The Most Vulnerable Patients in Health Care

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Introduction
Our views on the protection of vulnerable persons in health care contain a paradox. We strongly agree that vulnerability is important and protections for the vulnerable are required. This consensus, which is central in the clinical management of weakened or marginalized persons, is taken up by international texts that often deal with the protection of vulnerability, and of the most vulnerable persons in priority, as a minimum requirement (Institute of Medicine 2003; WHO 2008; WHO Regional Office for Europe 2005). Yet at the same time, we have very little idea regarding what vulnerability is or how to protect vulnerable individuals. This difficulty is illustrated by how often we get the protections for vulnerable persons wrong. To correct this, we need a clear view of what makes us vulnerable and of what appropriate protections might look like.

What We Talk about When We Talk about Vulnerability
In attempting to define both of these levels, we do not aim for comprehensiveness, but for clarity instead. Neither do we want our view to be dependent on a specific view of morality, or of the human condition (Tavaglione et al. 2015). Our primary concern is with how vulnerability could do the sort of work expected of it. How, in other words, the concept of vulnerability included in the Special Protection Thesis, according to which vulnerable persons or groups in health care deserve special attention, care or protection, can be fleshed out (Macklin 2003; Tavaglione et al. 2015). In the now traditional contrast between general—or ontological—vulnerability and specific—or particular—vulnerability (Martin et al. 2014; Rogers et al. 2012), the jury is still out on whether the former delivers useful content for the purposes of designing protections for vulnerable persons. In the case of specific vulnerability, however, there does seem to be something there: this vulnerability is the differential. Our view is that it signals the added difficulty in fulfilling duties that we have in any case (Martin et al. 2014).
Our aim is, then, to propose a moral view of vulnerability. There are two valid options here: specific vulnerability can be based, with varying degrees of comprehensiveness, on either harms (which may be wrongful or not) or on wrongs (which will include wrongful harms). In the first case, there will be instances of morally neutral vulnerabilities requiring no special protection. In the second, vulnerability will be a reason for special protections by definition. We choose the second option because our initial question was how to design appropriate protections and this does rest on moral claims. This does not of course exclude protections designed to help persons in the absence of clear wrongs. Such protections may, for example, be justified in cases where they are designed to help individuals to help themselves, even if harm to ourselves is not admitted as being a wrong.

The literature on vulnerability in healthcare contains at least five different versions for the content of vulnerability. The first is general or ontological vulnerability, or simply human finitude. Vulnerability in this sense is a fundamental characteristic of human beings: we are precariously and fleetingly embodied, interdependent, fallible, capable of suffering and mortal (Callahan 2000; MacIntyre 1999; Rendtorff 2002). This notion is, of course, important. Were we not vulnerable in this sense, our moral life would no doubt be very different. Medicine may have little reason to exist at all. Because it is common to all human beings, however, this form of vulnerability cannot provide grounds to identify persons requiring special protection.

The second version of vulnerability is an incapacity to defend one’s own interests. In this version, persons are considered vulnerable if they are incapable of giving free and informed consent, or if they are more likely to be exploited (Lott 2005). This view is based on wrongs, but only a few.

In the third version, vulnerability is viewed as resulting from barriers to health. Persons are considered vulnerable if their access to care, or their chances for good health, are limited (Danis and Patrick 2002). This is also a wrong-based view, but it focuses on different wrongs than did the previous one.

The fourth version of vulnerability is fragility. Here vulnerability is viewed as a greater risk of injury or physical or mental harm (Kottow 2003). Etymologically, vulnerability denotes the ability to be hurt. This is a harms-based view, and it raises predictable questions as to the forms of harms that justify special protections. Some freely choose to place themselves at risk; should we identify as vulnerable anyone who—even freely—makes a choice that is deleterious to their own health? (Broock 2002).

In a fifth version, some abandon the goal of providing a view of vulnerability altogether and consider whoever is on a list of vulnerable populations or persons to be vulnerable. Different lists have thus been compiled, mostly in research ethics guidelines (CIOMS 2002; ICH Steering Committee 1996). Some of these lists are so extensive that it becomes unclear that anyone can truly be considered as not particularly vulnerable. The common denominator of these lists is difficult to grasp, and it thus becomes unclear why some are included and others excluded.

Vulnerability as a Greater Likelihood of Being Wronged

In effect, none of these definitions adequately capture cases where particular vulnerability might exist. For this reason, we propose a sixth version that in our view better illustrates how previous views of vulnerability all capture a part of the same concept.

First, it seems important to distinguish general—or ontological—vulnerability, common to all and rooted in our common biology, and the special vulnerability that underpins requirements for additional protection (Martin et al. 2014). This special vulnerability we define as an increased probability of being wronged (Hurst 2008), or of having our morally protected interests unjustly considered (Martin et al. 2014). This applies to any form of wrong, to any morally protected interest and to any reason why these interests may be unjustly taken into consideration or thwarted. This means that there are many ways in which we can be vulnerable. Rather than being "rivals," the definitions presented in the literature can be viewed as complementary dimensions of the same vulnerability.

We are thus in a position to reword the Special Protection Thesis: persons having a greater likelihood of being denied adequate satisfaction of some of their claims deserve special attention, care, or protection (Tavaglione et al. 2015).

As long as you recognize that we are beings who have morally protected interests, or claims (Tavaglione et al. 2015), then vulnerability should be a relevant concern to you. What claims you recognize will be subject to controversy as well as what the correct grounding for them is. Our account, however, outlines how the concept of vulnerability can do the work expected of it without being dependent on specific views of morality. It also provides an account of where the requirements of special protection for the vulnerable are grounded: not in vulnerability itself, but in requirements we recognize for other reasons. Finally, it provides a framework to design protections.

Protecting the vulnerable will require that we identify the wrong a person is vulnerable to, the source of this vulnerability, suitable safeguards and those who share responsibility for protection. In a first step, wrongs that can occur in a given setting, such as a study protocol or a healthcare program, should be identified. For example, patients admitted to a hospital have a claim that confidentiality be respected regarding their private information. In a second step, any potential participant who is predictably more at risk of incurring this wrong should be identified. When healthcare providers are admitted as patients in a hospital where they work, for example, it is harder to protect confidentiality in their case since their direct colleagues may be involved in their care. They are thus particularly vulnerable; they are at increased likelihood that their morally protected interest for confidentiality...
will be unjustly taken into consideration, and the reason is that the circumstances make confidentiality more difficult in their context. The third step is to devise suitable safeguards. In this case, risk can be minimized either by avoiding admission to the care of direct colleagues when this is feasible, or by more strictly limiting access to information on a need-to-know basis than is usually the case. Since there is still some added risk that persons may have such access even when the patient would have preferred that they should not, options to be admitted to a different hospital altogether should be facilitated for health-care professionals. Each case of vulnerability will require a similar step-by-step approach. If any of our morally protected interests are fragile or threatened, then there is vulnerability. The same morally protected interest can, of course, be threatened by different mechanisms. Protections will need to be tailored to the fragile interest, to the source of vulnerability and to the circumstances where vulnerability arises.

Fragile Claims

What, then, are the morally protected interests relevant to research and health care? In the case of research, ethical principles underpinning the morally protected interests of participants are summarized chronologically as collaborative partnership, social value of research, scientific validity, a favorable risk-benefit ratio, fair recruitment, independent review, informed consent and respect for participants (Emanuel et al. 2004). In health care, there is less overall consensus as to what our morally protected interests, or claims, actually are. Indeed, it is precisely because different views of morality can yield different lists of claims that we propose a definition of vulnerability that leaves this part out. As a first step, two categories can be distinguished: some morally protected interests form a ‘core’ over which a great degree of consensus exists, while others are more controversial.

Examples of interests about which there is no real doubt that they are morally protected in health care exist. Typically, the ‘core’ of patient rights includes access to care within certain limits (these will, in turn, be controversial); autonomy, which implies self-determination for decisions affecting our health and our intimate sphere; and confidentiality. Substantial barriers to access to care is thus a source of vulnerability (Newacheck et al. 1996), as is the underestimation of decision-making capacity in the elderly (Dreyer et al. 2009), or important variations in respect for confidentiality for adolescents (Akinbami et al. 2003). This is not a complete list of morally protected interests in health care. Other examples could include an interest in maintaining our family ties when we are treated within a health system. In this case, having a rare disease requiring care away from home could be a source of vulnerability.

Some interests relevant to health care are not so clearly morally protected. For example, although we clearly have an interest in being healthy, the degree to which this is a morally protected interest is controversial. In the case of adults, a growing focus on personal responsibility for health tends to deny that an interest in being healthy is morally protected (Minkler 1999). This does not mean that there is consensus on the lack of moral protection for health itself (Wikler 2002). However, it does mean that we should expect disagreement on whether someone could be considered vulnerable on the grounds that his or her health was more difficult to maintain or protect.

Similarly, there is controversy regarding the degree to which we have a morally protected interest in having access to the conditions of health. On the one hand, we clearly have a morally protected interest in being protected from active harm to our health by others. On the other hand, the extent of what we mean by active harm is often unclear. Pouring poison into someone’s tea without her or his knowledge clearly qualifies. Selling cigarettes, which supposedly involves a free choice by an informed buyer, is not similarly considered. Here it is often the freedom to buy or not, and the information on which this choice is made, which constitute the conditions of health. Thus there is some controversy over whether selling tobacco should be considered active harm. Nevertheless, there is agreement on some degree of protection since children who lack the conditions for making a healthy choice are prevented from making an unhealthy one (Hurst 2015). To take a different example, selling unhealthy food and drinks, even to children, is not banned. Since children are neither freer nor better informed to decide whether to buy sweets or cigarettes, the most plausible explanation for this difference is that it rests in the degrees of harm involved. How much harm, then, is too much? Answers here will predictably vary.

When controversy exists regarding the existence of an interest, on whether it is morally protected, or on the degree to which it ought to be so, then we should expect disagreement on whether it ought to be included in this approach of vulnerability. Despite these disagreements, however, we can require consistency. Recognizing that an interest exists and that it is morally protected implies that we also ought to recognize the patterns of vulnerability associated with it. It would be contradictory to recognize an interest as morally protected on the one hand, and on the other hand to exclude it in the application of vulnerability (Tavaglione et al. 2015). If we do not recognize the interest in question, of course, we will not include it in the application of vulnerability. In this approach, vulnerability is ultimately nothing more than the recognition that there are situations where fulfilling morally protected interests is predictably more difficult.

A List of Claims Relevant to Health Care

Proposing a list of claims on which to base protections for vulnerable persons in health care thus requires the identification of sufficient consensus regarding which claims we have. Here we face a problem. Reasonable persons disagree about the right and the good at the level of general theories as well as particular judgments (Engelhardt 2011). Rather than attempting
nonmarket access to at least part of health care, protections for a healthy environment and policies addressing the social determinants of health.

Medicine is practiced in a partly unavoidable asymmetry of power. Inevitably and to varying degrees, patients entrust themselves to health-care professionals. It is crucial that this power should not be abused. Norms for impartiality in the exercise of power must therefore apply here. This implies that discrimination must be avoided, as must other abuses such as cronyism or corruption. Treating patients with fairness, considering the interests of each to be worth as much as those of others, is important (Hurst 2009). Prisoners, or other marginalized persons, will be at greater risk here, as will those who generate negative affects in health professionals. Particular care needs to be taken to maintain impartial, equivalent care in their case (Elger 2008).

A claim for the social bases of self-respect is relevant to health care, although it is often neglected by medical ethics. Our sense of our own worth is very likely to be affected by disease, especially when our capacities become limited. Inasmuch as our self-respect is dependent on respect by others, it can also be affected by interactions with the health-care system. This is not only a question of individual interaction. Health systems can transmit an image of the sort of person they were designed for, and patients can recognize when they fail to fit this image. Other examples of vulnerability include persons who are unable to tell their own stories and who become at greater risk of being treated like interchangeable entities rather than unique persons with their unique biography. Persons who have experienced discrimination in other contexts are also more likely to expect it from health-care institutions, and this can become an obstacle to seeking care or even to believing that they deserve such access. This claim underlies the importance of avoiding condescension and our right to be treated as persons rather than as fungible things.

Finally, we have an interest in communal belonging, in seeing our family and social relationships respected while we are ill. Admission to an institution can imply distance from our usual social milieu and tensions in interpersonal relations that usually form an important part of our lives. Persons suffering from rare diseases, who are more likely to require care far from their home, are more vulnerable in this respect. A person who fears that diagnostic information may become stigmatizing, or who may be more at risk from breaches of confidentiality that could place her or him at such a risk, will also be more vulnerable.

Some protections act on several morally protected interests. One example is confidentiality, which can protect access to health care and through it physical integrity, but also autonomy, the social bases of self-respect and belonging. Persons for whom confidentiality is more difficult to protect can be vulnerable to wrongs associated with any or all of these claims. Examples include institutionalized persons, the chronically ill and prisoners, as well as health-care professionals themselves.
A Few Examples

Let us illustrate how this framework can work in practice. For example, some patients in the context of an emergency may have to make quick decisions with no time to ponder the pros and cons of a proposed treatment. Therefore, it becomes more likely that their claim to autonomy, and the associated norm of informed consent, will be frustrated. It follows that they are vulnerable to insufficient regard for their autonomy. A possible remedy here would be to give the patient the treatment that is necessary to address the emergency while postponing any nonurgent decisions until such a time when the patient can make balanced, informed decisions.

To take another example: in modern hospitals, patients often interact with a new professional at every appointment and have to give the same information, over and over, to an ever-changing roster of interlocutors. Many patients thus feel as if they are handled like fungible or interchangeable things—like numbers without a face. It may follow that their claim to the social bases of self-respect is thus frustrated. In order to address that form of vulnerability, hospitals need to remedy the lack of continuity in the patient-staff relationships. For example, they might hire continuity agents in charge of the required ‘personal touch’ and transmission of personal information.

Identifying the Most Vulnerable Patients in Health Care

This approach enables us to propose a framework for identifying vulnerable persons based on identifiable risks to specific claims. Understanding what vulnerability is, when protections are required and what these protections might be, is only a first step. Often, the different requirements for protection will conflict with one another. When this happens in research, vulnerable potential participants who cannot be sufficiently protected as regards all their claims are simply excluded from participation. This is not possible in health care. Here, different claims will need to be weighed against one another.

Several options exist to prioritize among competing requirements for protection. First, we might maximize the effects we can have on the protections of vulnerable persons, going for a consequentialist approach to prioritizing vulnerabilities. Alternately, we might attempt to equalize the degree to which everyone’s claims are protected, going for an egalitarian approach. We might also attempt to identify the most vulnerable persons, and prioritize their claim for protection. In all these approaches, it is relevant to identify the most vulnerable individuals. In a consequentialist approach, they are likely to gain the most protection. In an egalitarian approach, protecting them first would bring us closer to equalizing the protection of claims that we all have. In a prioritarian approach, they would be the targeted population.

Who, then, are the most vulnerable patients in health care? At least two strategies are possible to identify them. The first is to examine the factors determining the strength of the requirement of special protection and to develop an index or a scale on which the strength of the requirement for protecting different claims could somehow be integrated. The strength of these determinants could depend on characteristics of the claim, or of the agent responsible for providing special protection. A second, perhaps more easily accessible possibility, is to focus on the corrosive or cluster effect of the threatened claims (Wolff and de-Shalit 2007). This determinant is particularly salient in health-care institutions. Essentially, persons who have clusters of vulnerability are those for whom there is a mismatch between their individual claims and the way in which the health system responds to these claims. This can happen because they are excluded, because of how they are perceived by professionals or because the system is more difficult for them to navigate: either because their ability to understand is less, or because their situation makes this navigation more demanding.

One such cluster effect affects patients who do not legally reside in the country. Their claim to physical integrity is fragile because they are less likely to know that their consent is required for medical interventions, and because they have less access to care. Their autonomy is fragile because they are likely to receive fewer explanations and to have more difficulty understanding them. Their options are fewer and often riskier, which threatens their freedom. Their access to social provision is limited. Impartiality in the exercise of power can be affected in their case by resource limitations or by implicit biases (Sabin et al. 2008). The most salient feature of their vulnerability, however, is how clustered it is: virtually all their claims are rendered fragile by their situation. Moreover, some of these claims are fragile precisely because others are fragile. Limited access to social provision of care will itself limit autonomy and freedom, as well as the social bases of self-respect.

Persons for whom navigating the health system is more difficult can also present such a cluster effect. In some cases, this is due to barriers to understanding how the health system functions. Patients who are allophone or illiterate will be vulnerable in this way. As a result, their claims to physical integrity will be more fragile, as will their claims to respect for autonomy and freedom. Repeated failure to use the health system to their benefit and the understanding that the health system is not designed with them in mind can also threaten their claims for the social bases of self-respect. Inasmuch as the health system is a collective endeavor designed for the members of a social group, this can also affect their claim to communal belonging. Another category of patients who will predictably have difficulties in navigating the system are those for whom it is not understanding but navigation itself that is more difficult. This can be due to limitations in mobility in old age or due to a physical handicap. Those for whom coordinating the system is more difficult, for example those suffering from complex chronic
disease, will be placed in a similar set of difficulties. All of these situations can threaten claims to physical integrity, social provision of health care, the social bases of self-respect and communal belonging.

Patients who are dependent on others for their daily lives, such as some elderly patients but also some who live with physical or mental disability, will also present a cluster effect. Dependence on others for our daily lives can threaten all our claims because those upon whom we depend can be unwilling or unable to provide the protections that are expected of them. The dependent are at a greater risk of being ill-treated. For reasons associated both with physical difficulty and with the frequent complexity of their care, they are more likely to have difficulty in accessing appropriate health services. They are more likely to be considered incapable of decision making, even when they are not, and thus their autonomy is at greater risk of being unjustifiably considered (Breeze et al. 2001). Institutionalization inevitably limits freedom and can lead to separation from previous social interactions. It can severely affect the social bases of self-respect (Riedl et al. 2013). It can also lead to being placed under the informal tutelage of the next of kin by health-care providers, which threatens the impartial exercise of authority. Dependent persons are at risk of not attaining even minimal fulfillment of their claims. They are also at risk of not being recognized as equally legitimate bearers of these claims. Being with our families, not being alone unless we want to be, being free to come and go, recognized as full citizens, safe, with a stake in society: too often, we are not very good at protecting these very basic claims for the dependent, elderly, disabled, or chronically sick.

Although they are not usually described in this way, children present a cluster of vulnerabilities for very similar reasons, as they too are dependent on others for their daily lives. In considering the vulnerabilities of children, there is often an implicit assumption that parents will be their primary protectors. This, however, means that any circumstance that makes parents less likely to be effective protectors will compound the vulnerability of their children (Hurst 2015). In some circumstances, parents are unable to protect their children’s interests because they lack the resources that would be required to do so and that are available to other parents. Uninsured children of parents who are poor, for example, may lack access to health care and to protection of their physical integrity. In other circumstances, parents may not act in their child’s best interest, although they could. They may place the interest of siblings, or their own, above that of the child. They may, for example, select a treatment alternative more convenient to themselves. In all such circumstances, children can be placed in a situation of compound vulnerability, when their primary protector fails to protect them to the level that can usually be expected. More generally, disenfranchised or marginalized parents will have less ability to protect their children (Kipnis 2003). In addition to their own sources of vulnerability, these children are thus likely to partake of whatever vulnerability would also have affected their parents in a similar situation.

In all these cases of clustered vulnerability, targeting protections for the common source of fragile claims is likely to be a good starting point in designing protections. For example, in some cases it should be expected that the most effective protection for vulnerable children and other dependent individuals will be indirect and aim to either improve the ability of their parents or helpers to protect their interests or to provide them with an alternative primary protector.

Vulnerability as the Distance from Effective Protections

By presenting us with bundles of vulnerabilities in a—partly—predictable manner, health-care institutions provide us with examples of uncontroversial claims clustered to yield particularly high vulnerability in—partly—predictable situations. This is useful if we want to prioritize protections. It provides us with a principled reason to target protections for these individuals, and to target them further to those fragile claims that lead to other claims also becoming fragile.

There is a further reason why these situations of clustered vulnerabilities are striking; they resemble each other. In each of them, persons who present clusters of vulnerability are those for whom there is a mismatch between their individual claims and the ways in which the health system responds to them. In some cases, it is because they are excluded. In others, it is because of how they are perceived by professionals within the system. In others still, it is because the system is more difficult for them to navigate; either because their ability to understand it is less, or because their situation makes this navigation more demanding. The common feature of these very different individuals is that the system was not designed primarily for people just like them. Health care is designed precisely to address some of the morally protected interests that we all share. It exists to protect us. It is, in other words, one of our responses to our general—or ontological—vulnerability. It is when it fails in providing such protection that specific additional vulnerabilities are seen to exist. This happens when there is a mismatch between the protections provided for everyone and what would be required to provide similar protections to some. One reason for this mismatch is that a system designed for ‘everyone’ is often designed in practice for some paradigmatic set of persons whose protection is designed into the system. Those who are different from these persons will be provided with less effective protections, unless additional care is taken in their case. The greater the distance and the mismatch, the greater their vulnerability is likely to be. Vulnerability often seems to be due to environmental circumstances, to intrinsic characteristics of vulnerable persons or to a combination of both. The most vulnerable persons in health care, however, all provide us with examples
where the underlying reasons for all of these forms of vulnerabilities is this mismatch—this distance from effective protections.

Such examples of vulnerability as the distance from effective protections can also be found outside the sphere of health care. In the case of the vulnerable elderly, for example, much discussion centers on the importance of assisting their ability to function independently in daily life. Assisted autonomy, or perhaps we should say assisted freedom, is discussed with a view to its effectiveness in enhancing quality of life, but also with a view to its cost. In such discussions, it should be remembered that everyone's assisted freedom has a cost. We have collectively invested in transportation infrastructure to allow to come, go, and earn a living. In many countries, publicly funded schools take care of our children and provide them with an education, as they did for us. We have time to make the choices we make in our lives in part because other human beings make our clothes, grow our food and sometimes cook it. We are more than willing to pay for all of this. When we ask how much we can afford to pay for someone's assisted freedom when what they require is different from what most people require, then it cannot be only because it costs something. Usually, it is because we already harbor some doubts as to whether these persons deserve the same as others do. This is worth examining of course, and doing so would take us beyond the scope of this chapter. The crucial element here, however, is that such cases of vulnerability also represent distance from effective protections rather than either unavoidable circumstances or intrinsic characteristics of the individuals involved.

Conclusion

Understanding vulnerability in this way has important implications for discussions regarding the resources that we allocate to protecting particularly vulnerable individuals. If vulnerability is the name we give to situations where it is more difficult to fulfill the claims that we all have, then this provides us with good reason to provide the additional care required since the goal is the equal protection of everyone's claims. If the reason why these added difficulties exist is that protections available to all are less effective for some and if the reason for that is that we have designed them to align with some more than with others, then we have additional reasons to correct the situation. Rather than being a misfortune that we may have some duty to compensate, such situations represent a direct consequence of our collective actions that we have a much stronger duty to correct.

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Notes

1 This section is based on an earlier paper published in French by the same author (Hurst 2013).

2 For a critical discussion of this assumption, see Macleod in this volume.

References


