

## Ethics in cross-cultural encounters – a medical concern?

### Abstract

Modern medicine's investment in the disembodied, objective 'science' of biomedicine, where patients are transformed from suffering subjects to objects of investigation, calls for heightened ethical awareness. Around the world, ethical codes of conduct emphasize beneficence and non-maleficence. Lately, we have also seen a quest for autonomy and equitable health care for diverse populations. However, these tenets alone do not effectively address the problems which regularly occur in transcultural consultations. By developing a "space for reflection" based on selected writings of the moral philosophers Axel Honneth, Emmanuel Levinas, and Hans Jonas, my aim is to cast light on this issue. Given the differing aspects of the doctor-patient relationship, clearly there are no clear-cut rules to obey. However, a thematic analysis of a quote from a Somali, female refugee, supported by some other studies on medical practice, suggests that, metaphorically speaking, within the developed space for reflection, medical practice has worked itself into a corner. By neglecting the patient as a social being, lacking openness to alterity, and not conveying needed information, they make it very difficult for patients to take responsibility for their situation. In spite of doctors' benevolence, the result is alienation, increased suffering and thus, potential harm. Similar tendencies are reflected in a number of recent studies on medical consultations. Therefore, rather than blaming the single doctor for moral deceit, we should see these tendencies as a 'forgetfulness of recognition' that affects the medical profession, a disturbance which source probably is hidden in doctors training.

### Introduction

Within the medical profession, heated discussions have evolved around ethical problems concerning the ultimate limits of life; limits that modern technology has moved beyond social and economic capacity. A host of laws, regulations, and directives on medical practice have been implemented to secure patients' autonomy; that is, rights to confidentiality, informed consent and participation. Moreover, medical ethics has become an integral part of medical education,(1) although with mixed results regarding the impact on students ability to undertake sound moral reasoning. (2-4) It appears that over the course of their training, medical students increasingly frame presented problems as a 'purely medical'.(5) However, with regards to ethical behavior, it should be noted that there has been some confusion about what kind of knowledge and skills that are to be expected,(1) which has over recent decades led some authors to argue for a shift in focus from the "ethical decision" toward an ethic of relationship.(6,7) In spite of a rich literature on these issues, little has been said about how the regularly occurring processes of medical assessment<sup>1</sup> may contribute to the patients'

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<sup>1</sup> Medical assessment here refers to the identification of disease and how it should be addressed by the healthcare system.

suffering; a suffering probably experienced more deeply by people at the margin of society, for example people who differ in race and culture and subsequently might experience repeated, often unintended micro-aggressions.(8) Although cross-cultural communication, including cultural competency and humility has been incorporated into some curriculums,(1) and in spite of a growing awareness of how clinicians' stereotyping of ethnic minority patients might lead to service disparities, including barriers to access as well as less than optimal care, (9-11) ethical dilemmas that might arise in multicultural settings have been largely neglected or unaddressed.(12-14)

Katz & Alegría maintain that reflecting on our own culturally situated praxis is a prerequisite for navigating different cultures and for determining what matters most to doctors and patients in care.(9) If so, our one-sided investment in the disembodied, presumably objective 'science' of biomedicine, where patients tend to be transformed from suffering subjects to objects of investigation, calls for a discussion in the light of ethical standards in the field.

I am concerned about a possible decay in Western medicine, and in this article, I will reflect on some problems that may occur in our day-to-day medical practice with a special emphasis of relevant ethical aspects, particularly those arising in cross-cultural encounters. In this undertaking, I will go beyond principlist perspectives and seek inspiration from three European moral philosophers who have been highly influential in the post-World War II era: Axel Honneth, Emmanuel Levinas, and Hans Jonas.

The article is organized as follows: after briefly presenting some aspects of our medical culture and, further, sketching out relevant features of the doctor-patient relationship (I), I develop a "space for reflection" from selected texts by and on the aforementioned philosophers (II). Then follows a discussion of four themes developed from a Somali refugee's statement on encounters with the medical profession, guided by the dimensions of our space for reflection (III). I will the present recent research that sheds light on these same themes at a more general level (IV), before finally giving my personal contribution to how these insights can inform and eventually reform clinical practice in culturally complex societies.

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### Ethics in medical practice

The technical revolution within medicine has changed medical practice profoundly. Doctors of today excel in knowledge about their patients derived from a host of tests and investigations; knowledge that the patient himself often has no access to unless the doctor shares his insights. Moreover, economic growth and other socio-economic factors have transformed medicine in ways that have

modified “not only the role of the physician in his or her relationship with the patient, but also how medicine became dependent on social institutions for its economic viability”.(15)

Throughout these changes, the legacy of Hippocrates, who probably formulated the first set of standards and ethical rules for medical practice, has had a lasting influence on the ethos and identity of the medical profession.(16-19) However, the Hippocratic oath, to which many physicians still swear, is not the only ethical guideline. The *Oath of Sun Simiao* (581-682 A.D.) has been in use in China, *Vaidya's Oath* flourishes in Hindu societies, and *The Oath of Asaph* traditionally has been a tenet of Hebrew medical ethics.(20,21) Moreover, there is *The Prayer of Maimonides* (1135 – 1204 A.D.), named after a Hebrew physician and philosopher who figured prominently in the history of Islamic and Arab sciences. Several *Oaths of a Muslim physician* coexist,(14 22) and a specific oath for the Soviet physician was drawn up and approved by the Supreme Soviet of the USSR in 1971.(23) Following World War II, details of the Nazi doctors' trial at Nuremberg, ongoing secularization, and, not least, cost-benefit assessments prompted profound adjustments of the Hippocratic Oath, such as *The Modern Hippocratic Oath* by Dr. Louis Lasagna from 1964,(24) *The Declaration of a New Doctor*, (25) and the *Geneva declaration*, which has been regularly revised since 1948 (21)

A thorough discussion on differences and similarities between these statements is outside the scope of this article, but it should be noted that all of them emphasize beneficence, non-maleficence and confidentiality. And, with few exceptions, they prescribe limitations for the physician. However, regarding the balance between virtues and rules, and the meaning of and emphasis on compassion, objectivity, autonomy, and antidiscrimination, there are substantial variations. Not surprisingly, there is also wide variation regarding to whom doctors of different traditions make their pledge: from god(s) to humanity, from 'Myself' to the state. But even the most secular statements emphasize an obligation to respect human life and give a sense of transcendence due to terms like 'nobility', 'honor' and 'dignity'. Lately, autonomy and justice has been added to core values like non-maleficence and beneficence.(26-28) In culturally complex societies, we can observe promising efforts to promote equitable health care services.(29) Moreover, as the concept of individual autonomy does not resonate well everywhere, “relational autonomy” has entered discussions on individualization and personalization.(30-33) Whilst neither neglecting, nor opposing these prima facie principles, which I believe can be excellent “guidelines for the formulation of more specific rules”,(34) we need to observe the variation regarding the content of medical oaths due to different times, situations, religions, and political systems. Moreover, we question whether such norms actually can guarantee the ethical conduct they propose. To examine this conundrum, we need to take a closer look at the doctor-patient relationship.

## The doctor-patient relationship

Traditionally, the doctor-patient relationship has been regarded as highly asymmetric in knowledge and power. However, over the recent decades, patient centered medicine has gained a foothold and created possibilities for a more symmetrical relationship, giving the patient an active and empowered role. Other factors also play a part, raising crucial questions like: did the patients themselves take the initiative for the consultation or was it requested by some external agents, for example the court, or an insurance company? In other words, is the consultation *internally or externally motivated*? Then there is the degree of *urgency*. Is the actual consultation a routine checkup or an emergency, for example due to a cardiovascular catastrophe? The patient's *state of consciousness* also demands consideration. Is the patient unconscious, psychotic, or mentally sane? Perhaps of equal importance, is their health literacy adequate?(35-37) Taking different purposes, needs, and abilities into consideration, clearly the doctor-patient relationship is no unambiguous term. All dimensions mentioned here and possibly more act as determinants on reciprocity and symmetry in the relationship as each calls for a unique set of actions. This begs new questions regarding ethically sound behavior. Are the doctor's actions best judged by universal principles or is our judgement of what is morally good or bad dependent on the actual situation, the attitudes and dispositions of the persons involved?(26, 38 ) While this question seems to some extent to challenge simplistic views on principlist ethics,(34) it is thoroughly dealt with in virtue ethics, which concern seems to be not only about the doctor's character, but "what is best to do in a particular context, how we should perceive that context and what emotions are appropriate to the circumstance".(39) From these deliberations, it seems that in his or her practice, a doctor needs to strike a balance between universal principles and the actual situation; and between own virtues and the actual relationship. In this balancing exercise there can hardly be any 'either – or', that is either good or bad. Rather, in order to contain our reflections and judgements, we need to develop some relevant dimensions, which, taken together, can constitute a space; that will be our "space for reflection". In the following section, I will thus proceed by developing three dimensions based on selected texts by and on Honneth, Levinas, and Jonas. Given the specific objective of the current paper, these texts will be described and reviewed with a specific focus on their hypothesized role in medical consultations. For a fuller and more comprehensive discussion, readers are encouraged to refer to the original publications from these authors.

## II

### Axel Honneth - On recognition

Reaching back to Hegel's idea that we gain self-consciousness only through a process of mutual recognition, Honneth explores the difference between the act of recognizing a person and merely

identifying this same person.(40-42) His point of departure is Ralph Ellison's novel *The Invisible Man*, where an anonymous man reports, "he is, indeed, a real 'flesh and blood' man, but one simply wishes not to see him, one looks straight through him; he is simply 'invisible' to everyone else".(40) Obviously, in such case, 'invisibility' does not refer to a physical non-presence, but rather to an ascribed non-existence in the social sense that may range from harmless inattention to "demonstratively 'looking through' a person" - an act which the affected can only understand as a sign of humiliation, to some extent depending on how active the perceiving subject is in the act of non-perception. Thus, for somebody to *experience* being 'invisible', he or she must assume that (in Honneth's terms) "already they have been taken cognizance of as an individual within the spatio-temporal order". In short, social *invisibility* presupposes physical *visibility*, and it is within this dual construction the humiliating experience is constituted.

As antidote for this humiliating suffering, Honneth introduces 'recognition', not as a mere *identification* of "a person with particular properties in a particular situation", but as a *demonstration* of "an assessment of worth that accrues to the intelligibility of the person". Honneth holds that by making a gesture of recognition towards another person we performatively make that person aware that we consider him or her to be loveable, worthy of respect and solidarity. This implies that we see ourselves obliged to behave towards him or her in a certain kind of benevolent way, setting limits to the realization of our spontaneous impulses and inclinations. Expressions of recognition are of vital importance in formulating our sense of identity and self-worth and it is when such expressive gestures of recognition are absent we experience ourselves as invisible.

Honneth argues that the mere identification of a human being represents exceptional cases in which the original, spontaneous recognizing that we practice from our earliest infancy is merely 'concealed'. We simply *forget* to recognize each other. However, "forgetfulness of recognition" with its subsequent reification of human beings deeply affects our interpersonal relationships and therefore is to be considered as a source of human suffering, a "social pathology" that precludes possibilities of individual and social change and thus diminishes our freedom. It occurs when for example our cognitive goals become detached from their original context; or when we pursue a goal so energetically and one-dimensionally that we stop paying attention to other, possibly more original and important motives or aims; or when we deny somebody recognition for the sake of preserving a prejudice or stereotype.(43, 44) Through gestures of recognition we signal a "readiness to interact", and although the gesture's form may vary considerably between ethnic groups, the constitutive function for interpersonal communication remains constant. Translated to the clinical setting, the extent to which doctors recognize their patients as intelligible, worthy of love, respect and solidarity will constitute the first dimension of our "space for reflection".

## Emmanuel Levinas - The face of *the Other*

Levinas is critical of traditional conceptualizations of 'recognition'. According to him, recognizing *the Other* implies an unavoidable assimilation of *the Other* into one's own subjectivity. That is, we render *the Other* intelligible in our own terms, thus depriving him or her of their 'irreducible alterity'.(45) Rather, we should be sensitive to what is *fundamentally different*; what is not thematized in words and concepts; what is before dialogue.(46) In other words, it is not what can be *recognized* in "the face of the Other" we must be susceptible to, nor what can be assimilated into what we have already acquired of knowledge and understanding. The face of the Other should *affect* us, and Levinas holds that the felt responsibility evoked by the Other's distress and suffering is more important than cognition. It comes before our words, conceptualizations and themes, before all established cultural values and norms. "I am affected by a responsibility that I have not asked for and which typically does not fit at all."(46) This responsibility is not dependent on the Other's ability to reciprocity: We are all responsible, but in the face of the Other, I am the more responsible, and my responsibility cannot be shared or taken over by somebody else.

According to Levinas it is the "stepping out of indifference" when encountering "the face of the Other" that institutes the ethical relation, the fundament for any ethics, for our praxis as well as for our reflections.(46) In line with Hegel, Levinas maintains that it is through *the Other* that we become someone. But he also makes us aware that the question is no longer one of self-expression or self-preservation. My identity and solipsistic striving of cognition are set aside. It is all about being there for *the Other* – for *the Other's* time, that is, "a time that comes after my time"(46). Levinas' thoughts seem to be highly relevant within the medical context, as it already has been argued "the moral obligation of the physician is imposed by the patient as Other, an obligation that is prior to the interpretive framework of medical knowledge". (47) This call of the Other is fundamental, in Irvin's wording: by calling into question the same, it precedes, makes possible, all other forms of questioning, and thus all forms of knowing.(48)

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Honneth and Levinas agree that it is through encountering *the Other* that we gain self-consciousness. Both are concerned with what precedes cognition, and both have a lot to say about mitigating agency, thereby introducing limits for our self-expression and self-preservation. Regarding differences, Levinas maintains that *responsibility* is unevenly distributed, and that our relationship with *the Other* is therefore an asymmetric one, a stance for which he sometimes has been criticized,(49) whilst Honneth sees reciprocity close to a precondition and takes recognition to be a mutual endeavor. It is noteworthy that for Honneth recognition implies acknowledgement, and, as

we know, even phenomena that are completely new to us, can be acknowledged, depending on our desire to see and experience, that is our “need-to-know”.(50). Contrary to this, Levinas equalizes recognition with assimilating *the Other* into our own subjectivity and therefore disqualifies ‘recognition’ as a viable conceptualization of the ethical relationship. His deepest concern seems to be our tendency to let uncertainty and anxiety outstrip our openness to the Other’s irreducible alterity. Thus, the degree of openness towards alterity constitutes the second dimension in our space for reflection.

### Hans Jonas - Responsibility for the responsibility

Basing his tenets on a biology of cognition, Jonas argues that all living beings strive to accomplish goals - be it filling a need or, at a more abstract level, liberation from such strivings. This reaching out for a goal is in itself an expression of a being’s worth.(51) As humans, we can chose between goals and reflect on our actions. Therefore, we can take on responsibility, an ability unique for humans, and which implies a special obligation as guardians for others self-purpose.(52)

The archetypal situation is the cry of a helpless child. We can hear the cry, be affected by it, and act upon it. More specifically, being affected - an ability that Jonas consider as the most valuable product of evolution and a necessary precondition for understanding people and situations - creates a feeling of responsibility. This feeling is linked to our duty to take responsibility; a duty that emanates from our obligation towards others’ self-purpose, and follows our power to influence the situation. For Jonas, ‘responsibility’ does not refer to something we should have done or not done, but directly to the actual case. We are responsible for other people, not so much for their own part, but for them as human beings, that they will be able to take on their own duty, a duty to be responsible. That is, as uniquely responsible creatures we become responsible for others’ responsibility. And, when what we do or do not do makes it more difficult for others to take on their responsibility, our behavior is irresponsible.

Realizing doctors’ differing roles and the shifting qualities of the doctor-patient relationship, Jonas’ concept of “taking responsibility for the responsibility” seems to take on a special relevance in the medical encounter. It is impossible for doctors to take responsibility for how their patients chose to live their lives, to any potentially destructive choices they can make. However, the doctor can take responsibility for facilitating and enhancing their patients’ motivation and ability to take on their duty to be responsible. In cases where the patient is not able to take responsibility for their own condition, the doctor can ensure that there will be people around them who can do that. Thus, being ‘responsible for others’ responsibility’ allows for the flexibility that the shifting qualities of the

doctor-patient relationship calls for, and will therefore serve as the third dimension in our space for reflection.

Jonas discusses the problem of *consent* in light of these principles.(53) A genuine, fully motivated, and informed consent requires from the subject a maximum *identification*; that is, the person has ownership of, and can fully identify himself with the purpose of the undertaking. This is different from attaining to a goal that does not concern them, or being engaged in a relationship where they have no influence. Second, it requires full *understanding*, not only about the purpose of the undertaking, but of the procedures as well. Lastly, *spontaneity*; that is, the person can freely decide whether to participate or not based on his own motivations. Only in this way can the person preserve his own identity and purposiveness in the collaboration. This follows from Jonas' claim that reaching out for a goal is in itself an expression of a being's worth. It is therefore important also in the clinical setting that patients have ownership of their suffering as well as their treatment. However, I presume that the patients' ability to take responsibility at least to some extent does modify this claim.

Jonas' concern is obviously not evil acts, but how our day-to-day, well-meaning actions can result in unforeseen side effects, which make his insights of special value to the clinical encounter. He specifies four duties to guide our actions: First, the duty *to know*. Because the consequences of our acts may not be in plain view, we have a duty to acquire knowledge about possible, long-term side effects of our well-intended actions. Second, the duty to *act on uncertainties* as if they were certain, realizing that the gap between what we can predict and what we can accomplish always will be there. Third, the duty to *take power over powerlessness*. Jonas is concerned about the technological development. Within technology resides an expectation of continued progress that eventually will secure our wellbeing, and therefore, it would be unethical not to take advantage of the possibilities created. However, in our modern age, technology has become autonomous and unruly, and therefore we need to take control over our inquisitiveness, our urge to manipulate and intervene. In other words, we need to take back control over the technological development. In our context, that is medical tests, manuals and other technical procedures. Lastly, we have "Denkpflicht", that is, *a duty to imagine*, to look beyond numbers and calculations; to visualize the faces of those who might suffer as consequence of our actions and to feel their pain.(53)

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The three dimensions here outlined, that is expressions of recognition, openness to alterity and responsibility for the responsibility, will allow for an assessment of the doctors' behavior, and are implied in the questions: 1) to what extent does the doctor recognize and acknowledge the patients'



“worth” as an intelligible being, that is their needs, judgements, knowledge and abilities? 2) To what extent does the doctors allow themselves to be affected by their patients’ alterity? 3) How engaged and flexible are doctors regarding their patients’ ability to take on responsibility for their health condition?

### III

The following is a reflection on a Somali woman’s utterance, here directly translated from her still not fluent Norwegian, *“I let them examine me as long as they wanted, but they have not told me what they have, what is happening, nor have they asked me about where I am and who I am!”*<sup>2</sup>

The quote is from a report on newly settled refugees’ health in Trondheim, a report based on interviews of refugees whose health problems hampered their integration in the host society (n=31) as well as questionnaires to employees in the municipality’s department of health and welfare (n=127)<sup>3</sup>. Although the respondents expressed some satisfaction with the health care services in general, several of the refugees had been referred to the specialist services without receiving adequate help. In the report, which was prepared by the city’s expert unit on refugee’s health, and presented to the local government’s executive committee, the quote appeared as an illustration. We know nothing about this woman’s immediate context, her history, how old she is, how long she had stayed in Norway, the purpose for her seeking medical consultation, nor to what kind of question did she respond. Still, when first introduced to me by a colleague, the quote stroke a cord that resonates with my own experiences - both as former general practitioner and now as a researcher working in a research unit on immigrants’ health with access to an abundant literature, some of which is presented in Section IV - a cord that is felt vibrating “prior to the confines of knowledge or even culture”.(47 p.454). Inspired by Jonas’ *“Denkpflicht”*, I imagine the following scenario: A Somali, female refugee, I call her Hodan, sees her doctor, seeking advice regarding some disturbing symptoms that she herself is unable to explain or deal with. Presenting her problems to the doctor, she expected medical examinations to which she also gave her consent. As her symptoms turn out to be of a rather ambiguous character, her doctor refers her to the specialist services, which now take over the clinical investigations. More or less willingly, she turns herself into an object of investigation, consenting to become “a body”, a body that embodies her suffering – perhaps also some kind of disease - and on which the doctors now can perform their art. However, what subsequently happens seems by far to have exceeded Hodan’s expectations. One examination leads to another, then a third

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<sup>2</sup> The original text read: De har undersøkt meg så lenge de ønsker, men de har ikke sagt hva de har, hva som hender og de har heller ikke spurt meg om hvor jeg er og hvem jeg er!

<sup>3</sup> Unpublished report (in the sense that it was neither printed, nor to be found in the Internet): «Nybosatte flyktingers helse, med spesiell vekt på psykiske og psykosomatiske forhold. Rapport fra en kartlegging i Trondheim kommune i 2004/2005» Arkivsaksnr.: 05/33657.

and so on while due to lack of relevant information and support, she is left in a void, deprived of purpose and motivation. She has become invisible as a social being.

Hodan's uttering seems to be neither a complaint, nor an objection against services received. Nevertheless, it exudes disappointment due to unmet expectations. By showing no interest in her life story and what might be at stake in her day-to-day life, her helpers seem to ignore her suffering and her situation remains in the dark - to the helpers, but also to the patient who might have no one else to talk to about such matters, nobody who can elicit tacit knowledge about herself and her condition. I assume that feeling alienated, not only from her new society and her suffering body, but also from her helpers and her purpose of seeking help, her suffering is exacerbated and her trust in the health care providers falters. Moreover, lacking information about procedure and results, she is rendered helpless, incapable to deal with her own ailment and situation.

Although this interpretation is only one of several possible interpretations, I feel that Hodan's uttering calls for a deeper reflection as we already here can discern four themes of clinical relevancy: Her social invisibility, her alienation, the problem of consent, and her lack of information. Deprived of its immediate context, still the quote allows for some of its potentialities to be made explicit within the three dimensional space for reflection already sketched out, a space *elicited* by the principles: non-maleficence, beneficence, autonomy, and justice.

It should be, however, be emphasized that what in this section follows, is my interpretation of Hodan's words, which (at least to some extent) might differ from her intended meaning. The feelings ascribed to her are my feelings as I contemplate her situation, and any descriptions of her health care providers are based on my attempts to see them (looking at the text) through her eyes - in this process often encountering myself as a former general practitioner.

### Invisible as a social being

*... nor have they asked me about where I am and who I am!* Imagining Hodan's face when uttering these words, we can sense her feelings of being neglected and hurt. Translating Honneth into this clinical situation, for her to believe that her doctors are actively engaged in caring practices and that their concern is to serve her wellbeing, she needs responses that in symbolic abbreviation express the totality of actions that are supposed to be accorded to her as a patient "on the grounds of her situation".(40) In my reading, the term 'situation' does not refer only to the smaller context, that is being in the health care providers' premises, but to the specific physical and social surroundings within which she is situated as a person with a unique identity, that is her situatedness. Obviously, she is now in a new country with not only a different climate and unfamiliar physical surroundings. She encounters new people, new customs, new values and priorities. Seeking help for her needs,

probably she must relate to institutions and procedures quite unknown to her. Moreover, as a refugee it is not unlikely that her history is one where losses prevail. Departing from her home country, she left behind not only smells and sounds with which she was familiar, but many objects of sentimental value. She might have lost family members or friends in the acts of war. Perhaps she experienced violence or other atrocities before the flight or on the way to her host country. Perhaps due to traumas and hostilities she has lost some of her basic trust in other people. We do not need much imagination to see that her situation might be exceedingly demanding and her suffering deeply influenced by social events that impinge on her identity. For me, this seems to be Hodan's main concern, as she succinctly points out her helpers' lack of interest in her as a person, "where I am and who I am".

I further assume that Hodan's dissatisfaction is not because her helpers do not see her. Most likely, they have taken notice of her in her physical appearance as a patient in their office. Certainly, her name and identity code were registered. No doubt, they have asked her about her symptoms and initiated clinical examinations. Thus, she is visible, in Honneth's wording, "according to the character of the relationship, as an object with situationally relevant properties". But all that does not seem to capture, again in Honneth's wording, "the significance of the forms of expression that we reciprocally expect of one another in order to be 'visible' for one another." Potential feelings of being invisible arise from unmet intuitions that everybody with a presumably normal sociocultural upbringing share. It arises from *the absence* of certain types of spontaneous reactions that can affirm our existence, in Hodan's case from what her helpers did not, from their "forgetfulness of recognition". It is the lack of spontaneity that is experienced as humiliating. Although her invisibility is of metaphorical nature, as I see it, there is a real core to it, which is her feelings.

Moreover, because it is the *spontaneous* affirmative gestures that indicate her social worth, any attempt from her to prompt her helpers into recognizing her would be futile. Provocations would not result in a proper recognition (which is not to deny that some patients' might try out this strategy).

Gestures of recognition are a direct expression of an ethos of beneficence and non-maleficence, and when absent, the patients are left in a void, not knowing whether they can take for granted that their helper "possesses the motivation to act only on those impulses and motives towards (them) that are of a benevolent nature"? (40) Thus, as helpers, we do have a special responsibility for recognizing and affirming our patient's worth.

## Alienation

In illness, the body can no longer be taken for granted, nor can it be ignored as it emerges as an alien thing,(55) "a tomb in which one is trapped".(56) Diseased persons perceive themselves to be no

longer a 'whole person' but 'less of a person', an object of medical investigation rather than a suffering subject. In addition to this alienation, which seems to be an inevitable aspect of illness, we can in our case sense alienation on at least three other levels. First, because of her health care providers' seemingly unmitigated agency as they pursue their medical goals, Hodan might feel alienated from her purposes for seeking help. Second, left in a void, seemingly abandoned by her health care providers, she might feel alienated from her helpers. Third, being a Somalian refugee, newcomer to the Norwegian society, and, perhaps quite aware of negative attitudes towards immigrants and immigration that from time to time flourish in Norwegian media, it is not unreasonable to assume that she may harbor a sense of not fully belonging; that she somehow resides at the margin of society. Or, perhaps she has backed out from the larger society because of fear of being stigmatized as black, Muslim and woman. In any case, the fourfold alienation, that is from her body, from her purpose, from her helpers and from the Norwegian society, make it extremely difficult for her to take responsibility for herself and her ailment.

### Consent versus compliance

"I let them examine me as long as they desired..." To the extent that examinations are necessary to establish a diagnosis, it might be in the patient's interest to give his or her consent to such. Moreover, because symptoms might be due to serious disease, some patients will even claim their rights to be examined as fully as possible. However, in our case, it seems as if Hodan's helpers have excelled in medical tests far beyond her expectations while she, herself, seems to have lost both faith and interest in the ongoing (medical) examinations. In other words, as the tests are now solely her helpers' concern, her motivation for collaboration seems to have faded completely. I feel that her words, "I let them examine me as long as they desired..." suggests problems with her initial consent. Rather than testifying engagement in something for which she was genuinely motivated, her consent has now transformed into acts of compliance.

Thus, if Hodan's helpers on her behalf aim for something that she does not understand the significance of, she might not only be estranged from the purpose of testing. She is deprived of her purpose for seeking help. The situation is further aggravated by her doctors' neglect of her 'social worth'. Therefore, the sense of injustice that we can get a glimpse of in the formulation "I did...., but they did not...", stems not from the amount of examinations, but from what is taken away from her in a process that she initially more or less willingly agreed to.

### Lack of information

Excelling in tests and examinations, Hodan's helpers seem not to have told her about their procedures, nor explained to her the significance of the results. Lacking information about "what

they have and what is happening”, she is rendered powerless. There is nothing she can do to ameliorate her suffering, nor to cope with her circumstances. As I see it, this sense of powerlessness cannot solely be ascribed to personal inefficacy. Rather, she succinctly points out what kind of information she would need in order to act. More likely, her powerlessness is due to her helpers’ unmitigated, and evasive behavior, as they consciously or unconsciously hold back wanted information. The result is further humiliation, distress and suffering.

Again, it is what her helpers do not do that makes it difficult for Hodan to take responsibility for her condition. According to Jonas, the helpers then behave irresponsibly.(51) To the extent that these difficulties result in loss of trust in her health care providers, the dialogue between patient and helper will also suffer, and clinically important information might be difficult to elicit. Subsequently, decisions may fail. Patients well acquainted with the health care system may in situations like this, rather than relying on the health care provider, ascribe trust to the system within which the provider is working, a trust that probably can ameliorate their difficulties. For one unfamiliar with the system, as Hodan well could be, fear of what is unknown might instead aggravate her difficulties in the relationship, perhaps even create doubt about whether she is worthy of the patient role.

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#### [A note on the doctor’s point of view](#)

It would be unfair, however, not to give voice here to some possible concerns from her helpers’ point of view, and, as a former general practitioner, to me it is natural to see the situation from Hodan’s doctors’ eyes. In order to formulate a diagnosis, doctors might require from their patients that they partially turn themselves into objects of investigation. It is also common procedure that during medical examinations and interventions, patients are rendered (partially) invisible to the doctor - in extreme cases, as in surgery, the patient is covered up to the extent that only the operation field is visible. This is not only for hygienic reasons, but because the doctor needs emotional distance from the patient. Thus, in the doctor’s office, certain kinds of reification and invisibility are necessary. As these are usually of short duration, we, as patients, accept this. What was different for Hodan, was that she seems to have been no end to the reification.

Regarding the excess of medical tests, most doctors are aware of the ambiguous status descriptions like “medically unexplained symptoms” hold in our society. If an immigrant patient - newcomer and with unsure social standing – is left with such description, any ambiguities regarding the diagnosis might add to his or her burden. Therefore, it is reasonable that doctors do whatever they can to avoid this. This might imply thorough and repeated medical tests and examinations.

When it comes to the perceived lack of information, it is not obvious that all information should be given to the patient. Getz et al. maintain that “respect for autonomy should ... honor the person’s right *not* to be opportunistically confronted with knowledge about biomedical risks that are unrelated to his or her reasons for seeing the doctor”.(57) In line with this, it could be that the Somali woman’s doctors, by not telling her “what they have” wanted to protect her from information that could “cast shadows of doubt and insecurity over her life”.(57)

Moreover, doctors are supposed to provide equitable services independent of race, ethnicity, social position, etc. If too much information about the patient’s background and her social and physical surroundings are engaged, it is possible that the doctor’s impartial attitude might be endangered. Thus, if it is not obvious how knowledge about the patient as a person is relevant for the clinical setting, her doctors might have thought it better not to go into such issues and stick to their medical tasks.

As I see it, Hodan’s doctors balance a tightrope between, on one side, the danger of drowning in irrelevant information and losing professional distance and, on the other, the risk of ignoring the patients’ main concerns. For me it seems that in our reflective space, Hodan’s health care providers have worked themselves into a corner as their acknowledgement of the patient’s worth as a social being, their openness towards alterity, and their concern about her possibilities for taking responsibility of her ailments all appears minimal or undetectable. Moreover, juxtaposing the Hodan’s acknowledgement of her helpers’ need for (medical) examinations and their apparent lack of interest in her capacities and need-to-know, we are not only left with an impression of unmet expectations and a sense of helplessness and alienation. The quote also gives a rather strong sense of unjust treatment. Moreover, we are left with the question, “If her helpers are unwilling to be involved in issues external to medical procedures and the patient is left alienated and powerless because of lack of information and thus unable to take responsibility for her own situation, who can ameliorate her suffering?”

#### IV

From this interpretation of Hodan’s uttering, two concerns arise. First, are conditions like those here observed threatening to a person’s health? In other words, are they potentially harmful? Moreover, in line with this, is the potential harm solely due to Hodan’s assumed vulnerability, or are there reasons to believe that most patients will be affected under similar circumstances? Second, is the apparent behavior among Hodan’s health care providers’ due to their personal traits and inclinations, or does the case reflect prevailing tendencies in the Norwegian (and perhaps Western) health care system? Although Hodan’s poignant uttering can make us aware of the impending problems, these

questions cannot be answered from the previous reflections on her uttering. However, some recent studies do shed light on these questions, and in this section I will present a compilation of some of these studies.

### Feelings of alienation

Several studies show that feelings of isolation, disconnectedness, and not belonging do have aggravating effect on people's health. In fact, experiences within social relationships predict mortality as precisely as smoking and alcohol abuse.(58) Tomasdottir et al. introduced the term 'existential unease' to denote such relatively subtle, but demanding life circumstances, among other things the lack of social support, and found that this "unease" is significantly associated with multi-morbidity (probably due to non-stop allostatic load).(59) Self-estrangement, reification and powerlessness tend to become internalized into painful feelings of alienation,(60, 61) and "a sense of unfairness", which refers to the undermining of people's dignity and self-respect, has emerged as an independent predictor of both impaired health functioning and increased risk of coronary events, affecting people's health in a dose-response manner.(62)

### Lack of recognition

Among persons of color, "micro-invalidations" - a subcategory of micro-aggressions referring to communications that exclude, negate or nullify these persons thoughts, feelings, or experiential reality - may result in self-doubt, frustration, and isolation on the part of the target.(63, 64) Being subtle, mostly indirect, and often unintended, micro-invalidations are easy to explain away and correspondingly difficult for the target person to respond to. When considering raising the issue, being unable to determine whether an insult has occurred or not, many fear further humiliation as a result and therefore do nothing but "sit on their anger" (63). The dilemma linked to response versus nonresponse, that is, "damned if you do and damned if you do not", can result in denial of one's experiential reality and loss of integrity. Subsequently, together with pent-up anger and frustration, it will take physical as well as psychological tolls.(63) Indeed, Donovan et al. found that among black American women, micro-aggressions were significantly related to depressive symptoms, although not to the same extent as overt racist acts, which were also associated with anxiety symptoms.(65)

These studies suggest that 'forgetfulness of recognition', neglect of the patient's experience and situation, as well as reluctance to convey to them essential information, here ascribed to Hodan's case, undermine and endanger the patient's health, and this harm seems to be mediated through feelings of alienation and unfairness. Such feelings may be common, but can be intensified through the medical encounter when through medical procedures potential problems in the patient's social environment are transformed into personalized ailment. Because such harm is unnecessary, it is against the principle of non-maleficence.

Thus, while Hodan's uttering inspired our problem formulations, we from the above presented studies can infer that most patients will suffer under such conditions. However, in our case of a refugee person, the ethical issues linked to this neglect become more transparent, as refugees might be in an especially vulnerable situation. It should also be mentioned that contrary to this, an increasing body of research shows that a sense of social support – be it emotional, informational, tangible, or just a sense of belonging - buffers chronic stressors like life transitions, negative life events, and illness. For example, being confident that one has at least one person “who is there for me” is shown to reduce mortality significantly.(66) This alludes to the principlists' quest for beneficence, as a health care provider well might be one of those supporting persons.

### Some prevailing tendencies in medical encounters

From the report where Hodan's uttering was found, we learn that most likely several professions were involved in her case. However, in this paragraph, as a former general practitioner I will concentrate on studies on the doctor-patient relationship that can throw light on our next question:

*Is the apparent behavior of Hodan's helpers due to their personal traits and inclinations, or does the case reflect prevailing tendencies in the Norwegian (and perhaps Western) health care system?*

In a review article in *Medical Ethics*, Singer et al. find it troubling that “the doctor-patient relationship is deteriorating even as we congratulate ourselves on how well clinical ethics has progressed”.(67) As outlined in Section I of this article, taking different purposes, needs, and abilities into consideration, the doctor-patient relationship is diverse. The case's urgency as well as the patients' motivation, his or her health literacy and state of consciousness act as determinants in the relationship as each calls for a unique set of actions. However, research shows that there are some general tendencies. In a study by Agledahl et al., regardless of what problem the patient presented, the doctor sought to treat it within the framework of his medical knowledge, and in this process systematically filtered out and ignored the patients' experience, their values and feelings, and, moreover, what the suffering meant to them. In their study, there was no lack of courteous manners among doctors. However, their overt expressions of courtesy and friendliness left their patients puzzled as their behavior seemed to conceal an ongoing objectification to which the patients were unable to voice any protest. Subsequently, while their doctors tended to perceive the encounter as straightforward and satisfactory, their patients felt dehumanized and their distress was exacerbated rather than relieved.(68, 69) This resonates with Clifton-Soderstrom's claim that seen through the 'medical gaze, “persons are confined to comprehensive boxes, invalidating specificities that may have important consequences for their health. Insights that fall outside the scientific paradigm are lost or ignored”.(47, p. 457) In line with this, as mentioned in the introduction, it appears that over the



course of their medical training, medical students increasingly frame the presented problems as 'purely medical'.<sup>(5)</sup> Moreover, Sue McRae makes us aware that an alarming number of patients feel that they have not been treated with basic respect; they have not been provided with adequate emotional support, or their family has not been involved to the extent that they wished.<sup>(70)</sup>

Other studies show that doctors systematically underestimate patient's desire for information, and greatly overestimate how much time they spend informing patients.<sup>(66)</sup> Regarding immigrants, a large, Norwegian study based on data from the Regular GP database and the KUHR register<sup>4</sup> shows that patients with diabetes of African or Asian decent as well as patients with low socioeconomic status receive more medical tests, but fewer prolonged consultations.<sup>(71)</sup> Eliciting knowledge about their actual situation and providing them with necessary information so they can cope with their medical condition, necessarily take time. Moreover, in immigrant groups, language and cultural differences might act as communication barriers, and as newcomers with little knowledge about the Norwegian health care system, immigrants may have special needs regarding information. However, according to this research, compared to the time spent with patients with higher socioeconomic status, it seems as if GPs do not find it worthwhile to invest time in enhancing these patients' coping skills, and, rather than taking time to develop trust and collaboration, they exert more control.<sup>(71)</sup> Moreover, it is noteworthy that in this study, even the researchers take as a premise that more medical tests can be an adequate substitute for less time spent with the doctor, thus casting doubt on whether these patients actually receive less or worse service from their GPs.

In sum, although there obviously are many caring and conscientious doctors, it appears that modern doctors in general fail to elicit knowledge about their patients as persons. Rather, to comply with the gold standard in medicine, they filter out and ignore their patients' experience as well as the meaning of their suffering. This filtering out of what the doctors consider irrelevant is in medical practice "ingrained to the extent that doctors take it for granted".<sup>(69)</sup> Moreover, systematically underestimating their patients' need for information, they seem to value certain patient's biological material more than verbal exchange.<sup>(66)</sup> The studies referred to in this section are not limited to doctors' work with migrants. On the contrary, they refer to most doctors' preferred strategies. As our studies are limited to the doctor-patient relationship, we cannot infer that other health care providers share the same strategies. However, what we can learn from these studies are that the medical doctors who might have been involved in Hodan's case, were not alone in their neglect of

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<sup>4</sup> The KUHR register fee-for-service payments to GP's from the National Insurance scheme, which allowed for a sample consisting of 1,327,461 consultations with patients with diabetes type II that represented more than 90 % of Norwegian GPs.

contextual factors and personal issues. Rather, this neglect seems to be a prevailing trend in our Western health care system.

### Lessons learnt and some concluding remarks

From this reflection on a Somali refugee's utterance, facilitated by the space of reflection developed from the work of renowned moral philosophers, emerge insights which are confirmed by scientific studies and merit further discussions among health care professionals in general. However, in what follows, I will concentrate on some aspects relevant for medical practice.

Lack of recognition of patients as persons with unique needs and potentials not only creates feelings of powerlessness and injustice, this may actually aggravate the patients' suffering and result in further disease development. Moreover, neglect of patients' "need-to-know" might be experienced as unjust and alienating and threaten attitudes and skills that patients need in order to collaborate well with their doctors, take care of their own health and to make necessary changes in their life and surroundings. Thus, within our space for reflection, enlightened by the four principlist tenets, we can see that if doctors ignore patients' perspectives, protect themselves against alterity, and forget their responsibility for patients' ability to take responsibility for their ailment and condition, they may work themselves into a corner, unable to perform their art.

However, it will be unjust to blame the individual doctor for moral flaws in a practice that most doctors seem to take for granted. Rather, we should talk about a form of moral decay within the medical profession. This moral decay seems to parallel an increasing occupation with technology which can distract us from the more humanistic aspects of medicine (5). The lack of interest in patients as persons raise a concern about the state of the art, also pointed out by several other authors. Mjølstad et al. argues that, "Based as it is on evidence – impersonal, fragmented and de-contextualized in its nature – the current gold standard of clinical practice is too limited to serve as the foundation of an appropriate approach".(72) De Zulueta holds that, "For the scholarship of medical ethics to translate into good medical practice, it has to attend more closely to everyday ethics and the clear and uncontroversial goal of medicine: the relief of suffering. Therefore, medical ethics has to be placed within a philosophical framework that 'works' in the context of the lived experience of patients and clinicians".(70, 73) In other words, clinicians' lack of concern regarding patients as persons, what matters most for them, and their misdirected response to their patient's request for care, strike an ethical chord resonating throughout all western, technically advanced medical systems; there is a need to rethink how to conduct ethically sound consultations in our technological era. Despite the now well known fact that sound social relations greatly reduce mortality rates, this insight seems to have faded from current visions of doctoring, in medical education and practice,(66) as well as in research.(71)

What, then, can ameliorate the situation? Certainly, technology has been a blessing to humankind, creating many possibilities. This calls for its use. However, this call can take control over us to the extent that we forget what technology cannot do. Inspired by Jonas, I will suggest as a first step that we seek knowledge on possible adverse effects of our advancements, and work to ameliorate these adverse effects. Hence, we must regain control over unwanted technological developments that we are witnessing, realizing that “Every test carries a chance of mis-classification of disease and false positive results that lead to further interventions that do not benefit the patient and may cause harm.”(57) I believe the medical profession can take control over such uses of technology that overshadow our human nature and ignore our need for recognition and acknowledgement, - in the same way as we the last decades took control over the tobacco industry and now are working to promote ecologically sustainable environments. Then, “We need to become conscious about uncertainties and risks ..., realizing that the gap between what we can predict and what we can accomplish always will be there”.(53) Lastly, we all have a duty to imagine. We must imagine the faces of future generations of patients and doctors, their distress and suffering due to increasing alienation in the “gravitational field that attracts the instrumental and distorts the human”.(74) Based on our duties to imagine other’s suffering we can from what we already know about health promotion install more healthy approaches and procedures to medicine.

Can we leave it, then, to doctors to cure themselves of this “forgetfulness of recognition” that seems to grow within their profession? To be sure, change must come from within. But if doctors and others believe that intentions of benevolence will ensure morally sound practice, there need to be voices from outside that can make us all aware of our actions’ potential harm. This can be the voices of philosophers, like in our case, or voices of anthropologists or sociologists as well as our patients’; voices that remind us that if we do not open up to alterity, recognize patients as persons, and take responsibility for the responsibility in our world, medicine will be hollowed of its humanity and moral value.

There are today several models of effective cross-cultural communication, some of which are presented in the curriculum suggested by the Association of American Medical Colleges.(75) Evaluations also show that training in cultural competency can lead to a change in attitudes and skills. Moreover, a study on the cultural consultation model (which should not be limited to working with immigrants) shows evidence of significant satisfaction by clinicians using the service, suggesting that the gains are mutually beneficial.(76) Lastly, when contemplating our practice and the information and feedback we get from our patients, perhaps the space of reflection here introduced can be a useful tool, helping us to develop a sense of ethical consultations.

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