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▶ **To cite this version:**

Myriam Winance, Janine Barbot, Isabelle Parizot. From loss to repair. A study of body narratives in patient claims for medical injury. Sociology of Health and Illness, 2018, 40 (1), pp.53-66. 10.1111/1467-9566.12620 . hal-01803697

HAL Id: hal-01803697
https://hal.science/hal-01803697

Submitted on 30 May 2018

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SOCIOLOGY OF HEALTH & ILLNESS

Sociology of Health & Illness Vol. 40 No. 1 2018 ISSN 0141-9889, pp. 53–66
doi: 10.1111/1467-9566.12620

From loss to repair. A study of body narratives in patient claims for medical injury

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Abstract In this article we examine the body's status in the complaints that patients filed with a compensation agency. Taking a corpus of letters, we analyse the way in which the patients mobilise their bodily experience from the angle of the damage for which they demand compensation. To this end, we articulate an approach in terms of the sociology of complaint with an approach rooted in the sociology of medicine, health and illness. To analyse the body narratives, we use the notion of loss. We highlight the manner in which patients approach their losses as 'losses in practice'. These losses are defined by the patients putting forward the concrete experience of a body harmed by the treatment received, and by their formulation of expectations in terms of compensation. We therefore identify four ways in which the reality of the damaged body is given a form in terms of expectations of repair: the 'body-producer', the 'body-ecological', the 'body-help' and the 'body-self-image'. Our analysis adds to studies on the status of the body in care and in complaint by showing: the specific influence of the enunciative situation, the plurality of patient evaluations and their temporal dynamic.

Keywords: patient complaint, body, medical injury, compensation

Introduction

The social sciences have analysed the issue of complaints relating to medical treatment from various perspectives. Some have looked at how doctors and their professional organisations react to increasing litigation (Allsop and Mulcahy 1998, Barbot and Fillion 2006, Marjoribanks *et al.* 1996), at the different ways of managing medical errors and conflicts within healthcare departments (Bosk 1979), at the economic costs of medical malpractice claims (Danzon *et al.* 1990), and at how complaint analysis might help improve the quality of healthcare and of the dialogue between doctors and patients (Allen *et al.* 2000, Lloyd-Bostock and Mulcahy 1994, Mulcahy 2003, Nettleton and Harding 1994). Quantitative surveys have highlighted the low rate of patient recourse in relation to deleterious events, and, among complainants, the under-

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representation of the most vulnerable patients (Burstin *et al.* 1993, Localio *et al.* 1991). The observation of a difference between the number of deleterious events and the number of filed complaints led to questions about what the complaint process means for patients. Some studies have focused on the difficulties facing patients when they confront hospitals and when they have to deal with the asymmetrical statuses and competencies that can be exercised against them (Mulcahy 2003). In this article we continue these analyses of complaint from the patients' standpoint. Basing our analysis on a corpus of letters addressed to a compensation agency, we look more specifically at how complainants use and talk about their bodies when formulating their complaint and how they define the bodily harm for which they are demanding repair. To this end, we place ourselves at the meeting point of two approaches: the sociology of complaint and the sociology of medicine, health and illness. The former looks at what brings ordinary people to file a complaint, at how they define the problem and then construct their complaint. The second approach examines the question of the body in patients' experiences. Articulation of the two approaches allows us to analyse the way in which complainants perceive and describe their body damaged by the care and consider how it might be repaired or compensated through legal procedures. We develop this theoretical framework in the following section.

Analytical framework

The sociology of complaint

Various works, in fields other than medicine, have examined the work that ordinary people carry out when constructing a complaint. On the one hand, Felstiner *et al.* (1980) studied the way in which people transform their injurious experiences into grievances, and their grievances into litigation. According to these authors, if only a small proportion of these experiences lead to litigation, it is because there are three stages to complete prior to litigation: perception of the injurious experience – 'naming' – attribution of an injury to the fault of another individual or social entity – 'blaming' – and requesting remedy from the person or entity believed to be responsible – 'claiming'. These authors have highlighted the complex processes (subjective, interactional, unstable, etc.) and the diversity of the actors, devices or institutions which at different points in time affect the trajectory of the complaint. Their approach underlines the complaint's cognitive and moral dimensions, which can be related to each person's individual and social characteristics. On the other hand, in basing themselves on letters sent to a daily newspaper to publicly denounce situations of injustice (Boltanski 1984), and on letters sent to an emergency social fund (Fassin 2000), other authors have analysed the plurality of the arguments that people put forward and the way in which they are organised. They highlight the normative constraints proper to each device to which complaints are sent. They show that complainants generally try to align themselves with what they imagine to be the device's conditions of admissibility. In drawing on these studies, we analysed the argumentative work that persons who consider themselves to be the victims of a medical accident carry out in order to attribute bodily harm to the care received, to identify inappropriate practice or conduct and to formulate expectations regarding possibilities of repair (Barbot *et al.* 2015). More specifically, in this article we focus on an issue which has proven to be central to the case of medical complaints – that of how people mobilise their bodily experience in their complaint in order to define a bodily harm for which they demand compensation.

The sociology of medicine, health and illness, and body analysis

Analysing the experience of chronic illness, Charmaz (1983, 1995) proposed the notion of 'loss of self' to designate the identity transformation relating to the body transformation caused

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by the illness. This 'loss of self', which is a specific pain, is characterised by a dual rupture: first, between the self and the body and second, between personal identity (self-definition by the individual) and social identity (the identity formed through relationships with others). Charmaz then analysed the processes which allow people either to maintain the rupture (to maintain their past identity in spite of the transformation of their bodies) or to re-establish unity by working on the self (transforming identity in accordance with the bodily modification). Her works show how illness induces a definitive loss for the person concerned, and how the person reacts and adapts to said loss. In focusing on the question of identity, this approach stresses the cognitive dimension of people's relationships with their bodies. The body is a representation that people form on the basis of their experience. The notion of 'loss' will also be pertinent to analyse what the bodily harm represents for the complainants. Our use of the notion of loss nevertheless goes beyond 'loss of self' and includes losses of a different nature.

Referring to works from science and technology studies (STS), we will show that this loss also includes 'practical losses'. Authors from these approaches suspend any a priori definition of the body (as an organism, a set of perceptions, etc.) and examine how medicine works on and produces bodies (Berg and Akrich 2004, Mol 2002, Mol and Law 2004, Mol *et al.* 2010, Moreira 2004, Winance 2006). Instead of focusing on the identity-based work that people carry out, they analyse the dynamic processes through which different bodies are performed 'in practice' via heterogeneous arrangements (made up of actions, knowledge, techniques, places, etc.). These authors show how, within these processes, the unity 'of the body' or more precisely 'of the embodied self' is articulated to and even requires the heterogeneity of 'bodies', as subject or object (Akrich and Pasveer 2004, Cussins 1996, Thompson 2005). In line with these works, our analysis underlines the different realities of the body, as they are enacted in singular and local practices. Into these practices, we integrate not only daily practices, but also the specificity of the practice of the complaint.

Some STS researchers (Akrich and Pasveer 2004, Cussins 1996) have already stressed the importance of narrative construction of the self, considering a person's narrative not as something which reflects a reality but as constituting the reality the person is living. Extending this analysis, we consider the legal complaint as a kind of narrative which constitutes the reality of the person. We analyse the relationship between the specific enunciative situation (that of the legal complaint) and the constituted reality for the person. The enunciative situation of the complaint is one of the concrete elements that in practice lead people to say what their damaged bodies are. Filing a complaint thus appears to be a practice of articulation between several realities of the body. What people conceive and request in terms of compensation informs their damage: the body damaged is described by people as a body to-be-repaired. After presenting our methodology, we focus on the damage and the enunciation of losses and secondly, we centre our analysis on the body to-be-repaired. We conclude by exploring how this study transforms the analysis of the body's status in the complaints.

Methods

The study is based on a corpus of complaints filed with the French out-of-court settlement mechanism created in 2002. For patients, this mechanism constitutes an alternative to suing through the courts or attempting a face-to-face negotiation with healthcare providers or their insurance companies (Barbot *et al.* 2014). It implements two victim compensation schemes, one based on responsibility (for cases where a medical error has been made by an actor who insures the consequences), the other based on national solidarity (in the case of a no-fault accident, compensation then being provided by the health insurance system). Organisation of this

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mechanism is based on the one hand on the creation of 25 commissions tasked with examining the case files, and on the other hand on the creation of a new public administrative organ, the national office of compensation for victims of medical injuries, iatrogenic affections and infections (ONIAM), in charge of the compensation procedure. We conducted our study at the ONIAM between 2009 and 2011. We had access to anonymised data through a scientific partnership agreement between ONIAM and the French National Institute of Health and Medical Research (INSERM).

Our corpus was made up of written documents from 61 cases filed by victims (i.e. people who believe they have been the victim of harm due to medical activity). When using the out-of-court settlement mechanism, complainants must describe the extent and nature of the harm and identify the treatment and persons they consider to have caused it. To this end, they fill out a form, on which they answer the question: 'What harm and prejudices have been suffered?' They are also invited to attach a letter explaining the facts. These letters (not always provided) vary considerably in terms of length, content and style. For each victim, our corpus is made up of his/her answer to the question on the form regarding prejudice and the letter of explanation. For the purposes of this article, we focused on the letters written by the victims themselves. We excluded letters written by family members or partners, in as much as we were interested in how people rely on their own bodily experiences to formulate their bodily harm. We also excluded letters written by lawyers who were likely to have couched the complaints in legal terms, the logic for defining the bodily harm then being that of the law and no longer that of the victim, which we wished to analyse. The letters in our corpus were written by both men (n = 34) and women (n = 27). At the time of filing, one third were aged between 18 and 49 (n = 21), one third between 50 and 59 (n = 21), and one third over 60 (n = 19).

We carried out an inductive analysis of these letters based on the coding of extracts in which people talk about their bodies and their expectations in terms of compensation, on the identification of pertinent contrasts, and on the construction of transversal categories of analysis (Strauss 1987). All of the letters making up the corpus were first read separately by the researchers so as to identify the themes relating to the damage and the body. Coding schemes were then compared in order to agree on common categories and on theme definition. All letters were recorded by the researchers using the constant comparison approach. Throughout this comparison between the material and the analytical codes, the latter were constantly refined and adjusted in order to provide a more accurate account of people's experiences. Quotations from the letters are presented below to illustrate the themes which emerged from the analysis.

Findings

The expression of harm as a loss

When one undergoes medical treatment, one always hopes for an improvement, for one's pain to be relieved, or, at the very least, for one's state of health to stabilise. In their letters, the complainants speak of the harm (abnormal, unexpected, related or not to a mistake by a healthcare practitioner) done to their body during the course of treatment. Bodily harm is thus at the heart of people's complaints. Succinctly or in detail, they describe their bodies damaged by the treatment. They sometimes focus on the physical harm. They talk about their body ('paralysis', 'infection', etc.), or given parts of their body ('my leg seems to be dead', 'pain in my arm', etc.), sometimes using medical terminology to talk about these things. People sometimes also present their damaged body in terms of their subjective experience. They then talk about 'ordeal', 'nightmare', 'suffering', etc. They describe a life which has been changed or shattered, compared to what it used to be and to their hopes for the future. These two

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dimensions of the damage, objective or subjective, can be seen in the following quotation from Mrs. Y:

> On the 3rd February, I was operated on for a full hip replacement. A few days later I ended up at the emergency department, and on the 11th February they found a haematoma which required a further operation. On the 28th February, I started rehabilitation at the geriatric centre, where the doctor discovered an ulcer on my heel and sores on my toes, all of which had been caused by the compression stocking [. . .]. I can confirm that my life was shattered on the day of my operation. I depend entirely on my husband, and on my children when he is not there. The lives of everyone in the family have been changed. I know that from now on I'll have to live with my disability, all I can hope for now is to receive financial help which will allow me to secure my future.

Mrs. Y describes both her physical body ('haematoma', 'ulcer on my heel', 'sores on my toes', etc.) and the way she has experienced the change in her life. Her description of the harm is in fact quite similar to descriptions that patients give of their experiences of illness, as found in the analyses of the sociology of illness. However, the complainant's last sentence is cause to change these analyses, in as much as the concrete transformation of her day-to-day life is turned towards a 'hope . . . to receive financial help'. The legal mechanism we have analysed is a compensation mechanism. Whilst people have different and more or less accurate notions of this mechanism (of the way it works and its purposes), they all formulate a certain number of expectations in terms of repair, that is, they say what they would consider to be suitable and possible compensation for their bodily harm. To define their bodily harm, people base themselves on their bodily integrity, on the one hand putting their body into a context of action, and on the other hand placing it in a temporal dynamic that articulates and contrasts their body as it was, as it is, and as they want it to be.

Indeed, whilst the body damaged by the treatment received is at the heart of the claim, complainants rarely put forward a return to the previous state of health as a hope or a horizon of expectations. As explained by Mr. V., who has serious cardiac problems following chemotherapy:

> I am disabled for life (short) in an irreversible way and all I have to live on is 760 euros which is why I'm demanding compensation for this serious medical error, which will never give me back my health.

The harm is seen in terms of loss, whether this relates to a person's physical body and material damage, or to subjective experiences and non-material damage. The notion of loss, often used to analyse the experience of illness also plays a central role in this other enunciative situation of the complaint. But it is not only a question of the loss of capacities or social relationships which make up a person's identity and with which he/she must cope (a loss of self); it is also a question of practical losses that the person wishes to see compensated (by filing a complaint with the compensation mechanism). So in their complaints, people present their losses from the standpoint of what might or should be of a compensable nature. As we will see, they often do this by combining, in different ways and in relation to the notion of loss, both the objective and subjective dimensions of their damages. They set out what they feel to be the prejudicial consequences of the physical harm caused by medical treatment, and describe in their own words how this harm manifests itself and should be compensated in practice. People want the judge to understand the harm they have been caused, by giving form to their objective or subjective bodily losses, and the way this could be concretely compensated. To this end, they mobilise various bodies-to-be-repaired.

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Patients' expectations of repair

Depending on the complaint, and sometimes even within the same complaint, the body-to-be-repaired takes different forms. These forms are the result of all the things that people do to jointly express their bodily harm, their concrete experience of this harm and their expectations in terms of compensation. In the letters we studied, we were able to identify four ways in which the reality of the damaged body was given a form in terms of expectations of repair: the body-producer, the body-ecological, the body-help and the body-self-image.

The body-producer: restoring a financial balance

The body might be presented first and foremost as a functional body, seen from the point of view of its utility and earning capacity. It is a body-producer, both a source of income and a tool for saving money. In this case people focus on their financial situation, which has been affected by the physical harm caused and for which there must be compensation. The loss of physical functionality due to medical practice is converted into loss of earnings and/or new expenses. Compensation is seen as a way for people to once again cope with their finances, even if this involves to some extent reorganising or delegating them. It is needed to restore a person's economic situation, as it stood prior to the accident – to restore his/her body-producer – without requiring direct repair of the physical body. This focus on the body-producer can be seen in two areas: work and home.

In the professional area, the inability to work is the most direct reference to a body-producer which is considered to be a source of income. The existence of forms of remuneration governed by the law (salary, daily allowances, etc.) allows people to accurately describe the nature of their loss and the compensation they are expecting. The body-producer has a price on the marketplace, which allows a direct equivalence between the 'body-producer' and a demand for compensation. Suffering from an infection following treatment of a compound fracture of the leg, which led to complications, Mr. V. explained:

> I am therefore asking to be compensated for the loss of income engendered by me having to stop work for 9 months.

Yet some people are outside the most controlled forms of work. In such situations they perceive the difficulties relating to the legal recognition of these forms and hence to their compensation. They try to make this variety of forms of work visible and attempt to justify how important this body-producer is to them, in these non-institutionalised or unrecognised forms. Farmers' spouses, unemployed women who do occasional cleaning jobs without being declared, or other people working illegally all explain how their physical injuries led to situations of precarity, or, in many situations, added to existing precarity. Mrs. A thus mentioned the invisible work of 'voluntary employees' on family farms:

> Significant financial loss because I'm a 'collaborating spouse' on our farm so I receive no benefits and I have to employ a third party to do my work. Plus someone at home, but not for long periods as it's too expensive.

In the domestic area, people mobilise this body-producer to calculate new expenses relating to their inability to carry out a certain number of basic tasks (washing, shopping, housework, etc.). This inability is presented as an 'in-kind' loss which engenders or which is likely to engender new expenses if other people have to do the tasks in question. If no longer being able to work means a loss of income, people feel that having to call upon other people to do

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what they themselves could do before represents a loss of value. Furthermore, people integrate bodily activities which are not usually associated with work and with the production of resources, but which they nevertheless consider to be a direct part of a domestic economy. These activities, usually considered to be hobbies that people do for pleasure, are presented as economic activities when the person's incapacity to perform them has financial consequences. This is the case with gardening or DIY, which, sometimes only in the light of injury, are seen from the angle of a person's productivity, because they have an equivalence on the goods and services market. Having lost his capacity to do DIY, Mr. X's house is deteriorating (he can no longer 'do it up' as he had planned); so he now has to call on a third party whose services are an expense that Mr. X must assess. Another claimant points out that because he can no longer do the gardening, he is deprived of the resources he gained from this activity (from the vegetable garden):

> I had to stop gardening and buy my vegetables from the market. That's quite a budget for a family of 6!

In extreme cases, people who approach certain consequences of their physical harm in terms of financial loss transgress moral conventions which, in one respect, exclude monetisation of the human body. For example, they are led to make a direct link between sexual harm, a partner leaving and the drop in household resources. They therefore demand compensation for loss of earnings. In such situations, sexual harm is defined in a functional approach to the body and is viewed specifically in terms of its economic consequences.

The body-ecological: restoring a living environment

Demands might also be based on the body-ecological, a body which has various abilities because it is adapted to and has adapted its living environment (Moser 2009, Sánchez Criado *et al.* 2016, Winance 2006, 2016). In this case, people describe their physical injuries as restrictions of what they had been able to do 'before', on a daily basis, in their environment, be they basic activities (washing, eating, etc.), family activities (playing with their children, etc.) or leisure activities (going for a bike ride, gardening, etc.), and which have 'now' become difficult or impossible to do because their body is not anymore adapted to their living environment. They then correlatively describe the adaptations or technical modifications required to compensate them, that is, to re-establish the agreement between body and environment. The nature and extent of the demands for compensation thus vary considerably. These differences relate to individual characteristics (family circumstances, age, sex and social conditions), to what they feel they are entitled (or not) to ask for, and to their understanding of the technical possibilities for adaptation. They also relate to how, in practice, people envisage compensation for their body-ecological in terms of what we call palliation, rehabilitation or reconfiguration.

Palliation corresponds to situations where people focus on compensation for a single impairment, because compensating this impairment is for them the *sine qua non* condition for being able to return to their previous activities or begin new activities. This is, for example, the case with Mrs. B whose urinary incontinence following surgery upsets her day-to-day activities and is difficult to cope with due to her level of income:

> This incontinence is a major handicap in my everyday tasks. [. . .] The protection I use can only cope with one hour of my abundant urine leakage and this prevents me from doing any of the tasks and leisure activities I used to enjoy prior to the operation. [. . .] I only have a small pension and my incontinence costs me about 90 euros per month in pads.

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Mrs. B believes that receiving compensation which would allow her to purchase protections is absolutely vital for her to be able to do a minimum number of activities. When compensation of the body-ecological takes the form of palliation, this means restricting compensation to a dimension of this body-ecological that is considered to be fundamental, but also minimalist (in terms of what it can do). Yet whilst in certain letters the demand for compensation is limited to a demand for palliation, in others palliation is part of a broader demand, either in terms of rehabilitation or reconfiguration.

The rehabilitation horizon aims to re-establish a daily life which is similar to that prior to the medical treatment, in the previous living environment. People look to recover their capacities by using equipment and by reorganising their environment. Mr. Y, whose leg was amputated following a nosocomial infection, gives a detailed description of all the apparatus (two prostheses), equipment (an automatic car and an electric scooter), fitting-out of premises (his main and secondary residences) and services (gardening in particular) that he has had to, or will have to pay for in order to return to a 'minimum level of activity' and 'readapt to a social life'. He estimates the cost of everything that he considers to be necessary to compensating for his physical injury, this being the condition for a return to some form of validity, the reference for which remains his previous state of health and the social conditions of his previous life, to which he feels it is legitimate to aspire.

Finally, some people try to define a new daily life, to build a universe which creates better compatibility between their new bodily (in)capacities and their environment. In their demands, compensation takes the form of reconfiguration. Here it is a case, for example, of moving from the country to a city where property is more expensive but where there is a wider range of personal care services, etc. The environment is considered as a whole, in terms of the constraints and opportunities that it offers to people in their new state. Said state is then characterised by a reconfiguration of their capacities and activities which modifies their experience (for example, their feeling of dependency on friends/family) and redefines their interests (that which provided the basis of the environment as a choice might no longer be pertinent for people as they now see it in their new state). Mrs. C, who had suffered a loss of mobility after a hip operation, explains why she decided to move rather than transform the house she was living in. For her this move was a consequence of her accident and should give rise to financial compensation.

> In order to finalise my disability case, I would inform you that after talking to my doctor and to the social services in the region where I live, it seemed inadvisable to carry out work on our house so that I could live there (expensive work for average comfort), and on top of that remain isolated in the country. We decided to look for a house near the town, where there are local services (nurses available every day). We rent a house appropriate to my disability for 500 euros a month.

In mobilising the body-ecological, people aim to restore a daily life by realigning body and environment.

The body-help: restoring family interdependencies

The feeling of having become a burden is often stressed in works on chronic illness (Bury 1982, Charmaz 1983). In the complaints we studied, people talk about a double loss which relates on the one hand to the perturbations of previous family interdependencies, through their inability to fulfil/maintain their family role (no longer able to help others), and on the other hand to being an additional burden to the family due to the care that the damaged body requires (needing help from others). Mrs. D, who had become paraplegic following an operation on her back, writes:

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> It scares me to think about the future, because I feel I'm a burden, I always need someone to help me, I always need to ask for help, and it's very hard, I always loved to help and work with my husband.

These people want compensation which will allow them to call upon outside help to restore family interdependencies. In such a context, things often seem to happen as if the person is presenting recourse to external human aid as something which concerns his/her family. It is a question of helping his/her family to carry out the tasks that this new situation demands. We therefore observe a refocusing of the definition of needs, from the person with the damaged body, towards the relatives upon whom they have become dependent. Complainants thus look to justify the helper's need for aid, and the way in which this aid will restore the balance of family interdependencies, redefining or re-establishing the role that each individual takes on. In their narratives, we can see two ways in which people envisage the extent and nature of this recourse.

Some people refer to the notion of responsibility to justify the need for help from their families: family members are presented as not having to cope with a burden for which neither they nor the victim deem themselves to be responsible. People also express a need to re-establish a relational balance. They demand the right for their families to be relieved of the pressure, to break away from them. They talk about the need to preserve the nature of their relationships, to have them as they were before. It is a case of removing a duty which might befall a family member because of their family links, but which would significantly change the nature of the family relationship.

On the other hand, other claimants sometimes have to directly address the issue of the workload that they feel it is 'normal' to impose upon their family caregiver. They then define the nature of the financial compensation that is expected, depending on the status of the caregiver. Some family members are considered to be natural helpers, whose support might not initially be thought of as requiring remuneration. We observed for example differences between men and women. These differences relate to individual situations of employment, and to representations and practices associated with gender. A woman who does not work might appear in the form of a multi-helper who is shared among many assisted persons (elderly or isolated parents, spouse who is ill). When the multi-helper is facing a newly expressed need and is unable to cope with all these workloads, she requires partial release from her responsibilities. However, the role of helpers is presented from different angles. From a financial standpoint, the status of helper might involve leaving employment and thus a loss of income. The request for compensation is therefore based more on that loss of earnings than on the idea of a contribution which would be based on the value of the help provided (this not being perceived as directly monetisable). Highlighting the work done by helpers can also be a way of demonstrating the extent of the victim's impairments: the need for human help and the time spent by the helper make it possible to assess the extent of the harm, rather than measuring the help itself and the financial equivalence which might be awarded. So it is often through the expression of concerns (the family helper growing old or becoming weaker) that the need is formed to ask that other equivalences be determined, by raising the issue of using outside services. These outside services are rarely seen as covering the needs of the victim, but rather those of the family helper.

The body-self-image: restoring a person's integrity

The body-to-be-repaired can also be described in terms of a desire for the restoration of a person's integrity as subject – in which case the complaint focuses on an alteration to the body-self-image. First and foremost, this body might be presented as a body which the person no longer recognises as his/her own. The medical care, which was supposed to resolve a health

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issue, instead drew the person into a physical deterioration with which he/she says he/she cannot cope, that he/she cannot integrate into what he/she is. In such a situation, the bodily harm is perceived not as a loss of functionality, but as a loss of self. Some people express this loss of self by referring to their past: not just to what they were but also to what they hoped to become. They are thus highlighting their anguish about the future, about their previous family or professional projects. They say that they 'can no longer trust their bodies', can no longer rely on them to construct their lives. For example, Mr. V was a chef; following a fracture of the tibia which in his opinion was poorly treated, he has to wear a prosthesis, and he is worried:

> The fact that this is not a definitive prosthesis and that no-one knows at what frequency it will have to be changed is very worrying and it's stopping me from living a normal life ... I've lost a great deal of peace of mind, serenity and self-confidence and physically speaking I feel I'm a lesser person.

People might therefore consider the abandonment of their professional project not only in terms of financial loss (the difference between income from the previous profession and that which is predicted for the future), but also as harm to the self, caused by a body which has become defective. Even if the physical consequences are presented as being minor, people talk about how hard it is, due to the existence of a breaking point, to re-establish continuity between themselves and their bodies.

People thus see the complaint and the ensuing compensation procedure as recognition of their status as victims, recognition which is important in itself to make their reconstruction of identity possible. Furthermore, in some letters, the fact of obtaining compensation as an act of recognition by a third party of the harm done to the *body-self-image* is mentioned in its relational dimension. People formulate the idea that in order to restore personal integrity one must satisfy an expectation of truth or justice. To obtain compensation is therefore to achieve recognition, both for oneself and in relation to others (family and health professionals), for the fact that one's physical impairments are (or were) very real and, furthermore, that they relate to outside factors, that they were caused by the medical care, either accidentally or through the fault of a healthcare professional.

For example, one young woman talked about 'everything she had endured' after a cholecystectomy. She describes the extent to which she had been affected by the fact that her family did not recognise the reality of her physical suffering:

> My morale took a huge hit because my family did not believe my pain.

She wants it to be established that her pains or her inability to live are by no means due to personal failings, but have (or had) a real physical cause. Here, to give compensation is to authenticate and to recognise the reality of an endured physical ordeal. The compensation process might then involve removing the doubt that weighed upon the victim, which leads to her loss of self-confidence and sets her at odds with others. When people find themselves in such a context, they often talk about compensation as something which will allow them to gain closure (to bring a traumatic event to an end), to 'start over' or to 'live normally' once again, and to regain dignity.

Restoration of the body-self-image is thus at the heart of specific expectations for repair. The analysis of written complaints shows how, by mobilising a body-self-image, people say what has been affected and what must be preserved and restored in order to re-establish agreement between them and their bodies. More often than not, compensation is integrated into a

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process of recognising the harm caused by the medical care – and through this recognition it makes possible a process of reconstructing their physical, personal and social integrity.

Conclusion

The aim of this article was to analyse the different ways in which complainants perceive and describe their body which has been damaged by care, its consequences and how it might be repaired or compensated. We have shown that the damaged body about which the complainant speaks is a body defined both in practice (through the way in which his/her life is empirically changed) and in accordance with the meaning that these practices hold for that person in his/her narrated story (that of considering him/herself to be the victim of a medical accident and to demand repair via legal complaint). Using an analysis of the letters sent to a compensation agency, we analysed the various ways in which people perform their body damaged as body to be repaired. The relation that exists between the body-damaged and the body-to-be-repaired is not one of causality, but one of reciprocity: the expectations of people (in terms of compensation) are what give form(s) – bodily reality(ies) – to their damage. We then highlighted four forms of the body-to-be-repaired that people use to establish their bodily damage: the 'body-producer', the 'body-ecological', the 'body-help' and the 'body-self-image'. We also wished to demonstrate the existence, among the complainants themselves, of significant variations in one or more of the four shapes of the body-to-be-repaired that were mobilised: for example variations in the nature and extent of the compensation demands (for the body-ecological), variations in the definition of what is normal to expect of a family member who has become a helper (body-help).

We would now like to discuss two consequences of this research for the analysis of the body status in the complaint. The first consequence concerns the heterogeneity and multiplicity of the body, shown by STS researchers. In their opinion, the body takes on various realities depending on the specific and heterogeneous arrangements that define it. In this paper, we have analysed four of the various realities of the damaged body. Although certain patients mobilise several of these realities in their letters, they tend to concentrate on just one or two types of damaged body. The multiplicity of the body would not appear to be infinite; on the contrary, it would seem to be limited by the value that a person attaches to the bodily loss and by the meaning that compensation has for him or her.

Second, this analysis invites us to question the temporal dimension of the body. By analysing the processes through which bodies are defined, STS works have drawn attention to the body's temporality and to the articulation between the 'body' and the 'self'. The body is no longer a defined and stable entity, but an entity whose coherency is relative to its context of production, produced by the articulation between different modalities of the body. However, in these works there is an implicit hypothesis concerning the flexibility of the body, constantly defined and redefined through specific heterogeneous arrangements. Our analysis of the damaged body highlights the incorporation into bodies of 'irreparable' harm, compensation for which can only be based on efforts to establish a compensatory equivalence. The harm done to people is experienced and put forward as a loss which irreversibly transforms their bodies. The body is not indefinitely flexible, even if its reality changes shape through the specific arrangements that define it.

Works on the experience of illness also integrate time into their analysis of the body, albeit in a linear perspective. They analyse the identity transformation that follows on from the body transformation. Charmaz (1983, 1995) thus looks at how illness induces a bodily and social transformation experienced as a loss of self; and then at the way in which people engage in

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processes of adaptation which once again transform their identity. For Charmaz, these are two successive stages of a chronological process. People engage in a process of adaptation once the transformation has taken place and been accepted by the person concerned. Yet analysis of the body to be repaired demonstrates that the experience of the damaged body is defined by past and present experiences and by anticipations of future experiences.

Indeed, to define their bodily harm, people relocate their bodily injuries in a temporal dynamic that compares three reference points: the past, the present and the future. In referring to the past, people talk about their body as it was, whilst accepting that it will never be fully restored; they also point out the irreparable dimension of the loss. On the other hand, in order to show what aspect of the damage might be the object of compensation (based on a financial equivalence), they look ahead to 'their repaired body' and, in relation to that, their 'present body' and their 'actual losses'. In the way in which people describe their damaged bodies, the past (a harm they believe to have been caused) is intricately linked with the future (the concrete bodily compensation that they expect). They inter-define one another. A person's definition of damage is linked to the process of repair to which he/she has committed. They are not two successive moments in the bodily transformation.

To conclude, we would like to mention certain avenues of reflection through which to continue this work. This analysis of bodily harm, in the context of patients' complaints, raises the issues of the processes for assessing and quantifying the prejudices, and of how people and professionals differentiate between these processes. When describing their harm, people try to highlight what is compensable. To achieve this, they borrow from administrative categories (contract of employment, for example) and from everyday categories (incapacities), etc., whilst at the same time working on these categories so as to integrate their specificity. Moreover, whilst people want to use concrete descriptions to make their prejudice objective, they do not necessarily try to quantify it. It is rare for people to go so far as to quantify their prejudice in their letters. It might therefore be interesting to analyse the links that the forms of the body-to-be-repaired have with the categories of compensable harm which are set out in the law governing repair for physical harm and which are used by the compensation mechanism. We might analyse the adjustment or maladjustment between the categories used by the patients and the legal categories, between lay expectations of repair and specialised approaches of injuries implemented by lawyers or medical experts. Furthermore, our article might provide useful tools with which to more broadly examine the ways in which patients claims are transformed by successive confrontations with the various actors within the compensation mechanism and outside it (for example, in the relationship with doctors who continue to provide care to these patients, and participate in the way they perceive their damaged body). These confrontations can reconfigure patients' experiences of the care received and their expectations in terms of repair.

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Acknowledgements

This research was made possible through financial support from the Agence Nationale de la Recherche (ANR), the Institut de la Recherche en Santé Publique (IRESP) and the Haute Autorité de Santé (HAS). The study could not have taken place without a scientific agreement between the Institut National de la Santé et de la Recherche Médicale (INSERM) and the Office National d'Indemnisation des Accidents

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Médicaux, des Affections Iatrogènes et des Infections Nosocomiales (ONIAM). We are also grateful for the logistic support provided by Isabelle Cailbault (research assistant), Vanessa Thérin (technician), and Christopher Hinton (translator).

References

Akrich, M. and Pasveer, B. (2004) Embodiment and disembodiment in childbirth narratives, *Body & Society*, 10, 2–3, 63–84.

Allen, L.W., Creer, E. and Leggitt, M. (2000) Developing a patient complaint tracking system to improve performance, *Joint Commission Journal on Quality and Patient Safety*, 26, 4, 217–26.

Allsop, J. and Mulcahy, L. (1998) Maintaining professional identity: doctors' responses to complaints, *Sociology of Health & Illness*, 20, 6, 802–24.

Barbot, J. and Fillion, E. (2006) La 'médecine défensive': critique d'un concept à succès, *Sciences Sociales et Santé*, 24, 2, 7–33.

Barbot, J., Parizot, I. and Winance, M. (2014) 'No-fault' compensation for victims of medical injuries. Ten years of implementing the French model, *Health Policy*, 114, 2, 236–45.

Barbot, J., Winance, M. and Parizot, I. (2015) Imputer, reprocher, demander réparation Une sociologie de la plainte en matière médicale, *Sciences Sociales et Santé*, 33, 2, 77–104.

Berg, M. and Akrich, M. (2004) Introduction – bodies on trial: performances and politics in medicine and biology, *Body & Society*, 10, 2–3, 1–12.

Boltanski, L. (with Darré, Y. and Schiltz, M.-A.) (1984) La dénonciation, *Actes de la Recherche en Sciences Sociales*, 51, 1, 3–40.

Bosk, C. (1979) *Forgive and Remember. Managing Medical Failure*. Chicago: University of Chicago Press.

Burstin, H.R., Johnson, W.G., Lipsitz, S.R. and Brennan, T.A. (1993) Do the poor sue more? A case-control study of malpractice claims and socioeconomic status, *Journal of the American Medicine Association*, 270, 14, 1697–701.

Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health & Illness*, 4, 167–82.

Charmaz, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill, *Sociology of Health & Illness*, 5, 2, 168–95.

Charmaz, K. (1995) The body, identity, and self, *Sociological Quarterly*, 36, 4, 657–80.

Cussins, C. (1996) Ontological choreography: Agency through objectification in infertility clinics, *Social Studies of Science*, 26, 3, 575–610.

Danzon, P.M., Pauly, M.V. and Kington, R.S. (1990) The effects of malpractice litigation on physicians' fees and incomes, *The American Economic Review*, 80, 2, 122–7.

Fassin, D. (2000) La supplique. Stratégies rhétoriques et constructions identitaires dans les demandes d'aide d'urgence, *Annales – Histoires, Sciences Sociales*, 55, 5, 953–81.

Felstiner, W.L.F., Abel, R.L. and Sarat, A. (1980) The emergence and transformation of disputes: naming, blaming, claiming, *Law & Society Review*, 15, 3-4, 631–54.

Lloyd-Bostock, S. and Mulcahy, L. (1994) The social psychology of making and responding to hospital complaints: an account model of complaint processes, *Law & Policy*, 16, 2, 123–47.

Localio, A., Lawthers, A., Brennan, T., Laird, N., *et al*. (1991) Relation between malpractice claims and adverse events due to negligence. Results of the Harvard Medical Practice Study III, *New England Journal of Medicine*, 325, 4, 245–51.

Marjoribanks, T., Good, M.-J.D., Lawthers, A.G. and Peterson, L.M. (1996) Physicians' discourses on malpractice and the meaning of medical malpractice, *Journal of Health and Social Behavior*, 37, 2, 163–78.

Mol, A. (2002) *The Body Multiple. Ontology in Medical Practice*. Duke: Duke University Press.

Mol, A. and Law, J. (2004) Embodied action, enacted bodies: the example of hypoglycaemia, *Body & Society*, 10, 2–3, 43–62.

Mol, A., Moser, I. and Pols, J. (eds) (2010) *Care in Practice. On Tinkering in Clinics, Homes and Farms*. Bielefeld: Transcript.

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Moreira, T. (2004) Coordination and embodiment in the operating room, *Body & Society*, 10, 1, 109–29.
Moser, I. (2009) A body that matters? The role of embodiment in the recomposition of life after a road traffic accident, *Scandinavian Journal of Disability Research*, 11, 2, 83–99.
Mulcahy, L. (2003) *Disputing Doctors: the Socio-legal Dynamics of Complaints about Medical Care*. Maidenhead: Open University Press.
Nettleton, S. and Harding, G. (1994) Protesting patients: a study of complaints submitted to a Family Health Service Authority, *Sociology of Health & Illness*, 16, 1, 38–61.
Sánchez Criado, T., Rodríguez-Giralt, I. and Mencaroni, A. (2016) Care in the (critical) making. Open prototyping, or the radicalisation of independent-living politics, *ALTER – European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap*, 10, 1,24–39.
Strauss, A.L. (1987) *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press.
Thompson, C. (2005) *Making Parents: the Ontological Choreography of Reproductive Technologies*. Cambridge: MIT press.
Winance, M. (2006) Trying out wheelchairs. The mutual shaping of people and devices through adjustment, *Science, Technology & Human Values*, 31, 1, 52–72.
Winance, M. (2016) Rethinking disability: lessons from the past, questions for the future. Contributions and limits of the social model, the sociology of science and technology, and the ethics of care, *ALTER – European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap*, 10, 2, 99–110.

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