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Egg Cell Preservation and the Right to Die in The Netherlands: Citizens' Choices and the Limits of Medicine

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It is a funny thing with the Dutch. On one hand, they seem preoccupied with death and adamant that patients be allowed to decide for themselves in what way they want to die. On the other, contrary to popular belief, the Dutch physician is allotted a very influential role in treatment decisions, far more prominent than in many other Western countries. From an American perspective Dutch professional ethics may seem quite paternalistic:[1] a patient's freedom to decide to have a particular medical treatment is limited by the physician's professional assessment of the medical need of this treatment. The question arises: What is the relationship between the professional responsibility of Dutch physicians and the right of Dutch patients to decide for themselves? This question is illustrated by the ongoing national debate in The Netherlands on euthanasia and the growing demand for a further reaching right to self-determination concerning ending one's life. However, contrary to popular belief, not all Dutch ethical debate concerns end-of-life questions. Therefore, it is also instructive to look at a totally different discussion, centered on the possibility of vitrification of egg cells for women who want to preserve them in order to improve their future chance of fertility. This debate features the same tension between a plea for autonomy for patients and the felt need to preserve a professional autonomy on the part of the experts.

Vitrification

Because of relatively new techniques, it is possible to fast freeze egg cells (oocytes, not embryos) to preserve them for fertilization at a later stage. This technique enables women to safeguard young and healthy egg cells for a time when they may want to become pregnant but their egg cells may be too old or damaged. It could therefore be helpful to women who, as a result of medical problems, may not have healthy oocytes or who have to use in vitro fertilization in order to have a chance at pregnancy. Apart from these medical indications, the technique may also be helpful to women who have not yet found a partner but hope to find one someday and have a family. It may also prove attractive to women who, because of their working circumstances or career choice, want to postpone motherhood. A lifestyle choice, one might say.

In the spring of 2009, the Amsterdam Medical Centre announced the intent to make available the fast deep freezing technique of egg cells to women who want this technology for nonmedical but social reasons. Parliament, however, objected,[2] especially the Christian parties that called the nonmedical availability of this procedure against nature and therefore undesirable. Instigated by the

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Vice-Minister of Health, a committee of the Dutch Association of Obstetrics and Gynaecology (NVOG) in cooperation with the Association of Clinical Embryologists (KLEM) published a report on the different possible uses of the vitrification technique for egg cell preservation.[3] In the meantime, the debate continued on television, in national newspapers, and in professional ethical circles. In November 2010, a documentary titled ''Egg for Later'' was shown on national television, made by a woman aged 35, Marieke Schellart, who decided she wanted her eggs preserved for the future.[4] The documentary is a highly personal account of a young, educated, single woman who would prefer to have a family together with the father of the child(ren), rather than choosing to be a single mother. In the documentary she shows her personal predicament, her reasons for wanting to lengthen her options, and the reactions she received from people around her. The very personal perspective of the documentary draws attention to the predicament of involuntarily single women whose biological clock ticks on. ''It is still ticking,'' the filmmaker concludes, ''but now it ticks a little bit less fast.''

Arguments and Reactions

In their 2009 article in *Human Reproduction,* ethicists Dondorp and De Wert discussed the desirability of fertility preservation for healthy women.[5] Their arguments subsequently appeared in the public discussion and were featured in the 2010 NVOG/KLEM report. Among others, these arguments concern the gender inequality present in fertility, the objection that this kind of fertility-preserving technique pushes against natural boundaries, and the advantages of having genetically related offspring. A central objection to the technique is the argument that vitrification offers a medical and technical answer to a broader, nonmedical problem. This touches on a larger issue: that medicine is frequently called upon to solve problems that do not really belong to its realm. This issue directly concerns my analysis of the relation between self-determination and professional autonomy. The argument of unwanted medicalization is not without its appeal: harvesting egg cells after a heavy course of hormonal stimulation, then deep freezing the oocytes, thawing them at a later stage, performing in vitro fertilization, and implanting resulting embryos seems a lengthy, hazardous, and needlessly technical way of becoming pregnant when there is no strictly medical reason not to follow the natural course. IVF procedures are not always successful, and although the vitrification technique seems promising, it is not known what harm will be done to the egg cells in the long term. It is true that women who want to preserve their oocytes for social reasons face a dual problem: the preservation of their fertility is not outside the medical context, but the problem of their being single is. Although finding a partner might be a less medical and technical solution—albeit perhaps not easy—medicine may offer a way to ease the pressure on this account.

In the debate in newspapers and magazines the focus is often on women who give priority to their career and therefore want to postpone motherhood. Many writers commenting on Internet sites also speak derogatively about these women and, generally, the women receive broad condemnation for their decision.

Dondorp and de Wert are not convinced by the argument that vitrification would be an unnecessarily medical way to address the issue. It is a societal problem, they state, that cannot be solved at an individual level and whose

solution would come too late for those women immediately facing this issue. "They cannot afford to wait until society has changed in a way that would allow them to have it all at the right time."[6]

Harm

There is another major argument against the use of this medical technique to solve a social problem, namely, the traditional norm that unjustified harm should be avoided. Even if a woman wants a procedure, if the risks and harm are not outweighed by the results, doctors should not comply. Generally speaking, the only justification for a risky and burdensome treatment is the medical need for the procedure or the suffering that can be lessened, and the right risk–benefit ratio. So the question is raised whether the procedure to obtain egg cells for deep freezing for social reasons does not conflict with the adage "First do no harm" to the woman in question. A counterargument could be that a comparable lack of a strictly medical need is seen more often in contemporary medicine, and many elective cosmetic surgery procedures risk substantial harm. Also one should not underestimate the suffering caused by involuntary childlessness, women without a partner not excluded. It is up to the woman in question, the NVOG/KLEM committee states, to weigh the potential harm of the procedure after careful counseling. Respect for the individual autonomy of the woman in question is a competing value to the adage *Primum non nocere*, they argue.[7]

Here we arrive at the question of the balance between the wish of the woman in question and the judgment of the physician. Some argue that the vitrification technique should only be used at this point in experimental settings, for women who have a clear medical reason to want to preserve their oocytes. Obviously, it is the lack of medical need that makes people hesitate: medical need makes the decision easier. Apparently the lack of a medical need opens the debate to other categories of normativity.

Dutch Society

Placed in a broader context, the discussion on egg cell freezing tells something about the position of women in Dutch society. However free-thinking the Dutch may seem in the eyes of the rest of the world, women's freedom of choice seems to be limited by all kinds of cultural and social-historic norms. This shows in many arguments offered against the vitrification of egg cells for nonmedical reasons: preserving fertility for women would go against nature; it would be bad for children to have an older mother; these women should try to find a man instead of preserving their egg cells; medicine should not be asked to provide an answer to this nonmedical problem; career women should realign their priorities—these arguments all seem to level a judgment on women who might consider the technique. This should not surprise us: the subject matter concerns women and sexuality, a combination often leading to injustices.

At the same time, the debate touches on the social issue of motherhood in Dutch society. In the Netherlands, the mean age of women having their first baby is one of the highest in Europe, namely 29.4 years in 2008 (10% of the children born in 2008 were born when their mother was 38 years or older).[8] For years the Dutch government has proclaimed the slogan "A smart girl has her children in

time,'' but this public relations push has not seemed to change behavior. Dutch women apparently tend to postpone motherhood. A reason for this is often sought in the burden of combining work and family. There are long waiting lists for day care, and the costs are high. Added to this there is an ingrained idea that it would be bad for children to spend more than 3 days per week at a day care center (this contrasts with general ideas in surrounding European countries). So many women work only in small part-time jobs: the percentage of women who have a paid job but are economically dependent is 33%.[9] Research by the Council for Public Health, however, shows that socioeconomic and infrastructural problems are only part of the reason why women in the Netherlands postpone starting a family: there is also a significant cultural factor.[10] I believe this is also shown by the fact that different standards are applied for men and women, both in the acceptability of fertility techniques and in moralizing about good motherhood (fathers do not work part time nearly as often as mothers; nobody complains about older fathers).

The debate on egg cell freezing shows the struggle of modern society to offer individuals freedom in their life choices. Self-determination is limited by the sociohistoric and sociocultural context of the position of women and mothers. The room for people to decide for themselves is limited by society's ideas of what is good for them. Even if doctors are willing to provide a service, society may not permit it.[11] The debate also shows the struggle with the question how to think about medical technology and who decides when, and for whom, it may be used.

Let us turn now to the subject we Dutch are known for around the world, end-of-life decisions, and see if there are notable differences.

"By Your Own Free Choice"

One would imagine that by now the Dutch should be accustomed to discussions about euthanasia and choosing one's own death. After all, has not the public debate been as open and involved as many segments of society as possible? Still, the national media, including newspapers, radio, and television, paid rapt attention to the citizen initiative ''By your own free choice.'' The movement began with an advertisement in national newspapers in which prominent Dutch citizens, age 70 and above, made a public plea for help with dying upon request.

> Our constitution guarantees every Dutch citizen the freedom to live his life as he wishes and to decide for himself. This freedom should also extend to the last phase of life and decisions concerning dying and death. Nobody has the obligation to live. Self determination, an essential principle in our civilization, anchored in our society, is the foundation of this citizen's initiative. ''By your own free choice'' is aimed at the self determination rights of elderly people. A free person, who considers his life to be completed, should be allotted room to decide for himself how and when he wants to die.[12]

By collecting signatures of at least 40,000 fellow citizens, Dutch citizens can cause a topic to be put on the parliamentary agenda. The initiative ''By your own free choice'' aimed to collect enough signatures to force parliament to debate the possibility of euthanasia for elderly people who are not suffering from a terminal disease, but who are simply finished living:

> The aim of the citizen's initiative "By your own choice" is the legalization of help to die for elderly people who consider their lives to be completed, at their explicit request and conforming to requirements of carefulness and open to assessment.[13]

To understand the reason for this initiative, it is important to understand that the Dutch legislation on euthanasia places the decision to actually administer euthanasia squarely in the hands of the physician.[14] Of course the necessary condition for euthanasia to be acceptable is that the patient freely and explicitly requests it; but it is the treating physician who determines whether or not all due care requirements have been met (e.g., the patient's request is voluntary and well considered, whether the patient suffers unbearably and without the chance of it ever getting better). Although the law instructs the physician to solicit a second opinion by an independent physician, it remains, in the end, the doctor's decision.

Dutch doctors are under no obligation themselves to perform euthanasia, but they do have an obligation to refer the patient to another physician. Therefore, strictly speaking, Dutch patients who suffer from unbearable and untreatable conditions and who decide for themselves that they want aid in dying have no *right* to that help. They can only hope that their treating physician agrees with their situation and is willing to relieve that suffering by performing euthanasia.

The Physician's Right to Decide

Euthanasia, with its emphasis not solely on the patient's choice but also on the physician's estimation of what is good care, reflects a fundamental aspect in Dutch healthcare and medical ethics. Dutch physicians, in their relationships with patients, have significant latitude to decide what they consider to be good medicine. The model treatment agreement between doctor and patient includes a clinical decision by the physician as to the right treatment for this patient with this disease at this moment. The physician explains these options and the patient then either agrees (thereby giving informed consent) or disagrees. In ethical terms we might say that *a patient has a strong right to refuse, but a weak right to claim care*, because this is limited by the physician's professional judgment. This arrangement is the basis of the Dutch Medical Contract Act[15] and also appears clearly in the legislation on euthanasia.

The moral basis for physicians reserving the right to decide what actions they are prepared to take is imbedded in discussions on professional autonomy. The Dutch ethicist Hilhorst argues that professional decisions cannot be determined by protocols or standards, because a weighing of individual factors is always needed. A medical decision is actor specific: it always implies the personal involvement of the physician who acts. Good medical care cannot be done without personal involvement, and this has consequences for the physician's role in the decisionmaking process.[16]

Medical treatment is provided in the context of a relationship between caregiver and care receiver; a connection is formed that entails more than the delivery of services. The modern trend of picturing the patient as a customer (in the sense of "who pays, decides") falls short of the moral complexity both of this relationship and of medical treatment decisions. Physicians are not neutral actors. They are not just performing a task; they are giving care. Within the

boundaries of the professional standard of care, physicians must come to their own conclusion as to what entails good medical care and must be able to morally justify their actions. The uniqueness of each sick individual, the uncertainty of outcomes, the search to find answers to what would be best for this particular patient, the unfeasibility of forming a good doctor–patient relationship without investing something of oneself, the significant risks that are involved, and the great interests of the patient that are at stake—all these factors underline the intrinsic morality of medical action. Practicing medicine cannot happen without interaction between physician and patient because it cannot be done without the involvement of both the actor and of the other person who responds. Within this interaction it is not just the patient's choice that decides what shall be done: physicians are obliged to make their own well-considered judgment of what is right to do.[17]

Euthanasia and a Completed Life

Considering the moral complexity of clinical decisionmaking, it is not surprising that the Dutch have chosen to establish safeguards for physicians who do not want to administer euthanasia. Being asked to help a patient die is infinitely more burdensome than to be asked to give a doubtful treatment. The documentary *Deathly Dilemma* (broadcast on national television in January 2010) features three general practitioners who have agreed to administer euthanasia to a patient.[18] Compared to other documentaries on the subject, this film concentrates on the emotions and experiences of the physicians involved; the patients' own stories are only lightly touched upon. The film makes clear the enormous impact administering euthanasia has on a physician. Contrary to the way in which they are sometimes viewed elsewhere, Dutch doctors would far rather not participate in causing a patient's death, because that is the opposite of the goal of medicine. However, numbers suggest that most of them administer euthanasia at least once or twice during their career (this number differs a little depending on one's chosen area as euthanasia is primarily administered at home, by general practitioners[19]) because they are convinced it is the only solution to this patient's tragic predicament.

The citizens initiative ''By your own free choice'' raises the problem of the physician's emotional, moral, and professional qualms. The central focus of the campaign is that euthanasia should not be limited, as it is now, to patients with a medically classifiable disease that causes unbearable suffering, but should be available to elderly people who consider their lives completed. In the Dutch language we call this ''tired of life'' or ''finished with life.'' The citizens' initiative wants to open the possibility of assisted suicide for any elderly person of the age of 70 or older who feels life has gone on long enough. Additionally, the initiative proposes the possibility of physicians not being the only persons allowed to assist with suicide. Some parties within Dutch society make a plea for a system similar to that used by the Swiss, in which nonphysicians could participate in euthanasia, but, as yet, it is unclear as to what their role might be.[20] As it is, Dutch physicians are the ones who have to shoulder the responsibility of administering euthanasia and, thus, understandably are given the prerogative to decide whether or not they agree. So we must conclude that within the Dutch system, the patient has a legal right to *ask* for euthanasia, but cannot *demand* it.

The current campaign "By your own free choice" stems from the experience that people in the Netherlands have had with euthanasia over the past 10 years and what they have learned. Seeking to open up the possibility of euthanasia for elderly people who have decided that enough is enough and the controversial step to extend to lay people the task of helping people to die clearly broaden the Dutch patient's options for self-determination. It is important to note that, thus far, the campaign has focused on putting the subject on the agenda of Dutch parliament. What will eventually happen is still very unclear. Given the process of open discussion and debate about euthanasia that has been the Dutch tradition,[21] the changes desired by the campaigners have a long way to go. But considering the number of signatures gathered, the Dutch people are not opposed to moving forward.

Discussion and Conclusion

The issues discussed above, egg cell preservation by deep freezing and the aims of the "By your own free choice" campaign, do not have obvious overlap with regard to their content. However, I am convinced that the way public debate evolves with both issues will be instructive as to the place of individual autonomy in Dutch society. It is a curious phenomenon that discussions in other countries often appear more repressive and restricted (as, for example, the Terry Schiavo case in the United States). In the Netherlands, however, physicians have a strong medical and moral vote, thus restricting the patient's own powers of self-determination.[22] This is especially the case for procedures considered outside the regular medical realm (euthanasia is explicitly not part of regular medical care; vitrification is an innovative, still largely experimental technique), but also within standard medical practice it is generally accepted that physicians are morally obliged to defend the boundaries of good medicine and good medical care.

The question remains: Who decides in the Dutch clinic? Have non-Dutch doctors relinquished responsibility by dancing to the patient's tune, or do Dutch doctors too often deny their patients the right to decide for themselves? Perhaps it is our Calvinistic tradition, perhaps it is the national morality that argues against putting oneself above others in terms of claiming special treatment. But at the same time, perhaps it is a sound and realistic understanding of the limits of individual freedom. Perhaps a basic sense of gratefulness plays a role too—being grateful for what you do have. This tradition, whatever its origin, is waning however. Because of recent reform in healthcare, people are increasingly stimulated to reconsider their position and to weigh their options critically: we are told to turn from patients into clients or healthcare consumers and are supposed to choose our hospital, our physician, and our treatment. This means that people have to cope with a mixed message: on the one hand they are supposed to be critical and claim their rights, and on the other hand to abide by the boundaries set by doctors. It is not surprising that the filmmaker, Schellart was astounded to learn that she would not be able to have her oocytes preserved in the Amsterdam Medical Centre that is in the process of perfecting that technique (in the end she went to Belgium). Nor should there be amazement that people are incensed when the escape route of euthanasia may not be available to people who sincerely suffer, even if their suffering is not easily classified in medical terms.

The debates continue regarding the availability of medical techniques or procedures that exceed the scope of regular medicine, as well as regarding the relationship between the physician's interpretation of the patient's needs and that patient's own view.[23] Communication and open dialogue play an essential role; so does the fundamental recognition of mutual good intentions. Sometimes when the physician's medical expertise is coupled with the patient's own vested interest in the outcome, the result can be the patient's realization that, especially in complex medical matters, ''what is good for you'' is not always identical with ''what you want.'' Inevitably the term ''paternalism'' comes to mind. Although the term has a distinctive pejorative ring, it does not always carry such a negative weight. A thorough discussion of what patient autonomy entails goes beyond the scope of this report, but today most ethicists agree that a view of autonomy that diminishes the physician's role to give information and not a considered professional opinion actually means utter loneliness for the patient. Also, I am a strong advocate of physicians assuming their moral responsibility to decide what they consider to be good medicine and what kind of doctor they want to be. This responsibility is greater when the treatment desired by the patient is further outside regular medical care. A balance is needed between professional assessment and the individual patient's preference, infused by the seemingly old-fashioned value of mutual trust. The process of looking for this balance is very much ongoing in the Netherlands, even if not explicitly stated. Clients, consumers, patients—in the end we still call it ''healthcare'' and not ''health industry,'' do we not?

Notes

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