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Undermining autonomy and consent: the transformative experience of disease

Original research

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Abstract (132 words):

Disease radically changes the life of many people and satisfies formal criteria for being a transformative experience. According to the influential philosophy of Laurie Ann Paul, transformative experiences undermine traditional criteria for rational decision-making. Thus, the transformative experience of disease can challenge basic principles and rules in medical ethics, such as patient autonomy and informed consent. This article applies Laurie Ann Paul's theory of transformative experience and its expansion by Havi Carel and Kiddand colleagues to investigate the implications for medical ethics. It leads to the very uncomfortable conclusion that disease involves transformative experiences in ways that can reduce people's rational decision-making ability and undermine the basic principle of respect for autonomy and the moral rule of informed consent. While such cases are limited, they are crucial for medical ethics and health policy and deserve more attention and further scrutiny.

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Introduction

Disease is a transformative experience (TE) to many people. It changes the way they see the world and shows them aspects of life that were previously unknown. Moreover, disease transforms people as persons, as they cannot be who they previously were, do as they formerly did, or have the same life- plans as they had.[1–4] According to the recent influential philosophy of Laurie Ann Laurie Ann Paul, this satisfies the criteria of a transformative experienceTE.[5]

However, if this is so, it can undermine a person's decision-making capacity with respect to disease because we cannot properly understand necessary aspects of the transformative experienceTEs.[5] This would strongly affect important institutions in medical ethics, such as respect for patient autonomy and informed consent.

To investigate this, the article will start with applying Paul's philosophy to investigate disease as a transformative experienceTE. Then, it will investigate the implications for basic principles and requirements in medical ethics, such as respect for autonomy and informed consent. Third, the article will present Havi Carel and Ian James Kidd's fourfold extension of Paul's framework and its implications for autonomy and consent.

The purpose of investigating disease as a transformative experienceTE is to clarify important (epistemic and personal) aspects of disease and to investigate how this influences key elements of modern bioethics: the principle of autonomy and informed consent.

Disease as a transformative experienceTE according to the framework of Laurie Ann Paul

In her book Transformative experienceTE, Laurie Ann Paul[5] defines the concept of transformative experienceTE as «'a kind of experience that is both radically new to the agent and changes her in a deep and fundamental way.'"[6] While she mentions examples of experiences, such as becoming a parent, emigrating to a new country, discovering a new faith, or fighting in a war, it can be argued that becoming diseased is a transformative experienceTE, as it changes the person in a '"deep and fundamental way'."

Paul sets up two criteria for transformative experienceTEs. Such experiences have to be both epistemically and personally transformative, which she defines as follows: '"An epistemically transformative experience is an experience that teaches you something you

could not have learned without having that kind of experience. Having that experience gives you new abilities to imagine, recognize, and cognitively model possible future experiences of that kind. A personally transformative experience changes you in some deep and personally fundamental way, for example, by changing your core personal preferences or by changing the way you understand your desires and the kind of person you take yourself to be'.»[6]

The epistemic transformation of disease

Taking this definition and the criteria at face value, many instances of disease qualify as transformative experienceTEs. For many instances of disease as you learn new aspects of your body and mind[7] and you have to learn how to cope and manage in new manners.[8] For example, you need to learn a new social role as you may not be able to be (entirely) the same person that you used to be neither professionally nor socially.[7] For example, yYou may not be able to work or take care of your children or parents as before. As disease disrupts the biography of your life[2 3] you may have to make others learn about how you are changed. Moreover, you may need to learn to let others go or do, to receive help, to cope in new ways, surrender vanities, and to stop trying a wide range of things you did or could have done before.[8] You may also learn of life in new ways, e.g.for example, as an existential threat, uncanniness,[9] alienation, vulnerability, and as dys-appearance (gaining a different bodily self-awareness).

In sum, disease is epistemically transformative as it changes one's knowledge about one's physical, mental, and agential life.

The personal transformation of disease

Relatedly, disease can be personally transformative as many diseases imply suffering, sorrow, crisis, despair, dependency, in-ability, loneliness, vulnerability, shame, as well as the loss of identity and agency.[7 8 10] Moreover, disease can result in shift in identity, values, and desires, updated goals and ambitions, and shift in focus and worldview.[11] Suffering and reduced function (dys-function) hinders you from being the person you previously were neither to yourself or others,[4] and according to the criteria quoted above, disease can be a personally transformative experienceTE.[6]

In sum, disease can be both epistemically and personally transformative, and thus satisfies Paul's criteria for a transformative experienceTE. To investigate how this influences the application of the principle of autonomy and the rule of consent in medical ethics, I will briefly review Paul's thesis of how transformative experiences undermines decision-making.

Undermining rational decision -making

According to Paul, transformative experienceTEs challenge or even undermine rational decision-making models. Transformative experiences incumber individuals' ability prospectively to identify potential outcomes of a decision, assign values to them, and thereafter weigh the outcomes against individual preferences at given likelihoods. Pace Paul, undergoing an epistemically transformative experienceTE introduces '"a deep subjective unpredictability about the future'" and '"[w]e only learn what we need to know after we've done it, and we change ourselves in the process of doing it'".[5] Because '"if our choice

involves an outcome that is epistemically transformative, we cannot know the value of this outcome before we experience it'".[12] Even more: '"in cases of transformative choice, the rationality of an approach to life where we think of ourselves as authoritatively controlling our choices by imaginatively projecting ourselves forward and considering possible subjective futures is undermined by our cognitive and epistemic limitations'".[6]

"The problem is pressing because many of life's big personal decisions are like this: they involve the choice to undergo a dramatically new experience that will change your life in important ways … But as it turns out … many of these big decisions involve choices to have experiences that teach us things we cannot know about from any other source but the experience itself."[5]

Hence, transformative experienceTEs undermine our decision-making capacity as we cannot understand the content and extension of a future situation and because it alters the decision-making person in terms of values and preferences.

Disease undermining principles and requirements in medical ethics

While there is a vast literature on (the controversies of) autonomy and informed consent, there is reasonable agreement that autonomous acts as well as the ability to give a valid informed consent require understanding and decision-making capacity.[13–15] This is, for example, expressed in Beauchamp and Childress' definition of consent according to which '"[a] person gives an informed consent to an intervention if he or she is competent to act, receives a thorough disclosure, comprehends the disclosure, acts voluntarily, and consents to the intervention.'"[14] Hence, if experiences of disease are transformative in the manner defined and described by Paul, this means that disease can undermine the principle of autonomy and the requirement of consent in bioethics.

However, before reaching the radical conclusion that disease as a transformative experienceTE undermines autonomy and consent, it is crucial to notice that Paul's framework is developed for voluntary situations, such as choosing whether to have a child (or become a vampire). Disease is in most cases not a voluntary matter and many of the healthcare decisions are made when persons are diseased, and thus are well informed about the situation. While this limits the relevance of the framework for decisions in healthcare, there are some implications of crucial importance.

Limiting the argument: self-inflicted disease and disease prevention

First, the fact that disease is a transformative experienceTE can undermine autonomy and consent in cases where a person's choice results in disease. One example of this could be heart disease, kidney damage, peripheral neuropathy, or vision loss resulting from wilful neglect of diabetes (T1). Another example could be cases of body integrity identity disorder (BIID), for example, when a person wants to have both legs removed.[16 17] A third potential example is anorexia nervosa, which certainly fulfils both the criteria for epistemic and personal transformation. However, as with other mentally related conditions, we enter the

grey zone where the person's autonomy (voluntariness) can be questioned in the first place.[18] [19] Nonetheless, voluntary behaviour that results in disease should fulfil Paul's criteria and make it relevant to question autonomy and consent.

Second, the theory of transformative experienceTE seems relevant for healthy persons' decisions with respect to future disease. Such decisions appear in several cases, such as with respect to disease prevention, where not only the prevented diseases can be transformative experienceTEs, but also the preventive measures (and their consequences).

In disease prevention, there are a wide range of decisions where the person has not experienced the disease to be prevented, for example, prophylactic mastectomy and prophylactic oophorectomy to prevent breast cancer. The person may have observed family members having the disease, but with new mass screening options this may not be the case any longer. In addition to the prevented disease being a potential transformative experienceTE, the prophylactic measures are themselves epistemically transformative as the person does not know the situation that one will be in after the intervention. Correspondingly, they may be personally transformative as well. Again, the cases of prophylactic mastectomy and oophorectomy can be illustrative.

The same reasoning is relevant for a wide range of screening programmes. Healthy individuals are screened for a wide range of diseases they are not able to imagine the experience of. Moreover, they are not able to foresee or understand what it means to be overdiagnosed and overtreated, that is, to be unwarrantedly counted as diseased.

Thus, the result of screening can be as transformative as the disease. However, while the disease may not be voluntary, the screening participation is. It is worth noting that this applies both to primary and secondary prevention screening, but not necessarily to tertiary prevention, where the person already has the disease.

Hence, according to Paul's framework a person may have reduced decision-making capacity in cases where disease is the result of a person's own choice and in (primary and secondary) prevention where disease-related experiences are potentially transformative. Accordingly, one can argue that persons are not autonomous in such cases and that individual voluntary informed consent for interventions does not apply. This has radical implications with respect to how far the healthcare system can go in pushing people to avoid disease. S(see section belowVoluntary cases of future disease).

Before discussing this in more detail, it is important to investigate how disease as transformative experiencTEe has implications beyond the voluntary cases of '"self-inflicted disease'" and preventive measures. To do so, it is useful to apply Havi Carel and Ian James Kidd recent extension of Paul's framework to cases of transformative experienceTEs that are not voluntary.

Extended transformative experienceTE

According to Carel and Kidd, '"serious accident, chronic illness, … suffering severe depression'"[20] count as transformative experienceTEs. Carel and Kidd expand Paul's voluntary-based framework to two types of cases that are not voluntary: non-voluntary and involuntary cases. A person being held in a concentration camp is presented as an example of

the first and a person being injured when trying to save a child from being run over by a car is an example of the latter.

Hence, Carel and Kidd suggest a double expansion of Paul's notion of choice: '"First, many common and exemplary types of TEs [(transformative experiences]), such as those arising from serious illness, are not the outcome, and could not conceivably be the outcome, of a rational choice. Second, a coerced choice may be transformative even when devoid of all characteristics of choice (it is not free, minimally constrained, made positively, etc.). In short, coercive and unchosen situations may be transformative.'"[20]

In addition to this expansion of voluntariness, Carel and Kidd provide expansions of the conceptions of both personal and the epistemic transformations. To Carel and Kidd '"almost any change in one's preferences, desires, values, or goals can count as personally transformative'".[20] Correspondingly, epistemic transformations go beyond acquiring new knowledge. As explicitly stated, '"epistemic dispositions, virtues, stances, or psychologies: all of these can fundamentally change in ways we want to say are genuinely epistemically transformative.'"[20]

Carel and Kidd also distinguish between positive and negative epistemic transformation and positive and negative personal transformation and explore combinations of these as shown in Table 1table 1.

Table 1double_arrowPreviewCite Now2

Table 1Combinations of positive and negative epistemic and personal transformation as described by Carel and Kidd in.[20]

A	B	C
	Positive personal transformation	Negative personal transformation
Positive epistemic transformation	Having a successful long-term relationship	Having a child when being a poor, emotionally stunted parent
Negative epistemic transformation	Religious transformation (Aquinas, Pascal)	Suffering from dementia

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Carel and Kidd argue that all of these (four) combinations, which they call '"mixed TEs,'" count as transformative experience TE. Moreover, they introduce '"cumulative TE in addition to the dramatic life-changing TE, in order to explain human growth and change.'"[20]

In sum, Carel and Kidd expand Paul's conceptual framework of transformative experienceTEs in several ways:

1. 1.Beyond voluntary (and deliberative) cases to non-voluntary and involuntary cases.

2. 2.By having more inclusive (liberal) interpretations of epistemic and personal transformation.
3. 3.By logical expansion of criteria for transformative experienceTEs: From conjunction (of epistemic and personal transformation) to disjunction (where only one is a necessary condition).
4. 4.From digital to analogue expansion: From either-or to gradual (accumulative).

These expansions are relevant for disease as a transformative experienceTE.

Before addressing the implications of these expansions, it is important to notice that while Carel and colleaguesKidd have written about illness[11] and suffering[21] as transformative experience TEs, this study has focuses on disease. There are a wide range of illness-experiences that are not relevant for the health carehealthcare setting, and thus beyond the focus of this article. In this study, '"disease"' is applied rather than '"illness"' to limit the discussion to respect for autonomy and consent in healthcare settings. Certainly, illness can be experienced disease,[22] but instead of writing '"the parts of illness experience that is related to disease"' I have shortened this to '"disease'." [The reader or reviewer may prefer a special connotation, such as illness^{D} or disease^{I}].

Expansion of the transformative experienceTE of disease

While disease can be non-voluntary when it is forced uponon someone, for example, in biological warfare, most cases of disease are involuntary. In both cases, disease is experienced by people to be a transformative experience TE.[11]

According to the second and third expansion, many instances of disease result in personal transformations as they imply a '"change in one's preferences, desires, values, or goals"' with and without epistemic transformation. Correspondingly, many diseases result in epistemic transformations as they alter a person's '"epistemic dispositions, virtues, stances, or psychologies"'[20] with and without personal transformation. Accordingly, a wide range of diseases are transformative experience TEs.

As both the epistemic and personal transformations of disease can come in grades, very many diseases result in some kind of transformative experienceTE (fourth expansion). Moreover, the framework of positive and negative kinds of transformation that Carel and Kidd introduce (Table 1table 1) can be applied to disease as shown in Table 2table 2.

Table 2double_arrowPreviewCite Now1

Table 2Applying Carel and Kidd's expanded framework for disease on combinations of positive and negative epistemic and personal transformation.

A	B	C
	Positive personal transformation	**Negative personal transformation**
Positive epistemic transformation	Being fully cured from an abrupt life-saving disease, with great gratitude and seeing life in a new perspective (both epistemically and personally)	Gaining knowledge about one's vulnerability and life's many aspects, but having limited potential to flourish due to disease
Negative epistemic transformation	Gaining new desires, values, and goals in life when learning about physical, mental, and social limitations of disease For example, adapting life style to manage well with diabetes (T2).	Suffering from a disease that alters the person's epistemic dispositions, virtues, stances, or psychologies and changes the person's preferences, desires, and values. Suffering from dementia (Carel and Kidd's own suggestion)

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Expanded transformative experienceTE of disease undermining autonomy and informed consent

While Carel and Kidd and colleagues explicitly ask how the subjective experience of disease (illness) alters informed consent,[11] they do not answer the question beyond suggesting to inform patients better about uncertainty. Barnabe Hole and colleaguesHole and Selman also point to the problem in the context of advanced care planning: '"where futures include transformative experienceTEs, prospective estimation of wellbeingwell-being becomes impossible … yet existential transformation means the 'self' who has the experience is different from the one deciding whether to have it.'"[23] Despite the foundational challenges to informed consent (related to advanced care planning), Hole and colleaguesHole and Selman do not explicitly address this issue. The reason may be that they are mainly preoccupied with the phenomenology of illness.

Acknowledging the underexamined challenges of changed preferences (changing selves) for theories of autonomy, Richard PettigrewPettigrew points to four fundamental problems relevant for how transformative experienceTEs may undermine autonomy and consent. First, there is a problem that there is no stable entity that can make a decision (The Problem of the Fractured Self); second, it is difficult to define the entity that is supposed to be autonomous (The Problem of the Unit of Autonomy); third, any attempt to bind one's future choices based on present preferences may reduce future autonomy (The Binding Problem); and fourth, any attempts to nudge may incite paternalism (The Problem of Paternalism).[24] While Pettigrew

points to the problems, no solutions are provided: '"I have sketched the problems here, but I have not offered anything in the way of solutions."' (ibid).

If Carel and Kidd's expansions of transformative experienceTE apply, a wide range of experiences related to disease are transformative.[11 20 21] If all of these are not subject to rational decision-making (following the general theory of Paul), then it can undermine basic ethical principles and requirements in healthcare and open the floodgates to paternalism.

The reason that Carel and Kidd do not address this problem may be that they are more interested in the phenomenology of illness than in the ethics of handling people's disease. As they say, their goal is to '"enable the concept to be broader, more attuned to the reality of many people's lives, less restricted to certain forms of life, have a richer taxonomy, and account for both voluntary and involuntary, as well as non-voluntary TEs, as well as for positive, negative, and mixed TEs."'[20]

Paul's framework is certainly not the only perspective that limits rational decision-making. Widely reduced autonomy can of course be supported by empirical research on clinical decision-making,[25] moral psychology,[26 27] behavioural economics,[28–30] but also in moral philosophy. However, abandoning autonomy and consent for all cases of disease which according to Carel and Kidd count as transformative experienceTEs would be radical as it undermines health legislation and practice which to a large extent is based on autonomy and informed consent in a wide range of countries.

First, it is important to notice that when you have a disease, you may already have made the transformative experienceTE, and hence you may be able to make rational decisions (with respect to this condition).

Second, as Carel and Kidd expand Paul's framework to cases that are not voluntary, the premises for autonomy are not satisfied in the first place. Hence, other things than the transformative experienceTE of disease may reduce autonomy.

Hence, when diseased, the transformative (epistemic and/or personal) experience has already occurred, and for choices that are not voluntary, you are not autonomous in the first place. This makes much of Carel and Kidd's expansion less relevant for the key point in Paul's theory, that is, reduction of decision-making capacity. Nonetheless, let us investigate some areas where it still may be relevant.

Not voluntary cases of present disease:

There are In cases where the a person with a given disease is forced to choose between treatment options that have transformative consequences. The person must choose, and the outcomes of disease treatment are transformative experience TEs which can undermine autonomy and consent. This is relevant at the end of life,[23] as death is an outcome for which we have no experience,[31 32] but also in cases where treatments can change the life radically.

Not voluntary cases of future disease:

Even healthy persons may be destined to become diseased, for example, autosomal dominant disorders, such as Huntington's disease. In such cases, the potential disease is transformative

and not voluntary. This could be used to argue for a paternalistic approach to testing, as the disease is a transformative experienceTE and, therefore, decisions on testing cannot be informed. However, then we run into trouble with the right (not) to know.

To these cases that would fall under Carel and Kidds expansion of Paul's framework, we can add the voluntary cases that would fall under Paul's framework.

Voluntary cases of present disease

Deciding on treatment options for a disease with transformative consequences can undermine autonomy and consent as it involves transformative experienceTEs. For example, organ transplantation has been characterizedcharacterised as a transformative experienceTE.[33] It may be objected that this may not count, as the person may have experienced being healthy (before) and being dependent on dialysis. However, the transplantation, carrying another person's (relative's) organ, and being dependent on medication may not be experienced.

Voluntary cases of future disease:

As already pointed out, diseases resulting from (lifestyle) choices or being overdiagnosed and overtreated due to primary and secondary prevention are potentially transformative experienceTEs that undermine autonomy and consent. This can be used to argue for nudging lifestyle choice and for paternalistic prevention.[1]

Table 3Ttable 3 sums up the various combination of present and future situations (disease) as well as voluntary and not voluntary cases..[2]

Table 3double_arrowPreviewCite Now1

Table 3Summary of the situations discussed by Paul and expanded by Carel and Kidd.[20]

A	B	C
	Present disease	**Future** disease
Voluntary	Deciding on treatment options for a disease with transformative consequences. Transformative experiences undermine autonomy and consent	1. 1)(Lifestyle) choices resulting in disease 2. 2)Primary and secondary prevention The diseases (or the overdiagnosed and overtreated conditions) are potentially transformative experiences that undermine autonomy and consent
Not voluntary	Having to choose between disease treatment options with transformative consequences. The outcomes of disease treatment are transformative experiences which undermine autonomy and consent	Predictive testing for genetically dominant disease (e.g., Huntington's disease). The potential disease is transformative and not voluntary.

A	B	C
	Present disease	**Future** disease
		Testing appears voluntaryautonomous, but is not, as the disease is a transformative experience.

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Discussion

This study shows that Paul's philosophy of transformative experienceTE is not as transformative for medical ethics as could be feared. Deciding for treatment options for a disease where the treatments are transformative experienceTEs, (lifestyle) choices resulting in disease, and (primary and secondary) prevention of diseases that are transformative experiences are cases where autonomy and informed consent can be undermined. Carel and Kidd's expansion add cases of treatments for diseases with transformative outcomes and predictive testing for (inevitable) diseases. While these are cases where autonomy can be undermined, and consent can be over-ruled further and detailed studies of when and how disease does so are required.

Laurie Ann Paul's framework has been very influential on a wide range of fields, but also criticizedcriticised.[34–41] While Paul has responded to some of her critics,[42] others have tried to find alternative ways to make decisions related to transformative experiencesTEs rational,[43] for example, because we can '"rationally choose based on the belief that whatever that experience is like, we're fairly sure it's something we don't want'."[34]

Richard PettigrewPettigrew has reformulated deliberative decision theory in order formally to avoid Paul's challenges. However, he acknowledges that Paul's challenges '"do raise profound philosophical questions about the status of decisions we make using that theory.'"[39]

As pointed out at the outset, Carel and colleaguesCarel and Kidd have written about illness[11] and suffering[21] as transformative experienceTEs, while this study has focused on '"the parts of illness experience that isare related to disease'" shortened to '"disease'" in order to delimit the study to a health carehealthcare setting .

For one of the most radical findings in this study, that is, that people may not be able to be autonomous with respect disease prevention, it may be argued with Barnes[34] that it is sufficient to know that they do not want to have the disease. However, you may not want to have the bad outcomes of the preventive measures either, such as overdiagnosis and overtreatment. Being ignorant of the content of the benefits does not make you immune to the content of the risks.

Many details in Paul's theory as well as Carel and Kidd's expansion are relevant for autonomy and consent but must be studied in more detail than is allowed within the scope of

this study. However, while Carel and Kidd '"believe that this new, expanded view of TE will provide a broader, more inclusive notion which will therefore be relevant to more lives and to more of life'" this study has shown that it will reduce the need for respect for autonomy and consent only for some of them.

This study has applied generic conceptions of autonomy and informed consent defined in terms of two common key criteria: understanding and decision-making capacity. More detailed studies of how disease as a transformative experienceTE challenges specific conceptions of autonomy and consent must be conducted. The point here has been to investigate the general challenge that disease as a transformative experience TE may pose for key principles and requirements in medical ethics.

Moreover, the transformative experienceTE of disease may influence other aspects of decision-making capacity, such as a reasonable consistent set of values,[44] coherent reasoning,[45] distorted or '"pathological values'".[46] As such distortion in values are not detectable with standard capacity instruments (such as the MacArthur Competence Assessment Tool for Treatment, MacCAT-TMaCAT-T), it is interesting to investigate whether a transformative experienceTE is similarly undetectable. These are important issues for further studies in the field.

Conclusion

Paul's philosophy of transformative experienceTE is relevant for medical ethics in specific cases, such as deciding for treatment options that are transformative experienceTEs, (lifestyle) choices resulting in disease, and (primary and secondary) prevention of diseases. In such cases respect for autonomy and informed consent can be undermined. To this, Carel and Kidd's expansion add cases of treatments for diseases with transformative outcomes and predictive testing for (inevitable) diseases.

This study leads to the very uncomfortable conclusion that disease involves transformative experience TEs in ways that can reduce people's rational decision-making ability and undermine the basic principle of respect for autonomy and the moral rule of informed consent. While the number of cases where this occurs are limited, it is relevant for crucial areas of modern healthcare and deserves more attention and further scrutiny.

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Notes

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[1]However, this can also be used against paternalistic prevention if overdiagnosis and overtreatment are considered transformative experiences.

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[2]It is worth noting that with (lifestyle) choises the disease is what is voluntary, while with prevention it is the screening that is voluntary.