Human Dignity

A Living Right in Medical Treatment

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THE ISRAEL DEMOCRACY INSTITUTE

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Text Editor (Hebrew): Keren Gliklich
Series & Cover Design: Studio Tamar Bar Dayan
Typesetting: Irit Nachum
Printed by Graphos Print, Jerusalem

Cover illustration: Omer Klein

ISBN 978-965-519-293-3

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Introduction
Human Dignity as a Living Right

The fundamental right to human dignity [...] is a *living right,* one that must be realized every day and that cannot be reduced to constitutional formulas and theoretical clashes between the branches of government. [...]This right—along with deepening, expanding, and entrenching it—must be realized in every layer of life and in all of the political, social, and human contexts and circumstances where it must find tangible expression. Human dignity must be manifested in the day-to-day interactions between the authorities and individuals, in interpersonal relationships, in how the bureaucrat treats the citizen, in the attitudes of the media and the police. [...] The constitutional gospel is not limited to verbal declaration about the importance of human dignity but also relates to the substance, extent, and content of the implementation of the right in practice. [...] Respect for human dignity, and avoidance of any assault on a person's dignity qua human being, are values that must be entrenched in every part of society and, above all, in the legal obligations incumbent on the branches of government. It must be addressed in kindergartens, in schools, in the armed forces, in the colleges, and in the courses offered by community institutions. The value and

> objective of a constitutional norm are present not only in the constitutional obligation that applies to legislation, but also in its educational power. [...] It is appropriate that the implementation of this right emerge from the vital core of the values of the state and society in which it operates, and find its tangible expressions in daily life. [...] Accordingly it is clear and evident that human dignity cannot be guaranteed merely by talking about it, but only by giving real and substantive expression to its preservation. [...] Human dignity, in the constitutional context, is a legal concept; but it must also have practical expression in the daily human scene and in how the state, society, and their institutions relate to the individuals who live there (Chief Justice Meir Shamgar).*

> It took the collective lived experience of the loss of human dignity to focus the world's attention on its full meaning. Only in this way could flesh be put on the abstract concept. However, without the abstract concept to stimulate critical reflection, the lived experience would have been without meaning for those who were, themselves not deprived of dignity. But it was the lived experience that gave dignity its axiomatic credibility [...]
> By a "lived experience" I mean the way human dignity is perceived by human beings as they respond to the valuations of their worth and worthiness by others or by themselves. From a philosophical perspective, a focus on

* Meir Shamgar, "Human Dignity and Violence," remarks to students of the Law Faculty at the University of Haifa, December 11, 1994, to mark International Human Rights Day, in *Mishpat u-mimshal* 3 (1995/6), pp. 33–54 [Hebrew].

> experience re-embeds the concept in the complex daily life from which that concept was extracted. Neither the concept alone nor the experience alone can transmit the full meaning of the word. As a lived experience, dignity is the product of intra- and inter-subjectivity. The underlying conviction of this essay is that the intelligibility of so elusive a notion as dignity must be grounded in our lived experiences of dignity either personally or collectively or, as the rest of the world experienced the Holocaust and the other horrors of the last century, vicariously (Edmund Pellegrino).*

In this volume we would like to put flesh on the link between human dignity as a constitutional principle and human dignity as a fundamental right, and as a lived experience in medical treatment, as was presented, each in his own way, by the late Chief Justice Meir Shamgar and by Edmund Pellegrino, a world-renowned expert on medical ethics.

Human dignity is experienced more in its breach than its observance. That is what is special about it. When people are asked what value human dignity holds for them, they tend to answer in terms that related to its violation—the right not to be humiliated, not to be the object of inhuman treatment, not to be discriminated against, not to be excluded, not to be transparent, not to be exposed to bodily and mental harm. A tangible expression of this is found in the Basic Law: Human Dignity and Liberty, whose second article stipulates: "There shall be no violation of the life, body or dignity of any person as such."

* Edmund D. Pellegrino, "The Lived Experience of Human Dignity," in: Adam Schulman et al., *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics* (Washington, DC: The President's Council on Bioethics, 2008), pp. 513–539.

The fact that human dignity is experienced most acutely precisely when it is violated turns the attempt to discern the nature and quality of the principle into a protracted effort that demands an ability to deal with its clear and self-evident aspects alongside uncertainty, doubts, and ambiguity. The quest to define human dignity, in the deepest sense, is an attempt to define the very core of what it means to be human. There is an unbridgeable gulf between the elusiveness of the definition of human dignity and the sharp vividness of its violation. This volume was written with an awareness of this gulf and reflects it. In its chapters we interweave theoretical and constitutional definitions of human dignity with concrete testimonies of its abuse, and a survey of objective academic research with personal writings. By means of these diverse perspectives we endeavor to give life to the principle of human dignity as it relates to medical care.

Reviving this principle in that domain is especially challenging. Medical care has the potential to embody concern for human dignity in its purest sense, because it is intended first and foremost to enhance and improve a person's life by healing illness and reducing the pain and distress associated with the human condition. However, some senses of human dignity are threatened during medical treatment, because the sense of human dignity according to the Kantian categorical imperative—treating human beings as an end in themselves and never ever as a means—runs counter to the tendency of medicine, as a science and a practice, to see patients as an object, that is, to relate to them as just a "case" while ignoring their humanity. Thus the sense of human dignity as the prevention of humiliation—based on human vulnerability—challenges the asymmetry of power and knowledge and the dependency relationship that characterize the interaction between doctor and patient, in which the hope of alleviating the latter's suffering is in the hands of the former, who to a large extent creates the patient's sense of human dignity.

These threats intensify the paradoxical situation in which precisely those institutions that are charged with healing the sick, the medical staff that has taken upon itself the holy work of caring for patients, and the medical procedures intended to help them, are those that create a special need to safeguard human dignity because of their inherent potential to hurt the patient. This follows from the totalistic nature of medical institutions, the patient's vulnerability and dependence on the medical staff, and the nature of medical treatment that transgresses the boundaries. All of these mean that the affront to human dignity is unintentional. Usually the medical team, which works day and night and treats many patients with devotion and skill, despite limited resources and heavy workloads, is not conscious of causing harm and is not aware that it is doing so.

These threats of injuring to human dignity by humiliating patients and treating them as objects, which are corollaries of the inherent characteristics of medical treatment and the totalistic nature of the healthcare system, are also what underlies the inconceivable disparity between human dignity as an all-embracing and generally accepted principle of bioethics, one that is anchored in international conventions, legislation, and the ethical codes of medical organizations, on the one hand, and the daily reality of medical care, in which human dignity is sometimes infringed—not deliberately, not consciously, and sometimes not even felt by the therapeutic staff. It is from this gulf between the general agreement about the importance of human dignity as a key element of medical treatment, and its actual implementation as a living right, that our Human Dignity in Medical Institutions project was born.

The project, headed by Prof. Mordechai Kremnitzer, and led at various stages by Rear Adm. (res.) Amichai Ayalon and Assaf Geffen, ran from 2014 to 2016. We spent several months in each of three medical centers that are very different in their nature and the type of medical activity conducted in them. By means of observations, interviews, and surveys of patients, family members, and members of the medical staff we

investigated patients' daily experience, with the emphasis on respect for their dignity.

Our basic assumption was that human dignity is not a luxury in medical care, but rather an essential part of it. The measure of successful treatment includes both curing or alleviating the illness and the extent to which the patient's human dignity is preserved. Injuries to patients' dignity—humiliation, unjustified or disproportionate violate of their body or privacy, and denial of their autonomy or control of their own destiny—are liable to create a traumatic experience that will continue to haunt patients even after their discharge from the hospital.

Our presence in the hospitals alongside patients, family members, and the medical staff yielded a number of specific insights about respect for human dignity and how it is injured during medical care. In this book we share these insights so that they can serve as the basis for a deeper and more comprehensive discussion of the meaning of human dignity as a living right during medical care and hospitalization.

The first insight is the theoretical distinction we formulated between human dignity on the substantive level and the procedural level. On the substantive level, this is the core meaning of human dignity, which includes seeing what is unique in every human being and sensitivity to his or her inner world and perceptions, expectations, beliefs, and life circumstances. A respectful attitude towards patients includes the effort required to see the human being in front of you, with his or her uniqueness; it derives from the complex matrix of the patients' life and recognition of their intrinsic value as human beings, quite independent of their condition, abilities, limitations, and skills. Human dignity, in the substantive sense, is the product of the interpersonal encounter between the self and the other, such as that which takes place in the medical setting. The procedural dimensions constitute a sort of envelope around the substantive aspects and interface with the theory of service, but

are not identical with it. The procedural aspect is generally anchored in laws, regulations, professional codes, and organizational protocols (about privacy and confidentiality, for instance). The procedural aspects are essential for realizing human dignity in its core substantive sense, but are not enough by themselves.

The second insight that crystallized during the interviews and observations we conducted, as well as from testimonies published in the media, is the intolerable ease and banality with which human dignity is offended, and the traumatic potential of such conduct. From these testimonies we learned that the special nature of the violation of human dignity in the medical setting is a corollary of the contradiction between the essence of medical care—healing a person's body and soul—and the experience of being violated precisely in a place that should heal, at the hands of those who are supposed to heal. This sense of the betrayal of the body is incompatible with the feeling that precisely those who were supposed to help in fact hurt you. Precisely for this reason, even what appear to be trivial injuries that are often embedded in the medical routine are liable to be branded into the patient's memory as particularly traumatic.

The multiple sources indicate—as has been found by other studies—that just as human dignity is a lived right, its violation is a lived experience. As with trauma, after people feel that their human dignity has been violated even the passage of time does not heal the open and bleeding wound. The sense of humiliation, shame, anger, fury, vulnerability, helplessness, and degradation live on in those whose human dignity has been trampled underfoot.*

The "optsimistic" (both optimistic and pessimistic) insight that became

* Jonathan Mann, "Dignity and Health: The UDHR's Revolutionary First Article," *Health and Human Rights* 3 (2) (1998), pp. 30–38.

clear to us is that, in general, the innate spark of humanity is responsible for preserving human dignity; in its absence, medical care is reduced to an empty shell. To maintain patients' human dignity and avoid humiliating them, the prime requisite is humane resources: eye contact, heartfelt attention, empathy, compassion, recognition of another's pain, an equal relationship, asking for forgiveness when necessary, and the desire to heal the whole person—both body and soul.

But the ability to express this spark of humanity is impeded by the limitations of material and human resources and by the intolerable workload, which make the healthcare system and those working in it liable to offend against human dignity, unwillingly and unwittingly. These conditions affect not only the quality of medical care, but also increase the risk of a violation of human dignity, We saw, however, that even ample material resources and staff availability cannot guarantee that human dignity will be respected, and that their absence does not necessarily violate it. Patients are willing to discount and forgive procedural aspects of their treatment (the physical infrastructure and long waits) and sometimes even professional errors, provided they are treated with respect. We have also seen that even in places where the walls themselves shed tears (we are referring to dampness), the medical staff can rise to the highest level of respect for human dignity.

Another important insight that seems to be left out of the discussions but is very much present in the reality of the hospital relates to the importance of preserving the human dignity of the medical staff. Just as patients must not be treated as a means, so too physicians, nurses, and orderlies must not be reduced to faceless objects. Medical care is an interaction between the staff and the patient; even though it is always the latter who needs assistance, this does not mean that the members of the staff should be expected to sacrifice their own dignity in the caregiving situation. "Without awareness, recognition, and protection of the staff's dignity, neither its members nor the institution can show proper respect

for patients.". The staff cannot preserve patients' dignity and treat their family members with respect if their own human dignity is abused.

All these insights are here in this book, the fruits of a survey of the research literature on human dignity in the medical setting, of the interviews we conducted during the course of the project (excerpts of which are quoted anonymously in order to preserve the informants' privacy), of theoretical concepts drawn from the fields of sociology, psychology, and the law, literary sources, and testimonies collected from the media. The great diversity of sources on which we drew paints an extremely vivid picture of the various manifestations of human dignity and the threat that medical treatment and hospitals pose to it.

The book is divided into three parts. The first part (chapters one to three) reviews the definitions of human dignity in international law, philosophy, history, and religious thought, in constitutional law, and in the Israeli legal system. Chapter One takes up the definition of human dignity in general and its constitutional basis in international covenants and Israeli law. Chapter Two links the general concept of human dignity to the specific aspects of the medical system. Chapter Three maps out the research on human dignity and finds a dual use of the term in the medical context: in bioethics, "human dignity" is cited as the justification for various (and sometimes contradictory) positions on issues such as innovative genetic technologies; in the clinic and hospital, it is the standard by which treatment is judged.

The second part of the book (chapters four to six) focuses on the distinction between human dignity in the substantive sense and human dignity on the procedural level. The introduction to this section traces the trajectory of human dignity in these two realms and shows where these aspects deviate from service theory principles. Chapter Four tries to sketch the vague and elusive profile of human dignity in the substantive sense. Chapter Five offers examples of the ways in which an affront on

the procedural side can develop into a substantive assault on human dignity. Chapter Six looks at the tip of the iceberg of the question of human dignity at the end of life, in light of the distinction between the substantive and procedural aspects.

Finally, Part Three (chapters seven and eight) narrates moments when medical care detracts from human dignity. Chapter Seven consists of literary works that describe how human dignity can be injured or safeguarded. Poems by Zelda, Wisława Szymborska, Avot Yeshurun, Leah Goldberg, and Sivan Shiknaji, and a story by Yehoshua Kenaz expose the anatomy of the abuse of human dignity and give a hint of the spark of humanity that can preserve it. In Chapter Eight we analyze additional moments when human dignity is violated, in light of the concepts and ideas that emerged from the earlier chapters, and thereby uncover the unique traumatic character of these violations.

In the conclusion we lay out the Copernican potential of the adoption and inculcation of respect for human dignity as an essential principle of medical treatment and healthcare policy.

It is important for us to emphasize at the outset that the book's goal is to examine medical care through the prism of human dignity and to propose a way to ponder the essence of medical care, medical institutions, and the experiences of patient and staff. We hope in this way to help create a new language in which human dignity can serve as a code for deciphering the relations between caregivers and patients. But as the book makes clear, human dignity in the context of medical care extends to many weighty issues, including the patient's autonomy, the role and status of family members, informed consent, and end-of-life situations. We do not pretend to offer a full and exhaustive discussion of any of these issues, but seek only to employ the concepts and insights about human dignity as a lens for examining them.

It is also important to remember that to a large extent the book reflects the nature of human dignity, which is most visible precisely when it is being trampled. The book is accordingly biased towards the pole of violations of human dignity, even though none denies that most of the time the interactions that take place in the healthcare setting on a daily basis are a sterling example of respect for human dignity. We dedicate it with gratitude and appreciation to all the medical and paramedical personnel who save lives, heal the body, and care for the soul.

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