

## 13. Living with a Transplant

### Identity and a Good Life<sup>1</sup>

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#### 1. Introduction

The intuitive rationale behind transplants is that they save life and improve its quality. While obviously sound, these reasons can only be elements of any plausible answer to the more fundamental question about a good post-transplant life. ‘Good life’ does not reduce to survival or quality of life, or the two combined. A good life is a life that is good all things considered, taking account of all the values, circumstances, and considerations that matter in a particular person’s life or make their life worthy for them. It can include balance of pleasure and pain, satisfaction of desires or fulfillment of expectations, achievement of objective goods, pursuit of personal goals, discharge of obligations, and various other elements and circumstances, as judged from the objectivizing perspective human beings take when they reflect on their own lives.

Human beings are planning and decision-making beings. When they plan their actions or make decisions they ask the ethical question: ‘How should one live?’ (Williams 1985). An answer to that question, which relies on the person’s self-knowledge and self-understanding, entails a conception of a good life. To judge how well one’s life is going, all things considered, and to choose how to act, one must appeal to such an objectivizing view of a good life; to provide guidance to planning and action, the conception must be sufficiently stable and instructive and relate to the actual circumstances of the individual’s embodied existence. To *have* a good life, the human being needs a sufficiently stable and instructive conception of a good life.

This chapter will discuss the difficulties that transplant patients can encounter in their efforts to arrive at a conception of a good life as applying to their own life after surgery. While most authors discuss the social and psychological aspects of the transplant patient’s life, as well as its quality, they generally remain silent about the interaction between the transplant patient’s identity and their sense of how well their life is going. This is a serious omission. The decision to undergo transplant treatment and the process of recovery necessarily involve the most fundamental values and commitments (e.g. life itself, social bonds and relations, life goals). Those values and their

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interrelations contribute to the identity of the patient. The removal of a diseased body part and its replacement with one that comes from another person shapes that identity in the most basic, physical way, and thus, together with the demands of a post-transplant treatment regime, it often demands rethinking or rearrangement of one's own conception of a good life. Thus, the focus on a good life and identity is of central importance to the perception of transplant patients as persons or agents. It can also help medical professionals to achieve a rich, comprehensive and integrated understanding of the existential situation of transplant patients, and therefore to respond adequately to their needs.

In this chapter it will be argued that due to the embodied nature of a human being and the central place embodied identity must occupy in every conception of a good life, and in every judgment of the worth of an individual life all things considered, transplants, by modifying the patient's bodily make-up, challenge their prospects for arriving at a sufficiently stable and instructive view of a good post-transplant life, and thus a reliable judgment about how well their life is going. The instabilities and indeterminacies of that conception may in turn result in problems with the patient's future identity. The instabilities in the patient's present identity, and in their conception of a good life, can prevent them from developing a sufficiently stable and instructive future identity, and so from having a good post-transplant life. An adequate response to such challenges may involve not only reciprocal adaptation of the patient's post-transplant identity and their conception of a good life but also a reframing of the very concept of the good life when applied to life after transplant surgery.

The discussion that follows will not investigate the components of conceptions of a good life. Such conceptions can differ vastly from theory to theory and from person to person. There thus seems to be insufficient grounds for adopting an overarching framework that relates those conceptions to post-transplant life. Additionally, since well-being seems to be a necessary component of every conception of a good life, and well-being during illness is not necessarily significantly lower than when healthy (Angner et al. 2009; Chwalisz et al. 1988; de Haes & van Knippenberg 1985; Riis et al. 2005), one should not assume that post-transplant life is necessarily worse, all things considered, than life in health. An attempt to judge whether a post-transplant life is necessarily good or not would presuppose a particular view of a good life, and so it would risk an imposition of such a view on post-transplant patients, effectively foreclosing some intuitively plausible alternative views of a good life.

The discussion will focus on post-transplant identity as a prerequisite of the process of arriving at, and sustaining, a conception of a good life and judging one's own life to be good, independently of the particular contents or structure of such a conception. These processes can be explicit, involving cognitively and affectively committed reflection on various aspects of one's own life; but they can also be tacit and result in cognitive and affective engagement with life events; and they can be a combination of the two. The identity to be discussed will not be understood as an individual's or object's sameness over time, or a person's sense or feeling of being one and the same at different points in time, although some aspects of this will transpire in the discussion. The identity considered in this chapter refers to the embodied experiences that collectively constitute one biography of a human being, and in this way define a particular human being as having a personality composed of, among other things, beliefs, habits, preferences, skills, and traits of character (Goldie 2004; Rorty/Wong 1990). A human

being's biography is necessarily extended over time and susceptible to change. Thus, the identity of a human being is temporal, changeable, and therefore incomplete. To be a whole, a human being's life and identity need a significant degree of consistency between their events and phases. Although they may include significant disruptions, they can remain one biography and one identity.

This chapter begins with a phenomenological perspective on the embodied identity of the human being and illness. The insights deriving from this perspective will be then applied to the situation of the transplant patient. Such an outlook draws attention to the subjectivity of patients, thereby revealing the interrelations between patient identity and a good life, and moving beyond a focus on the physiological and socio-psychological aspects of medical care.

The theses that will be presented in this chapter regarding the possibility of arriving at a sufficiently stable and instructive conception of a good post-transplant life should not be understood as reports from empirical research or universal truths. Collectively, empirical data on the lived experiences of transplant patients form a repertoire of the various experiences that constitute illness and identity, and post-transplant identity. This repertoire will serve as the basis for an exploration of the interrelations between post-transplant identity, conception of a good life, and the potential difficulties in achieving such a life after transplant surgery. The elements of that repertoire form a range of experiences which can come in various combinations, depending, among other things, on the patient's biography, health status and history, social context, medical and lay ideologies, or the organ involved. Accordingly, the discussion of the possibility of achieving a sufficiently stable and instructive view of a good post-transplant life is not about universal phenomena. Rather, it is to be read as an exploration of the various challenges that transplant patients can face in their attempts to form a conception of a good post-transplant life.

The first section sketches the lived bodily experience of illness. It relies on the idea that a human body is not a mere Cartesian vehicle for a soul but a constituent of a specifically human identity, both species identity and identity as a particular member of that species. This section provides background for the discussion of post-transplant identity in the second section. As the available anthropological studies show, post-transplant identity is in many, often unique, ways fragile and unstable; it is frequently disrupted and in need of restructuring. In many respects this identity eludes the patient's control by subordinating their daily affairs to medical surveillance, and it is repeatedly challenged by the risk of organ rejection, the demands of immunosuppressive therapy, and medical complications. Building on these insights, the third section offers a philosophical investigation into the potential impact of post-transplant identity on the process of arriving at a sufficiently stable and instructive view of a good post-transplant life.

Due to the diversity and uniqueness of post-transplant experiences as they relate to the question of a good post-transplant life, this section cannot and will not report empirical data, although such data are appealed to. It is an exploration of the difficulties that transplant patients can encounter in their attempts to arrive at a stable and instructive conception of a good life. This exploration reveals that patients may need to reframe their conceptions of a good post-transplant life rather than merely rearrange or reconstruct them. A reframed conception of a good post-transplant life will often need to be open-ended to make room for the creative process of assimilation of the

conflicts, uncertainties and instabilities of the post-transplant identity. In this way the conflicts, uncertainties and instabilities of the post-transplant identity can become a whole which makes the patient's life undoubtedly theirs.

## 2. The Experience of Illness

The human body is the essential constituent of a human biological and biographical life. It is the basis both of an individual's membership in the human species and of their particular identity. An individual human body sustains the existence and identity of a particular human being over time and is the central instrument of their interactions with their natural and social environments. Embodiment makes human beings capable of good and evil, of having a conception of a good life, and of being susceptible to diverse benefits and harms. Additionally, human beings can form views of a good life because they are aware of the fragilities of their existence, which are brought about in a profound way by their embodiment.

The body is not only the physical substratum of a human being's existence (*Körper*); it is also the lived body (*Leib*) (Husserl 1989: §36) or embodiment, which is the conscious presence in, and involvement with, an environment. A person<sup>2</sup> as a particular lived body relates to the objects in their environment (which are perceived as really there) through their sensory experiences (Merleau-Ponty 1962), feelings, and emotions (Buytendijk 1987). In contrast to the physical body, the lived body is not simply the site of experiences, feelings and emotions. Experiences, feelings and emotions locate a human being as an entity in the world rather than as a sovereign Cartesian mind or mode of reference to things or to oneself. The lived body makes it possible to conceive of the objects and oneself as belonging to the same world. This double relationship to the things out there and to oneself establishes a particular person's sense of identity and individuality as a unique and separate entity (Merleau-Ponty 1962), and includes, among other things, their beliefs, habits, preferences, skills, and traits of character.

Despite its obvious centrality for human life, filled with thinking, planning, deciding, feeling, etc., the lived body usually remains transparent to human beings because life in health involves relating oneself as a whole, rather than as an aggregate of parts, to the objects in the environment rather than relating to oneself (Gadamer 1996; Leder 1990; Merleau-Ponty 1962; Sartre 1978 [1956]: 324–326; Zaner 1981). The absence of discomfort or pain makes one's own embodiment and the arrangement of one's own body parts imperceptible (Leder 1990; Zeiler 2010) and so unproblematic. One's own embodiment is brought to one's attention in health only occasionally, as a result of effort or fatigue (Van Den Berg 1987) or during pregnancy (Young 2005: 46–61). Unlike most instances of discomfort or pain, the absence of unpleasantness and pleasure does not have a specific place in the body. The lived body, which in various ways founds the person's being and presence in the world and mostly remains a transparent whole in times of health, can become an experienced sum of its parts in times of illness.

Illness, which is a fundamentally subjective experience, brings one's own body to one's attention, initially through a general and indeterminate discomfort (Zeiler 2010).

2 "Human being" and "person" will be used interchangeably. No substantive ethical assumptions typically associated with "person" are made in this chapter.

An attempt to make illness objective, or to develop an objective account of it, would presuppose its separation from the ill person. The resulting account would be alienated from the things which make the experience of illness possible and actual; it would also be limited to what is intersubjectively available (Agazzi 2001). Illness may begin with an unspecified and often pre-reflective experience that “something is the matter”, that “one somehow does not feel quite right” (Gadamer 1996: 111), or that something is wrong with the person (Gert et al. 2006: 136). At more advanced stages of illness, the experience can be conceptualized as biographical disruption (Bury 1982), disruption of the lived body (Toombs 1988), otherness or alienation of the body from the ill person (Cassell 1985; Svenaeus 2000a, 2000b; Zaner 1981), disconnection of the body from the self of the ill person (Leder 1990), objectification of the body (Toombs 1988, 1992: 201–226), uncanniness and unhomelikeness (*Unheimlichkeit*) of the body (Svenaeus 2000b, 2011), or doubt in one’s own body (Carel 2016: 86–105).

Illness drives a wedge between a person’s sense of the integrity of their self and their body, making the body perceptible to that person (Kass 1985: 220; Merleau-Ponty 1962; Sartre 1978 [1956]: 337–338) and problematic (Frank 1995). Illness is defined by dualities which are usually absent in life in health. The first, most prominent duality is that of the body and the self (Cassell 1985: 55–65; Toombs 1988). The pains and discomforts caused by a disease and the limited capabilities of the diseased body shift the person’s focus from the surrounding objects to the body, revealing it as an entity somewhat separated or distanced from the self. Bodily movements, whose technicalities usually escape the person’s awareness, as well as the wholeness of the body in health, are now analyzed into their parts and processes, which must be controlled individually. Pain in the knee, for example, usually requires planning of how to position the foot or balance the body’s weight while walking. The lived body in illness is no longer a unitary and harmonious whole, but a precarious structure made of processes and parts, which, due to the discord brought about by illness, need individual attention and corrections. The second duality in illness is a dissonance between the individual’s self-image and their actual presence in the world. By depriving the lived body of some of its experiences, as well as affording new ones, illness confronts the person with change at the most intimate level; it surprises them and calls for self-reflection and sometimes re-construction of the self-image.

The dualities of illness make the human being realize that their body is the only form of existence available to them; experientially there is no alternative to their embodied existence, which determines who they are. The dualities of illness show that the human body is not an instrument that occasionally works badly, has defects, ceases to work as usual, or lets the person down. They reveal that illness is a total experience. It is the whole human being who is ill, not just their body or its part. This suggests that the ill person is the ailing lived body in a way similar to that in which a healthy human being is a healthy lived body.

The weaknesses, limitations, and dualities of the ill human being’s diseased body can be experienced as chronic sorrow, frustration, anger and a sense of futility in making long term plans (Kierans 2005; Michael 1996), loss of self, diminished sense of self-identity, or as grieving for one’s former identity (Charmaz 1983, 1995; Matson/Brooks 1977). This is not to say that the weaknesses, limitations and dualities of illness have only negative impact on the ill person. They can also prompt adaptation and desirable changes, giving rise to the need to regain control over one’s own affairs,

promote personal growth and change (Michael 1996; Moch 1989), or struggle for normalcy (Öhman et al. 2003). Whether judged negatively or positively, the bodily changes brought about by illness affect the physical and perceptual abilities of the human being and their very subjectivity (Merleau-Ponty 1962).

### 3. The Fragility of Post-transplant Identity

While in illness identity disruption is likely, organ transplants, much like chronic illness, necessarily affect the person's identity due to the bodily discontinuity brought about by removal of the diseased organ, and the bodily re-constitution prompted by implantation of someone else's body part. Due to the temporal dimension of transplant treatment, the impact of a transplant on a person's identity must be seen as a process which starts at the latest at the moment of removal of the diseased organ and continues during recovery and, potentially, the rest of the patient's life. Not infrequently, this "identity process" begins before the surgery, with the illness reaching the stage at which a transplant is considered (e.g. burdens of the treatment of the underlying disease, dependence on health care services, waiting for the organ) (Ådahl 2013; Kierans 2005), and lasts through the surgery into the remainder of the patient's life (Cormier et al. 2017; Varela 2001). The gravity of the impact of the transplant process on the patient's identity will vary not only depending on the characteristics of the recipient but also on the experiential identity significance of the body part to be removed and replaced (Svenaeus 2012, 2016: 28). The identity significance of a body part can be related to its visibility (e.g. a hand), indispensability for the human being's survival (e.g. the lungs), potential for spontaneous regeneration (e.g. the liver), cultural meaning related to traits of character, and association with expression of the individual's perceived personality (e.g. the heart).

The identity-related experiences of transplant patients will typically have two stages, often overlapping and varying, depending on the identity significance of the body part to be replaced. One is the experience of the anticipated and actual loss of the body part to be removed, the resulting fear of a loss of one's self (Belk 1992), and the subsequent loss of the imagined past "(compiled of experiences, sensations and achievements) that transplant patients consider that they might have had" (Baines/Jindal 2003: 124) if they had not suffered from the disease that had led to the loss of this organ. Depending on the identity significance of the diseased organ or the life stage at which the loss happens, the occurrence, forms and intensity of grieving for the loss of the organ can differ. For example, adolescents who – due to the burdens of the underlying condition – may miss out on some developmental stages may not grieve after the organ is removed because they have not had an opportunity to assimilate it in forming that identity, a process still underway (Anderson et al. 2017).

The second stage of the identity-related experiences of transplant patients is connected with the acquisition of a new body part and the need to incorporate it into the patient's identity. Again, the form and dynamics of this stage will vary depending on the identity significance of the body part replaced and the stage of life of the patient. It will also be shaped by the patient's health status (urgent or planned) and prognosis, the type of donor (deceased or living), the information about the donor that is available



to the patient (ranging from anonymity to personal knowledge), and by the emotional links between the recipient and the donor (non-related versus related donation).

The following discussion of post-transplant identity covers both stages of the post-transplant identity process in its sequential dynamics of a living experience, whose elements – depending on the patient and their social circumstances – can be variously arranged and can differ in their prominence. Special attention will be paid to the post-transplant stage.

As noted in the section above, a person's own identity usually escapes their awareness, the body being taken for granted. The sequence of organ failure, removal, and replacement brings the individual's body to their attention. This sequence both questions their identity and reveals its importance, calling for its reconstruction. Clearly, the key element of the identity process in transplant recipients is the presence and functioning of a 'foreign' body part which, when combined with the patient's dependence on that organ for survival, can result in a conflicted or problematic identity. The foreign body part challenges the patient's identity by its presence in their body, but in most cases it simultaneously sustains that identity by making continued life possible (Nancy 2008). The patient must therefore incorporate the transplanted body part into their new or modified identity (Mauthner et al. 2015).

This conflict may be intensified by the patient's sense of connectedness to the organ donor as well as the contradictory messages medical staff communicate about the implanted body part. On the one hand, to motivate patients to comply with the demands of the immunosuppressive therapy, medical professionals often refer to the precious "gift of life", which imaginatively and affectively links the transplanted organ to its donor. Depending on the identity significance of the transplanted body part, such linking can initiate imaginative bonding of the patient with the donor, and in this way modification of the patient's identity. Not infrequently, patients contemplate the possibility of inheriting their donor's traits (Ådahl 2013; Bunzel et al. 1992; Inspector et al. 2004; Kaba et al. 2005; Neukom et al. 2012; Sanner 2001, 2003). Additionally, the stress on the value of the transplanted body part may trigger guilt over the fact that someone had to die to allow the patient to survive (Anthony et al. 2019; Forsberg et al. 2000; Inspector et al. 2004; Kaba et al. 2005; Mai 1986; Neukom et al. 2012; Sanner 2003; Schmid-Mohler et al. 2014). On the other hand, medical professionals routinely objectify transplanted organs as spare parts (e.g. the heart as "just a pump"), thus depersonalizing the sources of the body parts (Bunzel et al. 1992; Mai 1986; Sanner 2003; Sharp 1995). In combination with the gift-of-life imagery and corresponding to the identity significance of the transplanted organ, depersonalization can make it difficult for the transplant patient to perceive the organ as an integral part of their own body and identity (Nancy 2008), which can prompt confusion about their own identity (Forsberg et al. 2000; Tong et al. 2011). Accordingly, patients need to take steps to rebuild their identities and regain a sense of personal consistency and continuity.

As in life in health (Carr 1986; Ricoeur 1986), attempts to reconstruct one's own identity during serious illness often take the form of identity-shaping narratives (Bury 2001; Frank 1995; Williams 1984). The stories draw on the patient's biography as well as the (imagined or actual) biography of the donor and the implanted body part and reflexively shape the patient's biography. Since the transplanted body part belongs to the donor's biography, the recipient may view it as having its own story (Sharp 1995), which needs to be integrated, sometimes in combination with the donor's biogra-

phy, into the patient's life story. Thus, recipients sometimes personalize transplanted organs, internalize images of their donors, or integrate those images into their newly constructed identities (Forsberg et al. 2000; Sharp 1995).

The consistency and continuity of the post-transplant identity can be extremely difficult to achieve and maintain. The popular rhetoric (intended to encourage posthumous donation) of the cadaveric donors "living on" in recipients imposes the donor's (actual or imagined) biography on the patient's construal of their identity, which is thus modified or perhaps even compromised. Thus, as suggested by frequent retrospective conceptualizations of the surgery as renewal, rebirth, or becoming a new person (Ådahl 2013; Inspector et al. 2004; Kierans 2011; Neukom et al. 2012; Sharp 1995), post-transplant identity is not simply a modified pre-transplant identity; it can be a new identity which calls for its own narrative. The transplant patient may have to re-invent themselves as a unique individual who is both continuous with their pre-transplant self and transformed after the surgery. This process can be disturbed by the immunosuppressive treatment, which requires commitment to continued medical surveillance of their life (Cormier et al. 2017), and so it removes from the patient's control a significant part of their future life story and their new identity. Additionally, since the demands of immunosuppression regularly remind the recipient of the presence of a body part that comes from another individual, which, together with the fear of rejection (Baines/Jindal 2003: 133–136; Forsberg et al. 2000; Juneau 1995; Schmid-Mohler et al. 2014; Sharp 1995), becomes the recipient's lifetime companion, the transplant patient's identity is repeatedly questioned, frequently uncertain, dependent, and leaves the patient in the precarious space between a world of abnormality, illness, limited productivity and dependence, and a world of normalcy, health, productivity and independence (Juneau 1995; Schmid-Mohler et al. 2014).

The varieties of post-transplant experiences and their impact on post-transplant identity are akin to the experience of chronic illness. The need to incorporate a transplanted organ into one's body and identity, as well as to adjust one's affairs to the demands of immunosuppression, can alternatively lead to rejection, engulfment, acceptance, or enrichment (Oris et al. 2018). One may reject the fact of being a transplant patient by disregarding various aspects of the post-transplant regimen. Or having a transplanted body part may engulf the patient to the extent that it will dominate all spheres, activities and efforts in their life. Alternatively, the patient may accept the fact of having an implanted organ without being overwhelmed by it or by the requirements of the post-transplant regimen. Finally, the patient may be enriched by their new bodily make-up, seeing it as an opportunity for growth and personal development.

These beliefs and attitudes are responses to the lasting instability of the post-transplant identity, which is questioned, compromised, restructured, difficult to control, and uncertain – repeatedly and on many different levels. Such identity instability can have profound implications for the patient's ability to design their conception of a good life, and to live a good life at all. But it also harbors the promise of a good post-transplant life.



#### 4. The Continuing Challenge of Good Post-transplant Life

Human beings are not only cognizant of, and respond to, the environment. They are also aware of themselves, notably while thinking about their future (Klinger 1994). Future-oriented activities like planning and making decisions involve both self-awareness and awareness of the surrounding environment, which includes knowledge of its current and past states and causal links between its elements. These activities also include beliefs about agreement or disagreement between the objects of awareness and the self-awareness, and positive or negative attitudes towards these relations. These attitudes are not exclusively unreflective or instinctual. To a significant extent they rely on fundamental normative beliefs, which, when combined into sufficiently consistent wholes that include a person's 'ground projects' (Williams 1981), form that person's conception of a good life. Such a conception includes moral beliefs – such as those about obligations, values, rights, virtues etc. – but need not be limited or reducible to them (Nagel 1986; Williams 1981). Regardless of its contents, this conception offers the person an impersonal or objectivizing perspective on their life affairs that allows them to make judgments about their life as good or worth pursuing (Annas 2004).

Within such an objectivizing perspective, a conception of a good life mediates between the person's past and present identity and their future identity according to the normative beliefs that comprise that conception. A person's view of a good life makes it possible for them to care about their future identity as specifically *theirs* (Williams 1981) – that is, to combine their past, present and future into a consistent personal narrative (Ricoeur 1986). This process is a two-way interaction between the person's conception of a good life with a focus on the future, and their unique present identity as it has been shaped by the preceding events in their life. Accordingly, the fundamental normative beliefs that make up a person's conception of a good life necessarily belong to their present identity (Williams 1981). Making (far-reaching) decisions and taking an impersonal or objectivizing perspective on their present identities afforded by the conception of a good life, the human being shapes a future identity, conceived of as continuation of the present one. Thus, the mutual interaction of a person's identity with their conception of a good life leads to an interdependence between their identity's present and its future. A major change in a person's present identity is thus likely to affect their conception of a good life; modifications to their view of a good life can shape their future identity.

The interaction between a person's identity and their conception of a good life indicates that if a conception of a good life is to provide the required guidance for thinking and action, and if it is to successfully link their past, present and future, the present identity must be sufficiently stable and consistent. Significant instability or inconsistency of the present identity may prevent a person from successful formation of a sufficiently stable future identity, or even from making any attempts to shape that identity. Instabilities and inconsistencies in the person's present identity can result in their failure to implement their conception of a good life and may prevent their life from being good.

The conception of a good life involved in thinking, planning, and deciding is often explicit, but it need not be so. Judgments about how well one's own life is going can be overt, taking the form of cognitively and affectively committed considerations of

various components and aspects of human life, one's own biography, and relations between the two. Alternatively, a person's view of a good life and their judgment about how well their life is going can remain unarticulated; however, it can be reconstructed from their statements, decisions, actions, and commitments. Such a reconstruction can take various forms. It can be a list of priorities or goals and judgments; or it can, particularly in the face of such life-changing events as the onset of a serious illness or a demanding therapy, take the form of a patient's life narrative (Bury 2001; Frank 1995; Williams 1984).

There are at least three possible types of conception of a good life. The conception can be organized around the hedonistic idea of a life characterized by a suitable balance of pleasures and pains experienced by a person or, less subjectively, around the concept of a life of fulfillment of that person's desires; alternatively, a good life can be conceived of in a perfectionist way as offering the person access to the goods on a list of goods required for a human being (Parfit 1984). A conception of a good life can play its role of the standard of the worth of the life of a human being all things considered exactly because it relates to that person's identity. Since post-transplant identity is usually different from that of life in health, the transplant patient's thinking, planning and deciding on the ground of their conception of a good life can face challenges unknown to healthy persons or to those living with a serious or chronic illness.

As explained in the first section, being ontologically and experientially constitutive for an individual identity, the body in health is for the most part experientially transparent to the healthy person, leaving questions of their identity and a good life mute for the majority of the time. This fragility of identity, which belongs to the human condition, remains invisible in a way akin to the invisibility of the body in health. It is noticed at times of illness and 'forgotten' again after recovery. The fragility of the patient's identity becomes visible during (serious) illness, when the body becomes perceptible to them due to the changes, discomforts, and difficulties in controlling their affairs. By revealing these fragilities, such disruptive phenomena can prompt re-examination of how well one's own life has been going so far, and so they can encourage a critical reflection on one's own identity and one's conception of a good life. Except where illness is chronic or associated with extremely traumatic experiences, such concerns are likely to cease after recovery.

Post-transplant life is different because post-transplant identity is different. As the data on transplant patients' experiences suggest, the fragility of a transplant patient's identity is brought to their awareness by the fragility of their changed body. Additionally, the degree of fragility of the post-transplant patient's body and identity fluctuates together with crises that occur in the recovery process and the demands of the post-transplant therapy. As a result, the patient's body and identity will often be significantly more unstable than in passing illness, and identity persistently fragmented. The patient might need to reconstruct their identity because the replacement of their organ with someone else's brings their present identity into question. Their present identity can no longer be a fixed point of reference to which their conception of a good life can be readily applied in their planning, deciding and acting.

The instability of the patient's present identity in planning and decision making can be exacerbated by the demands of immunosuppression, which bring the fragility of the patient's body and identity to their attention. The repeated challenges to post-transplant identity, caused by the fragile reconstitution of the patient's body, give

rise to *recurring* explorations of their identity. Such explorations can impact deeply the patient's potential to arrive at a conception of a good life and make credible judgments of the worth of their present life. First, due to its fragility, the patient's present identity is likely to be less stable than their identity in health, and so it will be more difficult to design a conception of a good life which would be adjusted to a fixed identity. Although the identity of a human being is never complete, it usually remains sufficiently stable in the present and linked to the past to provide a basis for a conception of a good life. By contrast, a transplant patient's present identity is lastingly and profoundly 'unfinished' – due to the presence of a foreign body part, the responses of their immune system to it, and the regimen of immunosuppression – to a much higher degree than in health. Accordingly, post-transplant identity may require more frequent and perhaps deeper and more comprehensive redesign of the patient's conception of a good life as compared to responses to typical events of life in health.

Secondly, the patient's evaluations of their own post-transplant life may fluctuate more relative to their repeatedly rebuilt identity. The aspects of their identity to which the patient has adjusted their new conception of a good life may undergo changes caused by clinical events (e.g. onset of diabetes or high blood pressure) and the demands of immunosuppression (e.g. the regime of immunosuppressant therapy or effects of compromised resistance to infections). Such changes can be incompatible with the patient's recently developed conception of a good life. To the extent to which the new identity is beyond the patient's control (e.g. changes in the bodily composition or the limits placed on the patient's lifestyle), the conception of a good life will need more frequent adaptation and *redesign*. Thus, changes in the patient's identity and of their conception of a good life will be mutually dependent: changes of the patient's clinical status will require modifications to their conception of a good life, which will become part of their present identity, which, in turn, may necessitate changes in the conception of a good life, which, again, potentially will change the patient's future identity. The patient's thinking about a good life and identity cannot therefore be focused on their future to the same extent as in a life in health. The patient's preferred identity, that is what they, explicitly or not, intend, plan or wish to be (Charmaz 1987), cannot play the organizing role it usually plays in life in health because, potentially, the preferred identity is significantly less determinate and complete. While past events may still pertain to their identity, the events relating to the preferred identity are undefined.

Since, as already noted, the conception of a good life necessarily belongs to the person's identity, the fragility of post-transplant identity, rooted in the fragility of the transplant patient's body, can result in instability of their conception of a good life. These fragilities cumulatively affect the patient's life, and so they may affect its worth all things considered, in that they will make the central components of that life, whatever its constituents, uncertain and unpredictable (Inspector et al. 2004). The strategies of coping with uncertainty, such as resolve, benefiting from the support of others, or compliance with the demands of immunosuppression or lifestyle (Cormier et al. 2017), are likely to be insufficient due to the instability of the very conceptual framework of a good life brought about, sustained by, and nourishing the sequence of fragilities. The instability of that framework, intended to organize the patient's planning, deciding, and acting is likely to make a good life relatively elusive as an idea and problematic as a fact.

Transplant patients may respond to the conflicts, uncertainties and instabilities of their post-transplant identity and their conception of a good life in two ways. One is resignation and acquiescence to the limited, elusive, or in extreme cases, non-existent prospects for a good life, which might take the form of an express or tacit decision to live in the present and refrain from setting goals or planning for the future (Michael 1996). Attempts to design their own conception of a good life can then be seen as pointless or futile. This, however, would deprive the transplant patient of a good life. To the extent that human beings need a view of a good life, which is directed to the future to structure their current affairs, to have a good life, such a resignation can question the very decision to undergo the transplant treatment. Why save life or improve its quality if that life cannot be good, as measured by the standard of the person saved?

An alternative response to the post-transplant conflicts, uncertainties and instabilities of identity and the conception of a good life is to see those conflicts, uncertainties and instabilities as opportunities for enrichment, growth, and personal development (Oris et al. 2018). For this to be effective, it is not enough to rely on conceptualizations of a good life that presuppose a stable present identity rooted in a past identity. Whether in the form of a list of statements about what matters in life or as a narrative, the conception of a good life would need to be based on a re-conceptualized or reframed idea of a good life. Such an idea should assimilate or incorporate post-transplant conflicts, uncertainties, and instabilities. As a result of their heightened bodily awareness and (actual or imagined) connection to the donor, their family members, and perhaps (for example, through the feelings of gratitude) to society at large, the patient could make the conflicts, uncertainties and instabilities important parts of their conception of a good life. This conception could respond to the needs and experiences of the transplant patient based on their particular identity.

It is impossible to discuss the details of the reframed idea of a good post-transplant life here. These will depend on personal characteristics and the situation of a given patient. Some general points, however, can be made. First, a reframed view of a good post-transplant life would need to respond to the conflicts, uncertainties, and instabilities of post-transplant identity in its relationship to the patient's past. Seeking continuity with their pre-transplant lives, patients need to incorporate into their thinking both their own past as well as the (imagined) biography of the transplanted organ or, perhaps, of the donor. In such cases, a patient's conception of a good life would have to combine two pasts with one present and a future in order to reconstitute their identity and biography as undoubtedly *theirs*. Accordingly, their view of a good life would not only connect their own body with the received organ and the two biographies that precede the failure of their own organ into a sufficiently unified whole; it would also have to contain conceptual, imaginative and affective resources that allow the patient to 'domesticate' the implanted body part and its biography, that is, to make their presence in the patient's life a legitimate basis of the worth of their life all things considered.

One of the more specific and socially important aspects of the 'domestication' of the new body part and the biographies linked to it could be negotiation of the conflict between the idea of the gift of life and that of 'just a body part'. Since embodiment is central to identity and identity is the basis of a good life, a conception of a good post-transplant life will need to include appreciation of the organ without making the patient victim to the feelings of unrepayable debt or guilt. This may be difficult in view of the recipient's possibly unstable health status and the demands of the recovery pro-

cess, which makes reappearance of the conflicts, uncertainties and instabilities of the post-transplant identity more likely.

Secondly, as explained above, the conflicts and tensions inherent to the post-transplant identity do not allow the patient to take their body and their bodily identity for granted as while living in health. By being repeatedly questioned, they prompt re-examination of the patient's perspective on their own life, and so of their conception of a good life. In this way the identity of the transplant patient is likely to be a process rather than a relative constant, and development of the conception of a good life a continuing task to be accomplished with relatively high awareness. Although the identity of every human being changes over time, the transformations are stretched over periods which are sufficiently long for identity to be taken as a given and a constant. In transplants, the changing nature of the patient's identity is perceptible, becoming more prominent in periods of medical crisis, in proportion to the identity significance of the transplanted body part. This processual aspect of post-transplant identity calls for an analogously processual conception of a good life whose components are dynamically related to the patient's life events. In such a conception of a good life the patient's bodily fragility and uncertainty about their future are essential. Thus, plans will often need to be open-ended and responsive to unexpected changes. They will have to result from a creative and learning approach to new events in order to maintain a sufficient level of consistency and continuity of the post-transplant life.

## 5. Conclusion

Good post-transplant life is not limited to quality of life. It encompasses medical and psychological as well as existential and moral aspects of life, which are intimately related to the patient's goals and priorities. A transplant patient's identity can be seriously disturbed due to the embodied nature of human existence. The taken-for-grantedness and transparency of the lived healthy body, which is normally underappreciated as the basis for both identity and a conception of a good life, tends to disappear after transplant. The conflicts, uncertainties and instabilities of the post-transplant identity call for the reconstitution of identity as well as the reconstruction and, more fundamentally, reframing of the conception of a good life. Since after transplant surgery the patient's embodiment is acutely perceptible and their identity prone to contestation, their conception of a good life may need to include the conflicts, uncertainties and instabilities associated with the transplant identity process and the processual nature of the conception of a good post-transplant life. The patient's bodily and experiential identity will have to be negotiated to be included in their view of a good life. Since these negotiations are ostensibly inconclusive and may recur due to the demands of immunosuppression and the fragile status of the patient's bodily integrity, a patient's view of a good life must include resources necessary for adequate responses to their potentially changing identity.

Thus, not only is it the worth of a person's own life, all things considered, that is repeatedly re-examined in the face of the fragility and instability of the post-transplant identity, it is also their very view of a good life. Thrown into question by the uncertain status of the implanted body part, a patient's limited control of their affairs brought about by the demands of immunosuppression and medical surveillance, as

well as by the chronic uncertainty of the future, post-transplant identity not only calls for a new perspective on the worth of the patient's life; it also calls for reframing of the very idea of a good life.

The reframed conception of a good post-transplant life needs to respond to the recurring episodes of questioning of the patient's identity by becoming an explicitly unfinished and open-ended process in which the patient's bodily fragility and the relatively high instability of their future are an inherent part of that conception. Because consistency and continuity in the patient's life are necessary preconditions of its worth for the patient, all things considered, the patient needs a health care environment that provides a more creative and adaptive approach to their future as well as personal skills to help them design the best possible conception of a good post-transplant life.

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