these fundamental changes in her life: She perceives neither her chronic post-transplantation condition as illness, nor her lifelong dependency on intense medical treatment as exceptional. But as the last sentence in the first quote indicates, she continuously has to intervene into her body. The treatment regime after her liver transplantation requires an active, flexible self that is capable of long-term discipline and self-governance (Rose 1998). She has to treat her body in a mode of extensive carefulness.

That Marlene Lukaz plays down the burdens of her treatment regime and instead emphasizes that she has “*a normal life*” can be interpreted as a successful coping strategy, a learned tactic: the outcome of what will be called *normalization practices* in the following. In this article, we will analyze how transplanted persons *normalize* their extraordinary condition, and we will ask how this sense of normality is achieved. Which everyday life practices and normativities are mobilized and (re)negotiated in the process?

To understand what counts as normal in the eyes of our respondents, what strategies they apply to normalize their post-transplantation situation, and which social and cultural mechanisms of in- and exclusion they have to face in doing so, our case-based analysis will explore respondents’ narratives of normalization practices. Analytically we differentiate between three levels on which the post-transplan-

tation condition is normalized: (1) a personal level, (2) a level of intimate others and family, and (3) a societal level. Drawing on a comparative perspective, we will show that sociocultural differences play a much greater role in *interactive normalization practices* (levels 2 and 3) than in *individual coping or self-normalization* (level 1), where universalized medical knowledge provides a framework that supersedes the role of cultural or social differences.

## Material, Methods and Theoretical Perspectives

The following analysis draws on empirical material collected in the framework of the EU-Project “Challenges of Biomedicine: Socio-Cultural Contexts, European Governance, and Bioethics” (2004–2007).<sup>2</sup> The comparative project explored attitudes towards and experiences with transplantation medicine and genetic testing based on focus group discussions with patients, their relatives and laypersons, as well as ethnographic interviews with selected focus group participants.<sup>3</sup> This article draws on focus group and interview material from Sweden, Cyprus and Germany concerning experiences with transplantation medicine, namely the accounts of 18 transplanted persons, 5 relatives of organ recipients, one of whom donated a kidney to her husband, and 4 persons on the waiting list for an organ.<sup>4</sup> Despite the many social and cultural differences of the 27 participants and their different residences in Berlin, Germany (11), the region of Lund, Sweden (7), and Nicosia, Cyprus (9), central for all respondents was maintaining “*a normal life*”, (re)gaining control over their bodies, mastering medical uncertainties, and coming to terms with the individually and socially challenging situation of living with a chronic health problem.

Normality is *the* important point of reference when respondents describe their past illness experiences and their current situations. Yet, what counts as normal is not a matter of fact but a dynamic valuation that is negotiated in specific contexts and in differentiation to what counts as abnormal (Canguilhem 2000). It implicates “*how things are*” just as much as “*how they ought to be*” (Hacking 1990:

163), ambiguously combining description and norm (cf. Therborn 2002). It is here that sociocultural difference enters the equation, since ideas about normality and abnormality are “culturally constructed and intimately associated with the social, political, and moral order” (Lock 2000: 259) of a given social context. What our respondents refer to as normal, that is, as typical, habitual, familiar or as natural, lies at the heart of anthropology’s comparative inquiry of common sense(s) (Herzfeld 2001: 14). Despite its somewhat difficult reputation in anthropology, and the challenges of creating comparability of phenomena (cf. Niewöhner & Scheffer 2010; Gingrich & Fox 2002), a comparative perspective provided us with valuable insights: Cross-reading the material from the three localities provided us with valuable insights into notions and variations of what counts as normal lives with or without organ transplants in these different European localities.<sup>5</sup>

Anthropological research on organ transplantation emphasizes that organ recipients have to work hard for their new lives (Hauser-Schäublin et al. 2001: 175).<sup>6</sup> Transplantation generally is understood to be a “transformative experience” (Sharp 1995), demanding from organ recipients that they harmonize their old and new embodied selves and synchronize their subjective experiences of their modified bodies with transplantation medicine’s objectified view on the body (Kalitzkus 2003). In addition, they have to “reconstruct their identities” by personally and publicly “rebuilding their sense of self” (Sharp 1995). Olivia Wiebel-Fanderl (2003) discusses individual narratives of coming to terms with transplantation as moments of biographic reconceptualisations of the self which point to individual and collective forms of coping as well as contemporary representations of transplantation medicine. We take respondents’ pronouncements of how normal their lives have become after transplantation as a starting point for exploring *normalization practices* as they are embedded in different social situations and contexts of living with an organ transplant. We will examine *narratives* of normalization practices, not practices themselves – we will analyze how our respondents speak about everyday practices in a spe-

cific social and interactive setting, be it a semi-public focus group or a more intimate interview with an ethnographer. These narratives are analyzed as instances of meaning-making practices, which, most of all, serve to establish continuity with the past and an expected or desired future (Jenkins et al. 2005), and they shed light on cultural meanings and practices that surround illness experience (Kleinman 1988; Garro & Mattingly 2000).

### *Normalization of Chronicity as a Distributed Practice*

Organ recipients may desire the normality an organ transplantation promises, but often find themselves in a state of “persistent liminality”, “betwixt and between the states of ‘health’ and ‘illness’, and ‘patient’ (who depends on others) and ‘normal person’ (who participates in and contributes to a family)” (Crowley-Matoka 2005: 827).<sup>7</sup> In accordance with this, we analyze “transplanted ‘health’” (ibid.) as a chronic health problem, in which a simple return to normality, a return to a recovered independent self as suggested in the sick-role model (Parsons 1951, 1964), is impossible. However, the Parsonian perspective on rights, obligations and reciprocities of everyday moral behaviour is nonetheless useful in understanding respondents’ normalization practices as strategies of dealing with “competing expectations of an ongoing sick role and of normal everyday roles” (Varul 2010: 81). Organ recipients tend to describe the post-transplantation period as normal not in the least because any reference to problems would clash with the collective expectation that the highly costly process of organ transplantation, an important hallmark of medical progress, might have failed (cf. Mongoven 2003; Fox & Swazey 1992). Narratives of leading a normal life then can be interpreted as the outcome of a complex process aligning collective and subjective expectations of normality.

From the perspective of *health psychology*, persons with a chronic health problem have to adjust to the new situation and regulate and restore their self by reprioritizing different goals and life domains; they have to find meaning and purpose in illness experience (Sharpe & Curran 2006). Adjustment is viewed

“as the process to maintain a positive view of the self and the world in the face of a health problem” (ibid.: 1161). What has to be achieved according to this perspective is a restored *psychological* equilibrium. Similarly, but focussing on *interacting* individuals, *medical sociologists* argue that the chronically ill and their relatives have to develop strategies to adapt to the new situation and to neutralize their exceptional status, their deviance from the norm, through processes of normalization (Gerhardt 1990). Ideally, this is achieved by means of a biographical reconstruction of identity or by various activities that manage daily life in to being as normal as possible, e.g. covering up limitations, redefining symptoms or inventing new routines (Strauss et al. 1984; Bury 1991; Charmaz 2000). However, the chronically ill have to *react* not only as patients to dynamic processes of disease, but also to *interact* in no less dynamic social contexts: “The ability to cope is located neither wholly in individuals’ personal strength nor in the condition itself. Social and material resources, life transitions and the responses of society and its institutions all impact on individual ability to cope” (Atkin & Ahmad 2001: 625). Strategies of normalizing remain thus precarious and vulnerable “to both changes in the condition, in personal and social circumstances and the disabling attitudes of others” (ibid.: 618). For that reason, illness experience in *medical anthropology* is conceptualized as “transpersonal” and “sociosomatic” (Kleinman 1988, 1997): Despite being unique and particular in its embodied subjectivity, illness experience is seen as highly embedded in social networks and life worlds, interwoven with sociocultural realities, collective patterns of meaning making and the politics of everyday life (Kleinman & Seeman 2000). Accordingly, illness experience is conceptualized as a product of complex negotiations between several social actors and cultural knowledges that are mediated through and expressed in personal accounts of perceiving, classifying and dealing with ill health and the resulting exceptionality.

Consequently, normalization cannot be adequately conceptualized as a transitory process with a (happy) endpoint of self-restoration; it is at best a

rather precarious *dynamic equilibrium*, produced in a process that requires continuous, ongoing activity: a Sisyphus work. In this context, self-motivation for unrelenting (self-)interventions are a pertinent task, threatened by exhaustion, weakness, loss of motivation or the permanent threat of organ rejection. Accordingly, we conceptualize normalization in the following as a dynamic process in the making, as a process in search of a dynamic “physio-psychosocial-cultural” equilibrium. Preconditioning this equilibrium are disciplined continuing activities and highly socially embedded practices: they routinely involve many actors, span diverse situations, and have to mobilize heterogeneous infrastructures. For this reason, we understand normalization as a *socialized, distributed practice*, involving and mobilizing personal relations. The normalization of the post-transplantation condition into a *way of life* implies a whole set of necessary normative as well as pragmatic (re)arrangements of daily (inter)actions and the negotiation of social norms and cultural expectations. Against this background, we will explore how respondents describe their medically entangled life after organ transplantation, analyze how normalizing practices unfold in this context, and finally we will examine how they deal with dependency and exceptionality. As already indicated, in the following, we will scrutinise normalization practices with respect to (1) relations to one’s self, (2) relations to intimate others like families and friends, and (3) to the wider social context.

### **Self-Relations: Normalization of Non-Standard Bodies and Selves**

Most of our respondents highlight the “*amazing*” results of transplantation and tell stories in which transplantation has been the “*last chance*” and a “*happy*” endpoint of a serious (often chronic and life-threatening) health problem. The underlying narrative plot corresponds with public presentations of transplantation stories in the media and organ donation campaigns; many tropes we encountered in these narratives are inspired by the rhetoric of transplantation medicine, depicting the substitution of organs as a technically sophisticated, but medical-

ly unproblematic fix.<sup>8</sup> Our respondents divide their health biographies into a time before and after transplantation, in which the time preceding transplantation is described as an exceptional episode, characterized by suffering, existential fears of organ failure and death, and the dramatic experience of waiting for an organ transplant. Whereas they mention the first days and weeks after transplantation mostly in passing, here and there illustrating the initial complications and overall hardship, they typically are quick to assure others that “*in the end everything worked out fine*”. In these accounts organ recipients are more often than not depicted as suffering, passive victims depending solely on external medical intervention and altruistic donation. What is muted is their agency, their own required actions before and after transplantation surgery: In order to be put on the waiting list for an organ, potential recipients have to demonstrate to transplantation surgeons that they are willing and capable of self-intervention and that they can deal with the tough medical regime after transplantation. While respondents retell life with a transplant as a biographic turning point, they mostly play down their struggles to adapt to a self-interventionist lifestyle in their narratives. They present post-transplantation stories in which coping with their current condition becomes a normal part of daily routine that goes without saying. What is made intransparent for the outside observer are the minute self-interventions and the social resources that have to be mobilized.

### *Learning the Dos and the Don'ts*

Organ transplantation saves lives by transforming ill health into a more liveable, yet medically dependent state. For organ recipients this means that they have to conform to a strict preventative regime. “*In the beginning that's the only thing you have on your mind*”, said Yvonne Larsson from Lund, who is in her late thirties and received a lung transplant in 2003, “*but I mean – you have to live.*” After six months, she was able to “*manage a little better*” and over time learned to “*live with*” the life-long requirement of adhering to the rules. Prominent among the things our respondents permanently have to “*keep track of*” are “*pills*”,

“*big ones, small ones, coloured ones, all sorts of*” that is, the immunosuppressive drugs they have to take, which weaken the immune system to prevent it from rejecting the organ transplant. The strict medication schedule (twice a day at regular intervals) has to be integrated into daily routines. For Hasan Çelik, a 47-year-old Turkish migrant who has lived in Berlin since the 1970s and who underwent liver transplantation in 1997, the intake of pills is serious work and requires the learning of new skills: “*When you're not used to it, it's hard. You'd take one after the other, and it never ends. Until I saw this woman taking them all in one go. I thought, I couldn't do it, but I tried, and it worked – it's easier that way.*” For Tobias Mårtensson in contrast, who is from Lund and had a lung transplant in 1998 because of his cystic fibrosis, the routine intake of pills was not new but a “*habit*” he had already developed before the transplantation. The self-administration of medication for him is one of many “*small things that you sort of learn to try to control (...) just something you have to [do].*”

The lengthy catalogue of dos and don'ts respondents listed for us can be interpreted as forms of *sub-medical* interventions into their lives. Whereas some respondents experience them as straining and as diminishing their quality of life, most consider them to be “*no problem*”, easy enough to habitualize. While they play down the extent of their interventions, the “*small things*” they do cover the frequent and thorough washing of their hands or inquiring about the health status of guests sitting next to them at a party. There are many things to avoid, like eating raw food at a restaurant or touching the door of public buildings at the handle where most people touch it. Such seeming trivia gives a full account of how respondents integrate practices and tactics of “*doing hygiene*” or “*doing medication*” in their everyday lives. The therapeutic regime following transplantation requires of our respondents to become *active* and *conscious* subjects of self-interventions and self-surveillance. Rules have to be interpreted with disciplined flexibility to make them fit into daily routines or desires. Accordingly, when Marlene Lukaz – contrary to medical advice – does not give up eating strawberries, she nevertheless follows the

rules of hygiene and performs a minute choreography: She examines and rinses every single fruit properly, eats them one after the other, and in case one of them tastes slightly rotten, spits it out and washes her mouth before performing the same procedure on the next one.

Apart from one's home becoming a location of therapeutic self-intervention, respondents regularly have to attend medical check-ups in which particularly the function of the transplanted organ is examined, in order to exclude the imminent danger of organ rejection. When respondents jokingly state that they are "*married*" to their doctors or hospitals, they refer to the frequent routine of their visits and the implicated rules of engagements with their doctors. Compliance with the treatment regime and medical knowledge play a central and unquestioned role in the lives of all our respondents. Yet, individual physicians are rarely mentioned in the Swedish and German respondents' accounts, instead, medical expertise appears in a generalized and impersonal mode expressed in phrases like "it's just – one cannot ..." or "the only thing is – I shouldn't..." Interestingly, individual doctors figure prominently in Cypriot narratives. We take this presence or absence of references as an indicator of the degree to which the physician's guidance is not taken as resulting from a *personal*, but from a *professional* relationship; in the latter case, the individual physician disappears behind a corpus of abstract expertise. Accordingly, the treatment regimen is presented and experienced by our German and Swedish respondents as generalized rules which have to be accepted and eventually become habitualized as a rather unquestioned part of daily, bodily routine. Cypriot respondents, however, rely on *and* expect modes of guidance that are more personal.

Generally, respondents have to deal with abstract values, data and figures that survey, monitor and measure their bodily functions. These "objective", medical observational techniques increasingly displace normal, unaided modes of introspection – "*listening to one's body*" will not do, as Regine Paulitz, a German participant who had a heart transplanted, put it: "*You have to let them [physicians] look at you*

*all the time, because I can't look inside myself.*" Since organ rejection cannot be felt by ordinary senses, respondents experience the feeling of losing control: they have to subject themselves to objective medical observation and have to rely on objectified medical facts and interpretations. This erosion of the ability to trust in subjective, circumstantial self-experience is perceived by our respondents as a fundamental shift in the way they experience their bodies. They have to adopt a new mode of reflexivity, learning to perceive themselves and their state of well-being through for instance blood parameters. Having learned the numerous lessons of self-objectification, respondents develop a remarkable mode of objectified reflexivity. They become experts in interpreting medical data and learn to infer how they are and how they feel through the interpretation of medical data. In these iterative "looping processes" (Hacking 2006) – from subject to object and subject again – they learn to trust in a technologically extended mode of self-perception. These self-techniques demand a self-controlling subjectivity that is already selected for *before* transplantation: As Yvonne Larsson put it, "*I don't get a transplant if they [physicians] think I can't handle it.*"

Overall, the therapy regime following organ transplantation structures the activities of our respondents in an intricate way, establishing a tight temporal-spatial grid and a highly disciplined individual. Medicine offers a strong framework that requires individual regularity and routinization as well as a new mode of self experience. Medical knowledge of organs, immune systems and the effects of immunosuppression is incorporated into everyday knowledge. Preventative practices after organ transplantation are based on a highly normalized – in the sense of a normative as well as unquestioned – choreography of temporal, spatial and social settings. Thus, the required self-interventions of health management become normal parts of everyday routines.

### *Accepting and Growing into Exceptionality*

What a chronic health problem is and means is learnt the hard way: "Lessons in chronicity come in

small everyday experiences” (Charmaz 2000: 282). All our respondents had to and “*did grow into* [illness] *little by little*,” and thus into a condition that finally resulted in transplantation. Equally gradual was the escalation of medical interventions set in motion by the first diagnosis. Retrospectively, several respondents describe that the step-by-step procedure of medical intervention and the subdivision of health problems into smaller units of medically manageable subproblems reduced fear; seeing not the “*whole process*” but rather only the “*next step*” tended to reduce fear. For many respondents the option of transplantation appeared less disturbing, particularly since a partiality of knowledge or even partial ignorance was perceived as reassuring. Exemplary is a statement of Sotiris Georgiou, a 63-year-old Cypriot who received a kidney from his wife, when he discusses the case of an acquaintance who lost her kidney due to a rejection and had to undergo retransplantation: “*It is harder than the first time or when under haemodialysis because during haemodialysis the person does not really know. The second time, he/she knows both situations and is afraid to go back and have the transplantation again.*”

He interprets his own health biography in terms of destiny: “*In my opinion, God gives us the opportunity to go through hardship in order to come closer to him.*” Similarly, Anna Kyriakou, a 19-year-old from Nicosia who had bone marrow transplantation, states: “*Of course, I asked where this disease [leukemia] comes from and even physicians told us they do not know, and therefore I took it as a sent sufferance.*” Here, illness-experience is normalized by integrating it into cosmological understandings and beliefs: individual suffering is understood as destiny or as sent from God. Interpreted in the framework of religion, illness appears to be normal or at least purposive, and personal coping with illness is transformed into a religious obligation. The role of medicine is to help deal with the consequences but it certainly does not provide sufficient explanation and support. Respondents, who present themselves explicitly as non-religious, also employ images of destiny. Many respondents use medical and non-medical explanations simultaneously to embed illness in everyday

cosmologies about life, because medical knowledge provides explanations that regularly fail to address questions of individual suffering.

“*To face life as it comes*” is an often used expression by respondents that seems to unveil a fatalist attitude but rather refers to active processes of ideational self-intervention: our respondents aim at redefining the meaning of illness and (post)transplantation experience as positive. In this regard, a Cypriot focus group participant who needs haemodialysis and is currently on a waiting list for a kidney says: “*My experience made me unafraid to live with the problem, and I tell everybody who has haemodialysis to befriend it in order to be able to deal with it.*” Getting used to going through haemodialysis regularly in his case is the result of accepting and creating a “friendship” with the process: he adapts to his situation by redefining it.

Generally, respondents state how important it is to adopt a *positive attitude*. The implementation of positive thinking involves the process of coming to terms with the chronicity of one’s health condition and accepting limited capacities. For many respondents this meant discarding the ideal self-image of healthy normality and taking an approach that emphasizes what they still can do. They implicitly contrast their own positions to attitudes of self-pity, passivity and feelings of capitulation, in order to reframe their coping strategies as good practice. For many respondents, good practice includes self-empowerment by acquiring knowledge and information of their health problem and transplantation. They view medical statistics as well as experiences of other organ recipients as helpful sources for facing their situation in an informed manner. These approaches entail a normative notion of how one should cope with transplantation and correspond to current images of successful ways of dealing with health problems which Cameron Hay identified for the U.S. context as a “culturally legitimated John-Wayne-model” (Hay 2010) where health problems are conceptualized as failure to take care of oneself (Greco 1993). The mastering of health in a continuous process of self-intervention thus becomes an obligation. In this sense, ideational self-interventions add to the practi-

cal activities with which our respondents take care of themselves. Usually these self-interventions are naturalized by our respondents by grounding them in their own personalities, instead of attributing them to painfully learned practices.

### *Two Modes of Normalization*

On a more abstract level we found two different modes of normalization based on underlying rationalities. First, there is the mode of *adapting* life through practical activities that restructure everyday routines in accordance with the treatment regime following organ transplantation. Here, *praxeologies* dominate that are mainly guided by medical discourses. In contrast, the second mode of normalization practices is exemplified by practices of *retelling* or *reconceptualizing* life. Here, *ideologies* dominate redefinitions or re-evaluations of self-images and self-understandings against the backdrop of commonsensical, vernacular normativities or aesthetic judgements. Both modes of normalization then, are intensely socialized and closely interwoven with and dependent on pre-existing sociotechnical infrastructures which act and give meaning to actions. The discourse of medicine, its vocabulary and technologies as well as its truth claims are central mediators (Beck 2007) for both strategies. Our respondents use medical knowledges and techniques as a powerful repository to integrate illness experience into everyday routines, to de-exceptionalize their respective conditions and to create new modes of self-relation, self-knowledge, self-reflection and self-representation.

Despite our respondents' different health problems, their biographies and strategies of restructuring life before and after organ transplantation, and their struggle to adapt life follow a common pattern. All of them are confronted with therapeutic interventions and treatment regimes of transplantation medicine's follow-up care that are characterized by a large degree of standardization across Europe.<sup>9</sup> Accordingly, they mobilize equally uniform self-interventions; as a result, respondents in Sweden, Cyprus and Germany pursue highly similar adapting strategies. More variation becomes apparent when we shift the focus from medical dominated self-interventions

to the mode of retelling life under the new conditions of being chronically ill. Yet overall, these kinds of normalization practices appear to follow common patterns, too, leaving little space for cultural differences. Beyond these generalizations, respondents' stories mirror the manifold individual competencies and sociocultural resources on which they can draw. These resources can be religious beliefs, practices, education and lifestyle orientations, prior experiences with illness or befriended doctors. What our material shows is that self-interventions refer to ways in which individuals recognise themselves, redefine ideas of (ab)normality and in the end position themselves in the shifting poles of being both normal and exceptional. However, the self-interventions we have described so far are only understood adequately if they are interpreted as highly embedded, socialized and cultured practices that unfold in interactions with others. This contextuality is even more relevant for normalization practices on the level of respondents' relation with intimate others.

### **Relations to Intimate Others: Familial Normalization and Mutual Obligations**

In addition to the individualized mode of adapting to the chronic health condition after transplantation, chronic health problems and ways of dealing with them require an interactive mode since relations to intimate others – the partner, relatives, or close friends – are substantially affected. These intimate others experience illness and transplantation as outsiders but regularly share the hopes and sorrows of their loved ones. Studies of the family setting within which chronic illness is dealt with show that the quality of family relationships strongly influences how disruptive the illness is experienced to be (Gregory 2005: 382). The transformations caused by illness, necessary therapeutic activities, acceptance of exceptionality or the redefinition of self-images affect ill individuals as well as their intimate others and have to be integrated into family relations (Corbin & Strauss 1988). Being “both unexpected and unwelcome,” serious illness and chronic health problems “can test the fabric of normal family life” (Gregory 2005: 376).



### *Redefined Relationships*

Without being affected themselves, the consequences of serious illness and transplantation affect the lives of those who accompany and support transplanted respondents during the uncertain process. This becomes apparent in the term “we” one Swedish focus group participant uses to refer to the shared experiences of hope and uncertainty when her husband was on the waiting list for a lung transplant: “*When we were on the list, well we – you become (...), it affects the whole family.*” Since the whole family is influenced, experience of illness to a certain degree is collective. On the other hand, transplanted respondents often state that their family members are not fully able to understand their illness since they are not sharing the bodily experience. This does not necessarily involve a lack of experience but refers to differing perspectives of the same situation. Hasan Çelik, for example, contrasts his and his wife’s experience of transplantation: While he simply “*woke up*” after surgery, his wife experienced the long hours a liver transplantation takes with all its uncertainty and anxiety. Most transplanted respondents and relatives of organ recipients alike experience illness and transplantation as intensifying mutual relations. This is typically expressed as “*getting closer to each other*” or as a new acknowledgment of “*appreciating things*”. Many respondents report a fundamental change in attitudes towards life and a reprioritization of goals in favour of non-materialist interests, spending more time with family and friends or trying to improve relationships with them.

However, several respondents mentioned that reactions of close companions can also be an obstacle on the way to normalization. Family members, more often than not, are described as hampering normalization by “*worrying too much*” or by displaying *too much* concern about the ill family members’ health condition, especially after organ transplantation. As a result, some respondents note that they do not always tell their family members when their condition worsens or they experience a little crisis. One 32-year-old German respondent distinguishes between her parents and her friends, indicating that the latter rather support normalization, for

example, when going with her to a bar and gossiping all night, thus engaging with her in the normal activities persons of her age do, despite her health problem. Altogether, intimate others hold an ambivalent position in respondents’ accounts as both saboteurs and supporters of the patients’ attempts to normalize their condition. Although respondents consider their close associates overall as supportive and helpful, they hardly ever mention the daily support given and the contribution to the daily needs of coping. Similarly, they often leave implicit the material and practical consequences of illness that might affect other family members. An exception is Anna Kyriakou who had to go to Great Britain for her bone marrow transplantation; she reflects about the grave costs for her parents. She was afraid that her illness would disrupt her social life (having to leave school) as well as the social lives of her parents: “*I was thinking about my parents and that they would come with me for six months, and have to leave their jobs. Where would they find money again etc. – they would lose their jobs.*”

Intimate others of transplanted patients care and take care; that they do so is mostly taken for granted. What is often described as “*coming together in the face of serious illness*” is perceived as normal by most of our respondents. This kind of taken-for-grantedness becomes especially apparent in the extreme case of 50-year-old Andreas Moysesos from Nicosia who is on haemodialysis and has been waiting for a kidney transplant for several years. His mother had been identified as a potential donor but in the end she opted out and did not proceed with donating one of her kidneys to her son, a change of mind he could not comprehend: “*After what happened to me and how close relatives and especially my so-called mother treated me, I believed that there was no humanitarianism. I was very disappointed, and I saw the world in black. I considered them all to be Judas – traitors.*” For him, his mother did not fulfil her natural obligations as she declined to sacrifice her health for her son.<sup>10</sup> Re-defining her as not his “*real*” mother makes his experience more acceptable in a society where the mother-child relation is expected to be strong and unbreakable.

### *Challenging Moral Economies in Intimate Relations*

Moral *cum* economic obligations within the family are a central subject for transplanted respondents, particularly when it comes to their own obligations. They particularly address role expectations of being a good partner and a regular contributor to family life as they are challenged by illness and transplantation. In this regard, Paul Meyer, a German in his late fifties who underwent heart transplantation twice, argues that “*it is not so surprising that so many women leave their heart transplanted husbands*” since they cannot offer “*certain things*” any longer. Health problems, bodily condition and side effects of immunosuppressive drugs may reduce earning capacities as well as “*libido*”. After transplantation, he had to give up his leading position in a company and for several years now relies on a small pension, a minijob, and the income of his wife. His reduced socioeconomic position in his family conflicts with dominant images of masculinity, his aspiration to be “*head of the family*”, as well as his self-image of being a “*good husband*” and the principal provider of family income. The altered sexual relation to his wife adds to the obstacles of his struggle to live up to his expectations. His efforts to cope with his new dependencies point to the redefinition of marital and gender relations that chronic illness might initiate. Moreover, it indicates unmet expectations that “*things will become normal*” after transplantation. The time and effort needed to adapt to the transformation from independent income provider to dependent early retiree is a topic of both female and male respondents.

Before and after organ transplantation respondents depend on different degrees of care and support from their families, a challenge to their sense of autonomy. Especially the Swedish and German respondents talk openly about their worries with respect to reduced working and earning capacities. However, these topics do not appear equally prominent in our Cypriot material. We do not interpret this as an *absence of problems*, but rather as the outcome of *different sociocultural constellations* and of the different histories and functions of the respective

welfare systems. More specifically, we interpret these results as the consequence of a dialectical process where welfare systems tend to individualize subjects by providing the chronically ill patient with a reliable, if small, source of income, as is the case in Sweden and Germany. Here the welfare state, and not family and the wider kinship network, is supposed to provide for the basic needs of the individual. In contrast, the Cypriot material suggests that extended families (Argyrou 1996) and peer groups are the most dominant and stable form of solidarity, at least concerning health care. In addition, family relations in Sweden and Germany tend to depend much more on the (re)negotiation of the family roles of the partners: traditional role models are challenged by many processes, for example in the economic, legal, social and cultural domains. As Viviana A. Zelizer (2005) convincingly shows in an analysis of similar processes in U.S.-American family life, family members have to *actively* negotiate how moral, immaterial, material and economic resources are utilized and exchanged, since traditional models are increasingly inadequate with lifestyles in a neoliberal setting.

More often than not, respondents discuss the issue of dependency only in terms of medical dependencies, or dependency on welfare and societal solidarity rather than in terms of dependencies on family members. How is it to be explained, that although our respondents briefly mention activities of family members and friends that support them, they mostly leave out the many activities concerning the self-management of disease which often become a matter of family management? On the one hand, this can be explained as a result of an ethnographic effect of the focus group and interview questions: We asked individuals, not families, how they cope with transplantation, enhancing a methodological individualism. On the other hand, this partial silence might also result from the fact that mutual obligations are taken for granted in families in all domains of social life, but especially in the face of grave existential threats. Additionally, many of the required self-interventions our respondents have to perform are related to gendered divisions of labour within families, for example taking consideration of strict

hygienic rules and preparing meals. To put it differently, familial solidarity is *tacitly* taken for granted and becomes topical for respondents only in the rare case when familial solidarity is challenged – as in the case of Andreas Moyses mentioned above. As became obvious even from the rare instances where respondents made the family involvement topical, a perspective that considers the familial context as central for normalization practices after transplantation is inevitable. Accordingly, a departure from the individualistic bias in the treatment regimes of transplantation medicine is necessary. As a Cypriot focus group participant put it: “[The] *environment plays a role in the course of [disease]. Where you live and the support you have play a role. I believe in this more than I believe in medicine.*” In the following, we will provide some insights into how our respondents perceive of normalization in their social environments beyond their families.

### Social Relations and Interactions

Above, we have conceptualized normalization as a relational process in the dynamic social constellations of the family. To achieve a sense of normality at the workplace or even in anonymous social environments involves many more contingencies and complexities for our respondents. Strategies of normalization outside of the close circle of intimate persons are to a certain extent in other people’s hands. In the following, we will take up respondents’ normalization strategies with respect to (1) social norms and stigmatization, (2) obligations of being a productive member of society, and (3) self-help groups as new forms of collective solidarity.

#### *Confronting Stigmatization*

Respondents frequently feel that they depend on other people’s opinion, understanding or positive evaluation when they try to normalize their health problems; and they experience these dependencies in quite a diverse manner. Of special concern are those interactions with anonymous others when there is no opportunity to explain one’s exceptionality and where stigmatization and prejudice have to be confronted. How individuals deal with stigmati-

zation depends on the stigmatizing attributes and on the visibility of one’s otherness (cf. Goffman 1963). Marlene Lukaz, whom we quoted in the beginning of this paper, suffered because of her “*big belly*” which made her stand out. For her, transplantation ended not only her yearlong suffering but also her exceptional appearance. For Anna Kyriakou, in contrast, transplantation resulted in her stigmatization because she lost her hair. She recalls an instance where she walked down Makarios Street, the most popular street in the centre of Nicosia, full of shops and cafeterias. When she was passing one of the cafés, someone sitting there commented on her hair and looks, whereupon others questioned whether she was “*a boy or a girl*”. For the 19-year-old, this short encounter was devastating. Makarios Street can be likened to a catwalk where pedestrians as well as drivers are subjected to anatomical, moral, economic and cultural inspection. For women of Anna’s age, a perfect body in this setting means to command *the* most important capital. That her peer group, men of her age and potential marriage candidates, were making fun of her was truly painful and frustrating to her.

Apart from Anna Kyriakou’s case, respondents’ references to stigmatization experiences primarily concern the time before organ transplantation. What is visible afterwards are transplantation scars, which often can be hidden, and in some cases side effects of immunosuppression like tremors or a “moon face”. Not surprisingly, it is mostly our female respondents who refer to such visible aspects of their condition which provoke hard to ignore looks and comments for contravening social norms that still apply more strictly to women (cf. Saltonstall 1993; Biori 2009). But our male respondents also wonder what impression others might get when confronted with their preventative practices. Hasan Çelik, for example, refers to the strict hygienic precautions he keeps up: “*That is something – to people who don’t know me I might appear – ‘Jesus, he’s so fussy!’ I’ve internalized it. Hygiene is on top.*” Such examples show that our respondents have a keen understanding of social norms and the play of social power relations involved in stigmatizing comments. Åke Lindgren, a heart-transplant recipient in his fif-

ties from Lund, brings in a different perspective on the matter of judging others: “*I guess I dissociated myself from [handicapped] people before [transplantation] (...) It’s completely different today.*” He relates this change in attitudes to the new values or a new perspective on life that he, like other respondents, claims to have developed after going through severe illness experience.

Whether respondents are able to cope with offending judgements of others depends on the social situations and constellations as well as of the position respondents have in social hierarchies. Nevertheless, the ability to prevent disclosure of one’s non-conformity can be understood as an important aspect of self-determination when coming to terms with illness and transplantation. Regarding the three different locations where our respondents live, we observed that in the small society of the Republic of Cyprus, the range of variation in what counts as normal or not is rather small and thus the pressure for respondents to conform is higher. However, the invisibility of health problems can be a burden too, since visibility affords opportunities for social recognition and legitimization of difference: “[P]eople who are unable to engage in everyday work, self-care, and social activity experience invisibility as a serious handicap” (Hay 2010: 267).

### *Working One’s Way Back into Society*

When respondents talk about personal and social consequences of illness and transplantation, references to personal careers are prominent. The possibility to return to work after transplantation, or to work despite being bodily and energetically restricted, is for many respondents a central means of normalization. Work can keep one busy when being on the waiting list or enables one to preserve a domain of life unchanged and normal. The ability to work and to earn a living fundamentally influences our respondents’ self-images, their sense of autonomy and secures their familiar roles in their families. Moreover, even partial economic independence defines relationships to systems of social solidarity in a specific way: Those who work pay taxes or social security dues, those who contribute to the na-

tional social security system do not feel completely dependent. Åke Lindgren perceives the return to work as a means of individual normalization but he interestingly does so in the framework of social values: After transplantation “*the demands come back, you have to be moulded into society, you have to get back to it.*” One needs rehabilitation and “*energy*” but in the end, “*that’s the point of it all, going back to a job.*” “To be moulded (back) into society” expresses in a strong metaphor the desire to return to being a normal, fully respected member of society. Living up to this demand requires self-intervention, yet, when Åke Lindgren started work training six months after his heart transplantation, he soon experienced the new limits of his capacities – working part-time was the new limit of what he could take. In addition, his attitude towards the relation of work and life had changed: “*Life comes first [now].*” Before his heart attack and transplantation, work came first. He describes himself as a career-oriented person who always worked a lot, a habit which took its toll, as he states. Nonetheless, he stresses the importance of going back to work to prevent what he views an illness identity. To support his claim, he contrasts his situation with that of an acquaintance who underwent heart transplantation at the same time he did. He describes this man as one of those persons “*who live in their illness,*” someone who “*lives in his transplantation role*” and, although he manages well and lives a decent life free of complications, he “*is nothing but a heart transplant recipient,*” someone who “*hasn’t gotten himself a life afterwards.*” More specifically, his acquaintance “*had a problem getting back into the labour market*” and thus “*ended up standing outside.*” His acquaintance fails in Åke Lindgren’s eyes because he does not make himself useful to society again and evades social demands. What he does not take into account, but what some of our respondents experienced the hard way, is the simple fact that it is not necessarily his acquaintance’s fault that the labour market is apparently not giving him a second chance. Like other respondents, Åke Lindgren emphasizes work as one of the main factors which contributes to the individual’s well-being and which is a prerequisite to really being a part of society. His

statements show how strongly social norms influence modes of rendering life as normal.

### *Forms of Organizing Solidarity*

A specific social form of organizing self-interventions and solidarity that relates to both the individual and the social levels, are patient groups. Here, respondents interact with like-minded or equally concerned persons and share the experience of understanding and managing a specific health problem and medical intervention (cf. Rabinow 1999; Kaufert 1998). Medical information, addresses of “good” physicians, but predominantly patients’ problems and experiences are shared in these groups – including experiential knowledge of how illness feels and tips for doing post-transplantation management. Several of our respondents think these support groups are as valuable as medical information provided in the clinics: whereas their physicians have no direct bodily experiences of the conditions they treat, here patients can tap into the direct experiences and understandings of fellow sufferers. In this sense, self-help groups have an important mediating function for both the medical system and patients. Taking place in hospitals, private houses, Internet forums, electronic or paper versions of magazines, these exchanges take on different forms of social communication. Respondents who are members of patient groups state that their participation supported their learning process and thus helped with normalization. Several of them learned for example that an organ rejection is not an abstract risk but is normal rather than exceptional. In order to normalize the risk and the occurrence of a rejection episode they mobilized different knowledges – of other patients or medical statistics. In such examples, patient groups provide a collective frame of sameness and a valuable instrument that allows the de-exceptionalization of one’s experience. Meeting patients who are in a better or worse condition than oneself, provides a comparative perspective that might be helpful for individual patients – a function largely unexplored in psychological studies (Dibb & Yardley 2006).

Self-help groups provide a normative framework and create an atmosphere where techniques of self-

intervention are highly valued, a mind-set which might appeal only to a segment of patients, excluding others (cf. Schmidtgunst 2005). Moreover, patient groups often combine internal activities of self-help and external initiatives like public relations and lobbying. When acting in the public sphere and making transplant recipients’ concerns and interests public, patient groups utilize strategies of both normalization and exceptionalization. When engaging in public campaigns in favour of organ donation, they usually stress the normality of organ transplantation and present themselves as living examples of medical success and a restored normality. Complications, ambivalences or necessary self-interventions are again muted. When respondents or patient groups lobby for financial support from the state or the healthcare system in order to maintain their place at work, or when they engage in public discussions about changes in transplantation law, they in contrast use strategies of self-othering and emphasize their exceptionality in order to receive attention.

Yet, going public can also be viewed as an expression of normalization from an individual perspective. Anna Kyriakou, for instance, talks openly about her experiences with leukaemia and bone marrow transplantation at public events or in schools in order to function as a “*vivid example*” and “*inform*” and “*sensitize*” people about the issues at stake. This can be interpreted at two levels: First, she successfully underwent transplantation and can now live a normal life – in a sense, her life is normal as it is. Second, her normalized life helps her to accept her experience and helps other people to do the same. Altogether, membership in patient groups offers flexible possibilities for making sense of illness experience and relates to concepts of both normalization and exceptionalization. More ambiguous is what respondents do with this duality of instruments provided. Our material suggests that there are two rather oppositional approaches to this: There are several respondents who participate in patient groups and for whom membership provides security, group identity and thus normalization in the sense of experiencing sameness. But there are many more respondents for whom *not* participating – keeping a

distance from fellow sufferers – indicates successful normalization.

### Conclusion

Scrutinizing how transplant recipients in Cyprus, Germany, and Sweden normalize their extraordinary condition and achieve what they call a normal life we have analyzed respondents' narratives of normalization practices on three levels of (inter-) action: differentiating between individual/self-related, familial and social practices of normalization. Differences between the three locations are more apparent on a meso- or macro-level, in relation to family, co-workers, or the welfare system than on the level of the individual; here the strict guidance of medical therapy regimes is dominant. The constant threat of losing the organ through rejection especially defines the limit of normalization for all our respondents and enforces an adherence to the medical regime and a highly disciplined way of life. Our respondents are simultaneously patients, who depend on advanced medical intervention and learn to see and feel their bodies mediated through the medical gaze, as well as normal participants of ongoing daily life (cf. Crowley-Matoka 2005). They have to reconcile these conflicting roles and expectations; most of them – as we have shown – do so quite successfully. In this regard, the two modes of normalization practices we have analyzed on the individual level – the adapting and retelling of life – as well as the analyzed rearrangements of familial and social relations attest to successful strategies of coming to terms with their condition after organ transplantation as a normal way of life. *On the one hand*, these normalization practices can be interpreted as ongoing attempts to stabilize their biographies and everyday lives in the midst of health-related uncertainties. For most of them, “sickness has become a way of life” (Stacey 1988: 143). But what is normal and routine is not an unproblematic given: Normalization understood as the long and sometimes painful process of producing normality means coming to terms with being exceptional, doing exceptional things – like taking unusual amounts of medication, taking hygienic precautions, legitimizing otherness

in diverse social contexts as well as being dependent on regular monitoring by medical experts. In this regard, biographical, cultural and social differences between our respondents are rather limited: Their actions are embedded in a medical praxeology. *On the other hand*, coping with transplantation is not restricted to the adherence to medical treatment regimes. Instead, it means negotiating relations with intimate or anonymous others about obligations, confronting stigmatization, and being disabled in certain aspects. It further means that transplanted persons have to reconceptualize their biographies and aspirations. In this regard, different cultural cosmologies, diverse social settings, as well as the way in which the medical system or the welfare state provides support, play a crucial role in affording an opportunity structure for transplant recipients which they can use for normalizing their lives.

The important role that the social environment plays in normalization goes beyond the current scope of this study that is based on the analysis of patients' narratives. A more thorough investigation of modes of normalization concerning our respondents' relations and interactions in a wider social context would require the observation of actual practices, hence: an ethnographic account based on participant observation. Only such a mode of inquiry could reveal how normalization strategies unfold in clinical contexts or family settings or social situations by negotiating the dynamics of everyday post-transplantation life-in-practice. To capture the complex dynamics of normalization on the level of everyday practices more systematically and to render our explorative insights more feasible, further ethnographic research is needed.<sup>11</sup> Such kind of research should follow organ recipients more closely during the (post)transplantation process and its different challenges to normalization. In addition to such ethnographic case studies, a more elaborate comparative approach (as opposed to the explorative one used in the context of this research) could provide further insights into the subtleties of culture at work in normalization practices. Particularly our finding that cultural differences appear to be marginal at the level of self-related normalization practices concerning the medical treatment regime,

asks for clarification regarding the question of how these findings relate to recent studies in medical anthropology and science studies that emphasize the local situatedness of medical practices. While we assumed – based on the accounts of our respondents – that clinical practices, medical knowledge provided, and interventions of physicians followed internationally established best practices a closer look at local differences might be highly enlightening. As we hope to have shown, a research interest in normalization practices could bridge the special interests of medical anthropology, a growing attention towards local differences in the functioning of “medical platforms” (Keating & Cambrosio 2000) and the general anthropological interest in everyday life practices and local understandings of normality or normativity.

## Notes

- 1 Names used for research participants are pseudonyms, all quotes from empirical material are italicized.
- 2 Project no. SAS6-CT-2003-510238, details available at: <http://www.univie.ac.at/virusss/cobpublication>; for a summary of ethnographic findings in Sweden, Germany and Cyprus, cf. Beck et al. (2006).
- 3 Participants were recruited via public flyers, key persons and the snowball system, hospitals, and patient associations, and were selected to be preferably diverse and balanced regarding criteria such as gender, age, education and religion. Regarding the latter less variety existed: Swedish participants were mostly Protestant and all Cypriot respondents were Greek Cypriots and Christian Orthodox. The variety in the kinds of transplants – in Lund (heart, lung), in Nicosia (kidney, bone marrow), in Berlin (heart, kidney, liver) – depended on locally present transplant centres. All transplanted participants got at least through the first two years of living with a transplant and they represent the rather successful, i.e. unproblematic, cases of transplantation.
- 4 Additionally, we could rely on previous ethnographic work and research carried out in the three countries by the respective teams, concerning transplantation medicine and biotechnology (Lundin), genetic testing, bone marrow transplantation and cross-cultural analysis (Beck), and the impact of medical/genetic knowledge and social aspects of health and disease on notions of solidarity and bodily integrity (Anastasiadou-Christophidou).
- 5 For a more detailed consideration of the usage of comparison in the project, which was undertaken as an epistemic practice by researchers and research participants likewise, cf. Amelang & Beck (2010).
- 6 For ethnographic analyses of the ways in which individuals and societies deal with transplantation medicine’s usage of human body material and its prerequisite of the donor’s brain death, see e.g. Fox & Swazey (1992), Hogle (1999) and Lock (2002). On the rhetoric of donation and altruism legitimizing the societal access of individual bodies in organ donation, see e.g. Ohnuki-Tiery (1994), Strathern (1997) and Lock & Crowley-Matoka (2008).
- 7 This “being in-between” applies to chronically ill persons in general, who are in medical terms confronted with a long-lasting or recurrent abnormality of the body causing discomfort or severe suffering and whose actual state of well-being as well as previous meanings, self-conceptions and ways of living are challenged considerably (Bury 1982; Charmaz 1991; Corbin & Strauss 1988).
- 8 Lundin’s research (2002) examines the cultural processes which embed biotechnological interventions such as xenotransplantation into everyday life and thus rework what is threatening into what is familiar.
- 9 The differences in the implementation of care for transplanted patients as well as contrasts in the institutional contexts of medical care or distinctions in the sociocultural contexts of health policies between Sweden, Germany and Cyprus cannot be taken into account here in a systematic fashion. For further information, cf. Beck et al. (2006).
- 10 To prevent organ trade, living donation is allowed between relatives and emotionally close associates only. Voluntariness is the key principle but neglects, as the case of Andreas Moyses indicates, the (pressure of) moral obligations within familial and close relationships.
- 11 Two in-depth studies in this regard are (1) Costas S. Constantinou’s ethnographic study of kidney transplantation in Cyprus (2009) in which he examines the reconstruction of normality with respect to the mechanisms through which the experience of haemodialysis and kidney transplantation as well as the social context in which it occurs is dynamically constructed; and (2) the nearly completed dissertation of Katrin Amelang, in which she tackles the anthropologically self-evident categories of everyday life and normality by scrutinizing how liver-transplant recipients and health professionals in Germany pick out everyday routinization and normalization as a central theme.

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