An Interview with Mildred Z. Solomon, President of The Hastings Center

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Mildred Z. Solomon is president of The Hastings Center, the world renowned bioethics institute focused on ethical issues in medicine, health care, life sciences research, and the environment. She is also Clinical Professor of Anesthesia at Harvard Medical School, where she directs the school's Fellowship in Medical Ethics. Before the presidency of The Hastings Center, Dr. Solomon was Senior Director of Implementation Science at the Association of American Medical Colleges. She was a member of the Secretary's Advisory Committee on Organ Transplantation, which advises the U.S. Secretary of Health and Human Services on national organ donation and transplantation policies. She has served on National Academy of Sciences committees and been a consultant to the Institute of Medicine, the Open Society Institute, and many other organizations. Thank you very much.

1. Could you explain the mission and the public engagement of The Hasting Center?

Yes. The mission, there are three primary things, we undertake original scholarship in Bioethics, so we are interested in tackling on conceptually difficult challenges and producing original scholarship. We do that through projects that we get funded where we bring teams of people together with our scholars to deliberate on unsettled questions, and the outcome of our workshops could be a book or a scholarly paper or set of recommendations or a briefing of some kind… so Scholarship, that is number one. Number two is; we like to do things to help promote the field of Bioethics itself, so we have two journals, we have a blog, we have around two hundred Hastings Center fellows from around the world, and we convene them annually so we try to find ways that our actions can continue to help build our field. That´s number two. And the third is public engagement. To my knowledge we are the only bioethics center that does its own original scholarship and has an equal commitment to educate the public. We do that in a variety of different ways, we have very strong public affairs department, we answer about two hundred calls from the media every year for providing background to journalists who are writing stories. We expect our scholars not only to do academic writing but also to be able to write for the public. They are frequently quoted or seen on the news or in a variety of different media outlets and that is considered part of the job; to be able to talk about these issues in a way that will help the public understand them. We are constantly trying to evaluate how we can do more of that. So, scholarship, public engagement and support to the field.

2. In which sense do you think the goals of the center are the same as initially, when the center was founded in 1969, and in which sense have they been transformed because of social changes too?

So, I would say that the overall goal is the same. And that was to try to anticipate the social and ethical implications of changes in health and healthcare, and in biomedical knowledge and emerging technologies, life scientific technologies. So, we have always, from the very beginning recognized that no technology is neutral, it brings with it potential benefits but also potential harms, and we wanted to always anticipate what the consequences of new technologies are and to figure out the best ways to try to integrate them to maximize their benefits and minimize their harms. And we have also always had a strong commitment to compassion and justice in healthcare and wanted to shape decisions about how we think about health and how we organize our society to provide health services and to promote Public Health in the best possible ways. So, the mission is the same, there is a lot of continuity. I would say there have been two major changes since 1969, when we were founded, almost fifty years ago, in 69. And, I think that two biggest changes are that our mission is needed more than ever because we have such growing income disparities and health outcome disparities, so the issues of inequity are even bigger than before, and that is very troubling. And, so our concern with justice issues are heightened. And the second change is, while we have always been interested in technologies, the technologies that are coming out now are far more powerful. So, in 1969 and in the early 70s we were talking mostly about life sustaining technologies, like ventilators or dialysis machines, and those were new then, and they were important and raised a lot of questions, particularly questions around, you know, would it be killing to turn off a ventilator. The technologies today are vastly more transformative, so we are talking about gene editing technologies, where we actually go in change the nature of the human species, in ways that will be heritable forever. This is an awesome responsibility. So, you know, we are talking about new forms or pre-natal testing, which, you know, if we can prenatally sequence the fetuses´ genome and identify that the fetus might be at risk for his adult onset diseases far into the future, this is not the same as a ventilator or dialysis, this is really huge, huge transformative capacities that we never had before. So, inequity and much more powerful technology.

3. The Hastings Center has an important group of researchers that include a staff of leading bioethics scholars and a worldwide network of experts. Most of your work is organized into five broad areas. Would you explain what these areas are?

Yes. Two of them have to do in different point in the life cycle. So, one is focused on children and families, and the other is focused on the other end of the life cycle, aging and end of life care. So, one is in children and families, we look at things like conflicts around psychiatric diagnosis and psychiatric conditions in children. We have a very interesting project on a sort of conflict within Psychiatry itself on whether children can have diagnosis´s that make sense and the use of Pediatric psychotropic medications, very controversial. A lot of use in young children for things like attention deficit disorder, very controversial. So, right now, in Children and families we got a very large ideal and engagement the next generation of pre-natal test which are not going to be amniocentesis on diseases or carotid blood sampling anymore, They are going to be much easier; a pin prick woman´s blood about ten weeks pregnant and there are fragments of the fetal DNA in the woman´s blood, making a very easy to do and provide all sorts of information about the fetus from very early on and this will transform how people make decisions about their pregnancy. So, that´s an example.

The second area, ageing and end of life care, we have two kinds of projects there, well many projects, but two sorts. One has to do with helping and families make decisions at the bed side about the use of life sustaining technologies. We have guidelines, about the use of life sustaining technologies for decades and so we recently updated the guidelines, I think in 2013, so these are clinical guidelines that are meant to help people decide how, when and whether to use amalgamator dialysis and go into cancer treatment, or hospices, you know all the hard choices there are patients and families have to make. There are a variety of projects to about improving that process. And on the other hand we have a new grant that is enabling us to think about population itself, about aging society, particularly about aging demographic in United States. I mean some of phenomenal number of people are going to complete 65 and over very soon so you are going to have an inverted pyramid, with a small number of people working, a workforce supporting a very large number of people. We are living longer, but that means not always well, so we are very longer but sometimes with extended periods of disability and difficulty and so we try to look at try to call attention to the social obligations that we should have for building societies that are more supportive for the ill and the elderly. That´s two, and that´s aging and end of life care.

The third one is called Science and the self and it´s really where we look at emerging knowledge from neurosciences and that are telling us more about what who we really are. There are lot of interesting ethical questions, psychological questions, as we learn more about biological reality, who we are as people and as human beings, we have lot of interesting projects there … One of the themes we have introduced this year is called the gift and the weight of genetic knowledge.

Fourth area is called Humans and Nature, and here we look at arising issues that are at the intersection on biotechnology and environmental protection. So, for example, I talked you about gene editing in and humans, but there is also gene editing in and non-human animals and plants. For example, it looks like with CRSPR and some other technologies we might be able to change the genome of mosquitos so they are not vectors for Malaria or Zika, or change the genome of mice so they are not the vector for Lime disease and it is not just gene editing with other technology, something called gene-drives.

So, this is an area where we have some of special niche where its merging biotechnologies that can change animals and plants in the wild. So, they have eco-systems implications as well as human health implications.

And then the final one is Health and Health care, which is at the policy level possible… so aging and Children and Family obviously have a lot to do with health but they are more clinical at the bedside, how health and health care are policy issues like good stewardship, scare resources, pricing drugs, just healthcare redesign insurance policies more about social and population and the other is about human interaction at the bed side level.

4. Let me move now to your research. The ethics of end of life care is one of the main topics along your career. In your article: *Modern dying: from securing rights to meeting needs*, you explain the problem of modern dying as a progressive story in at least three phases. The first is to secure the rights of dying patients by ensuring that they would not receive unwanted treatments; the second phase, to meeting patients' needs for better pain and symptom management; and in a third and future phase, you said that we must engage both a much broader set of issues and a much broader audience. We

should engage all clinicians and the health systems in which they work, as well as the general public, in finding and implementing solutions. What are currently the main responsibilities that health systems and hospitals have to face in regard to end of life care? And what is the role of society on that?

Yes, so, wonderful question. You know, health systems need to do a much better job on helping families and patients understanding when they are in the final stage of life. Right now, American patients confront a Health Care system that is very compartmentalized, very fragmented and if you have an advanced illness you are likely to be cared for very different specialist. And no one, very often, not always, but very often, nobody feels responsible to help organize and to sit down all the specialists, with the family and come up with a plan that meets families and the patient desires. Everybody just mainly focuses on their specialty; they don´t worry if your kidney is falling, we will give you dialysis, don´t worry if your heart is failing…

But nobody really says “What is your prognosis, how would you like to spend the last phase of your life?”. Nobody is really articulating what the actual situation is in the person´s life, and helping them navigate that. So, I think it is a responsibility of hospital system arrange, you know, for conversations like that and to have someone responsible for bringing all of them together for family consultations. The other question is what are the society obligations. We have focused so much of our attention and so much about financial resources on acute care in hospitals, and so much less on the social needs that the elderly experience and social and logistical needs. Most people want to stay at home but they need a home that is safe, they need a home where there is social interaction with other people or they need a way to get meals or easy traffic, easy way to navigate outside of the traffic, as people lose more and more abilities they need someone to come into the house and help them.

And we have a Medicare system that pays for all kinds of high tech interventions at hospitals, but we don´t really have a system that really provides for helping people stay in their home for as long as possible with social support. The exception is with Medicate but you only get that until you have exhausted all your resources and you basically have to became impoverished and be unable to pass any money on to your children, you have to lose everything in order to get Medicate and then Medicate usual requires that you have to go into a long term care facility and those people want to stay in their own homes, and many people could be help to stay in her homes if we felt the social obligations to create the support but so far we haven’t done that, we have a project right now, in fact I am going to Boston tomorrow because we have a meeting for three days in Boston, and interestingly the meeting we have is a really great incredible interdisciplinary group, people you might not think would be involved with ethics, so we are meeting with designers, at Harvard School of Design, to think about architecture and community design, and transportation, to sort of envision the community of the future, where this huge part of the population is going to have support; I am going to be one of them, I want to design it well for me…I will be sooner than you!

5. You also have claimed equal attention to gravely ill children, in regard to end of life, and you have founded The Initiative for Pediatric Palliative Care, which has produced an award-winning series of professional education films, and a comprehensive curriculum for clinicians who care for children near the end of life. Can you explain us how has been your experience in this area of pediatric palliative care? What are the main difficulties that you have had to face in this area, and also what are the best achievements?

So, this is one of the hardest areas, it is so difficult to work here, my heart goes out to the families, to the children, also to the care providers, you know, they are just heroic nurses and physicians who work with desperately ill children and it is a sad area, it is hard to keep your spirits up. We formed The Initiative for Pediatric Palliative Care because there has been a lot of work done for adults to ensure good pain management and to ensure good treatment decisions about when and how to use technology, and about how to use it and when to use it and when to forego it, but these were issues that nobody wanted to talk about what to do in respect to children.

So, we started off by interviewing parents who had lost a child and we interview providers who work in Neonatal Intensive Care Units and Pediatric Critical Care Units and we saw some recurrent themes, For one thing, you know, in adult Hospice, you could sign up when you are going to hospices, you know that you are close to death, six months to live or less, and you are making a decision to have the highest quality of life as possible, and you are forgoing some of the high tech things that could be a convenience or a burden or burdensome , and at least in United States, when you get the hospices, when you go on a hospice benefit, you tend to not do some other interventions.

One of the things we found in the Pediatric project is that you can´t ask parents to stop trying, even for a second. So, we encouraged a waver in a hospice benefits, so that´s parents don´t have to pick between aggressive curative oriented care and palliative hospices care. You can have both simultaneously in Pediatrics now, many people worked on that for a while.

Another thing we worked on was trying to have more information for parents in the NICU, we learnt from our research that the amount of choice that parents have when they have severely, a new born who has severe anomalies, you know, very severe damage, that make it impossible for him to relate or recognize love , people, and different parents might choose different pathways for that baby, our research showed that the different NICUS depended on who the doctor was that was in charge in NICU would give parents less or more freedom in making those kind of tough decisions and so a lot of what we did was focused on helping physicians recognize that parents should have a lot of latitude, not absolute latitude, but a lot of latitude and that there are ways to talk to parents about the choices for their child and open up that conversations more, so we did a lot to help doctors be comfortable holding these kind of conversations and empower the parents to be able to make, to be part of these decision making. So, that´s the two kinds of help that we do.

Nice job

Thanks

6. Traditionally, Medical Ethics training includes skills and abilities focused on the individual level, in the physician-patient relationship. In talking about the moral imperative to build learning health systems, you have expressed we also should have a system approach, thinking not only in the healthcare professional-patient relationship, but also in the role of healthcare professionals in transforming their organizations. How can healthcare professionals manage this tension between their responsibility to the patient in front of them and also the role that they have in involving the system to do a better job of community and population level of health?

Great question, good question, Janet. I think this is a big challenge for doctors today. And it is a challenge for nurses and other healthcare professionals, but I think physicians feel this the strongest. It is such a part of the physician´s professional ethic to be the champion for their patients. And yet we recognize more and more that we have to design a health system tries to be strategic and wise in where it puts it´s resources and so there are populations level and organization level concerns and it would be good for physicians to be leaders in selling policies that are likely to bring to the greatest benefits for the most people. So, at the individual physician level they often feel… (I have the privilege of mentoring physicians who work in the Harvard teaching hospitals). So, I know they often feel a tension between the responsibility for patients in front of them and concerns about cost of the whole system, or, you know, other kinds of things where there is a tension between the individual and the population. So, I just think it is inherent being a doctor. I would hope, and my advice when I talk with them, is that one advocates for the patient in front of them. You have to have that, that trust in the relationship is central in the whole health system and to the well-being of the doctor patient relationship, but, we should have guidelines that physicians play a role in for everybody, that should be established for everybody through some kind of transparent process that can be explained to the whole patient population. And if we do have physician leadership, but not only physicians, coming up with guidelines on key organizational questions like resources allocation, and the reasons are spelled out and people work out something, then when I am sitting across to my patient, I can say, I don´t think you need this extra MRI right now, our guidelines say… if you know, you can come back in two weeks and they still haven´t resolved, then we can talk about it but these are the guidelines that we all thought were fair and then we guide the community as a whole and I am transparently telling you that I am being guided by them, and I welcome you to get opinion from somebody else as well, and keep the door open for us to come and to look at this. So, it is hard, it is inherent to the job you know, but I do think that you can wear two hats and know which type you are wearing at which time…. It is difficult.

7. From your experience, what are the major difficulties related to ethic education in general terms in healthcare professionals?

Well, in the early days, there wasn´t that much education, and you got a lot of people who were good, for example, at ethics cases consultation in hospitals, and it is very variable and so some people especially because the field is new, quite quite recently new, we are starting to professionalize it and we now have standards about ethics case consultation, and you do really need some education in order to fulfil those standards. So, I think it is getting better, at the case consultation level, and one of the problems I see is that it is too easy to over simplify bioethics and it is too easy to “reify it”, so American doctors have, in my view, over-worn the principle of our time, and they apply it –some not all– in a very … … fashion, I have written about this demonstrating that on the false belief that patient autonomy means that you decide, and shove it back at the patient rather than seeing that my job is to share decision making , share information and together to talk about the best things to do. There has been a distance thing, you know: “patient gets to decide, well you go ahead now and decide or they come up with a DNR order and say if your heart should stop do you want us to start it… like that is executing something that is supposed to be respectful to the person. So, I think that Ethics education has sometimes been misunderstood and has led to a much more rigid application of principles than we ever meant for it to do. And in a second thing, there are lot of people are playing this role without sufficient education, especially in the ethics case consultation. I think that is getting better, there are now standards there is a growing body of Masters programs, so, this training is possible, you know, we have lot of things available for people. So I think it is improving.

8. Finally, I would like to ask you what do you think are the main challenges in the attempt to find a consensus in relation to ethics education in healthcare field in Universities and Hospitals worldwide? Is it possible, a kind of consensus about how to teach Bioethics?

Like should there be standards in Bioethics Teaching. I don´t really know the answer to that. I think it is a great question, I know that there is an effort by different organization that does applied ethics, which is not just Bioethics, it is engineering ethics, the environmental ethics, and a whole lot of sub fields of ethics are getting together to look at education and to see that there is some kind of standardization, just to describe what is going on, I am not sure of the name of that woman, but if you are very very interesting on that, I can try to find that out…

I don´t know, I don´t know, I mean, is medical education standardized? I guess it is, there are certain things you need to know and then you have to take a licensing…. So, should we be doing that in bioethics? I have someone you need to talk to, I think you could call Christine Mitchell, and ask her that question! She is in Harvard, and she is the executive director of the Center for Bioethics in Harvard. And Harvard runs a Master´s program, and she might have an interesting view about that.

But do you think it is desirable, I mean, something that we should try to find a way for? Or is it better to have different views on Ethics Education?

I don´t know what I think about that… Because I think if you are touching patients, and that means you are doing ethics case consultation, that should be standardized. But if you are doing Scholarship, I suppose there is a certain level of literacy you should expected to have, you should know certain things about the field. But one of the things that has been so exciting about Bioethics is how interdisciplinary it is. I don´t really consider it a discipline itself. I consider it an interdisciplinary field of inquiry, and that is why I haven´t been upset because there are no standards.

I think Bioethics is a field that takes expertise from all relevant possible places to think about a Bioethics question. I think it is our questions that innovate us. We can answer those questions in many different ways. So yes, if you are touching patients, you ought to have some standardization and some common basic skills that you need to demonstrate. But if you are trying to contribute scholarship to a question, I don´t know what standardization would even mean. We know a good Sociology Degree, or a good Anthropology Degree ought to cover certain things and I want people who have those different skills, to look at that interdisciplinary question, but I don´t know if Bioethics should ever be thought of as a discipline. I like to think of it as a field.

Thank you very much for your time and for your answers.