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Reproductive autonomous choice--a cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis.

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**Reproductive Autonomous Choice – A Cherished Illusion?
Reproductive Autonomy Examined in the Context of Preimplantation Genetic
Diagnosis**

Abstract

Enhancement of autonomous choice may be considered as an important reason for facilitating the use of genetic tests such as preimplantation genetic diagnosis. The principle of respect for autonomy is a crucial component not only of Western liberal traditions but also of Western bioethics. This is especially so in bioethical discussions and analyses of clinical encounters within medicine. On the basis of an analysis of qualitative research interviews performed with British, Italian and Swedish geneticists and gynaecologists on ethical aspects of preimplantation genetic diagnosis, the plausibility of the notion of autonomy within reproductive medicine is discussed. The analysis of interviews indicates not only that there is a gap between theoretical discussions and concrete practice, but also that an increase in choice – paradoxically - can hamper couples' choice.

Reproductive Autonomous Choice – A Cherished Illusion? Reproductive Autonomy Examined in the Context of Preimplantation Genetic Diagnosis

Introduction

The principle of respect for autonomy is well-rooted in liberal Western traditions, being one of its normative cornerstones. Its place within Western bioethics is likewise solidly established. Respect for autonomy recurs as a bioethical principle in the well-known work of Beauchamp and Childress as well as within the European project BioMed II (Beauchamp and Childress 1994; Dahl Rendtorff and Kemp 2000). Though commonly addressed as an evident element of bioethical discussions and analyses, the exact meaning of the concept of autonomy is not clear. Efforts to define the notion in a precise manner are complicated by the web of heterogeneous notions associated with it, such as self-rule, self-determination, self-control, freedom of choice, privacy, independence, authenticity and empowerment.

Within ethical discussions of reproductive medicine, bioethicists who advocate reproductive rights use notions such as procreative liberty, procreative autonomy and reproductive freedom as conceptual building blocks. In these kinds of reasoning, procreative liberty (or procreative autonomy/reproductive freedom) is typically understood as indispensable since reproductive technologies are bound up with procreative individual choice (cf. Robertson 1986).¹ Furthermore, procreative liberty is described as a negative freedom, identical with a negative right. It is due to this liberty that each individual has a right to make her or his own decisions concerning reproduction, without others' interference, as long as decisions made do not result in "substantial harm" for others and as long as a procreative interest exists. The latter is the case when someone sees a certain technological intervention or diagnostic method as a necessary condition for contemplating having children in the first place (Robertson 1994 p.29). Procreative liberty is, in this kind of reasoning, a right of "married persons to use noncoital and collaborative means of conception to overcome infertility," which "must extend to any purpose, including selecting the gender or genetic characteristics of the child or transferring the burden of gestation to another" (Robertson quoted in Tong 1997 p.262). This view has also been criticised, and often so from a feminist perspective, due to its possible consequences for women (e.g. Raymond 1995).²

Within this article, the notion of *reproductive autonomy* will be used. Reproductive autonomy is understood as a sub-category of autonomy in general, applied to the field of reproductive medicine.

Discussions of the meaning and plausibility of reproductive autonomy, in different senses, are not new. The importance of reproductive autonomy has been used as an

argument within discussions of prenatal genetic diagnosis (PND). It could also be used as an argument in discussions of 'new' technologies within reproductive medicine. Reproductive autonomy may be understood as extended into new areas and enhanced when surrogate motherhood, preimplantation genetic diagnosis (PGD), sperm- or oocyte- donations are available – or, in the future, germ line gene therapy or human cloning. Whereas the question in prenatal genetic diagnosis is whether to carry a foetus to term or not, these technological applications evoke the question of what embryo to implant.

The view of reproductive autonomy as extended and enhanced through the availability of new reproduction technologies can also be questioned. Drawing on one possible interpretation of reproductive autonomy, I intend to show how empirical research can be used to question a) the extent to which reproductive autonomy can be understood as plausible in practice and b) a too vague and sweeping use of the notion. Within the article, empirically based criticisms will be used in order to highlight concrete difficulties and even paradoxes when the notion of autonomy is applied to reproductive medicine. Empirical research indicates not only that there is a gap between theoretical discussions – theory - and concrete practice, but also that an increase in possible choices can influence people's free choice negatively. Personal decision-making costs as well as a possible reduction in social support for the birth of children with genetic diseases (diseases that can be avoided when e.g. PGD is available) must be taken into account (for the latter, in a discussion of PND, see Hildt 2002 p.70). Other difficulties are also present, as will be shown, and such difficulties may not be perceived when discussions are kept on a theoretical level.

The article is divided into three sections. First, a number of distinctions are introduced, in order to clarify different aspects of autonomy in general and reproductive autonomy in particular. Second, two kinds of empirically based criticisms are discussed: one concerned with the gap between theory and concrete practice and one concerned with negative consequences of increased choice in the context of PGD. Third, the severity of the criticisms as well as consequences of them are discussed.

Within the article, excerpts of interviews from the project *Lifeviews, Human Nature and Genetics* are used in order to problematise the use of the notion of reproductive autonomy in the area of reproductive medicine in general, and when preimplantation genetic diagnosis is used in particular.³

Autonomy Defined

As a point of departure, some clarifications need to be made. Autonomous persons will be distinguished from autonomous choices or actions. Not all autonomous persons choose autonomously, nor do they always act autonomously. The first is a matter of having the capacity for certain choices or actions, the latter concerns actuality, what

actually happens. Taking an example from the realm of reproductive medicine, someone may have reproductive autonomy in the sense of being able to choose – autonomously – whether to become a surrogate mother or not, but the law in that specific country forbids surrogacy (such as is the case in Sweden). In this way, the possible choice to become a surrogate mother cannot be exercised and it can be questioned whether the possible choice to abide by the legal system, and thus not be a surrogate mother in Sweden, can be seen as autonomous at all, due to the legal restrictions (see further down).

The distinctions can be further elaborated. Autonomy can be understood as a capacity within a specific person. Another notion sometimes used in definitions of autonomy is power. To be autonomous can then mean a) to have the power of self-government and b) to exercise this power (Nordenfelt 2000 p.129). Nordenfelt develops this view of autonomy by use of the notions of ability and opportunity. In order to have the power of self-government, someone needs both to have the ability and the opportunity to decide to do something. Likewise, in order to execute this power, someone needs both to have the ability and the opportunity to realise the decision – to make it come true. Returning to the example of surrogacy above, the person who wants to become a surrogate mother is not autonomous, since she, if she is aware of the legal restrictions, knows that her choice cannot be exercised. If a choice shall be understood as autonomous, we need at least to believe that it can come true. Furthermore, her ability to realise the decision, to do something, also presupposes that she has the ability to have things done for her. Her reproductive autonomous choice presupposes others' actions, without which it cannot be executed, and the law forbids these actions.

The power of self-government and the exercise of this power presuppose the non-existence of preventive factors. Preventive factors may be external as well as internal. Our power of self-government may be hampered through internal constraints, such as weakness of the will, drug use or lack of knowledge, which make us unable to come to a decision. It may also be hampered through external constraints, such as being continuously interrupted or having too little time to reflect on a certain matter. The exercise of the power of self-government may likewise be hampered by external constraints, such as certain legal and technical restrictions, and by internal constraints such as drugs. The former would hamper our opportunity to exercise the said power, and the latter our ability to exercise it. Furthermore, according to this view, ability and opportunity cannot be separated. Ability is relational in the sense of being an ability in relation to certain circumstances. Ability cannot exist in a vacuum (Nordenfelt 2000 p.131).

	<i>Power of self-government</i>	<i>Exercise of this power</i>
<i>Ability</i>	Internal constraints which make us unable to come to a decision	Internal constraints which make us unable to execute a certain decision
<i>Opportunity</i>	External constraints which make us unable to come to a decision	External constraints which make us unable to execute a certain decision

Table 1: Different kinds of possible constraints on reproductive autonomy

Within the article, the notion of reproductive autonomy will be used in two senses. I will label being autonomous within the field of reproductive medicine in the sense of having the ability and the opportunity to decide to perform a certain action – the power of self-government - as *reproductive autonomy as power*. I will label being autonomous in the sense of having the ability and the opportunity to exercise a certain choice as *reproductive autonomy as exercised power*.

Finally, reproductive autonomy as power/exercised power can be distinguished from reproductive autonomy as a right. Whereas the latter presupposes the former two, the former two need not lead to the latter. To have the power of self-government and to exercise this power within reproductive medicine need not lead to a right to reproductive autonomy. However, if there is a right, which I intend to exercise, I need also to have the power of self-government. Reproductive autonomy as power/exercised power can also be distinguished from reproductive autonomy as an ideal, i.e. as something that should be striven for (but that cannot be demanded). To have power of self-government and to exercise this power within reproductive medicine need not, but may, lead to a view of reproductive autonomy as an ideal.

Regardless of that, within a clinical context as well as in bioethical discussions, reproductive autonomy – when understood as a principle that should be respected – seems to be used either as a right or as an ideal.

Preimplantation Genetic Diagnosis

Preimplantation genetic diagnosis (PGD) will be used as an example for the discussion of reproductive autonomy. Preimplantation genetic diagnosis is performed after in vitro

fertilisation. It involves testing of one or two cells taken from an embryo of eight cells and selective transfer of embryos. The aim is to identify the presence of genes that will or might result in genetic disease and to diminish the risk of unconsciously implanting an embryo with such genes. It was first successfully performed (resulting in the birth of a healthy child) at Hammersmith Hospital, London, in the 1980's (Handyside *et al* 1989). Though no formal list of what diseases it is permissible to search for exists within Britain, Italy or Sweden (the three countries in the described study), PGD is often performed in order to test for diseases such as cystic fibrosis and Duchenne's muscular dystrophy.

Empirically-based Criticism No 1: A Gap Between Theory and Concrete Practice

Drawing on empirical research, the extent to which reproductive autonomy can be understood as plausible in practice can now be questioned.

A common prerequisite for autonomy in general is that alternatives are available. Alternatives need to be realistic, i.e. eligible and more or less equal in terms of costs such as personal trauma or economic expenses (Dworkin 1988; Hildt 2002). Furthermore, autonomous choice presupposes that correct information is given (e.g. Beauchamp and Childress 1994). In the following, eligible alternatives and correct information are understood as prerequisites for reproductive autonomy. Whereas this may be held to be the case in theory, an analysis of medical professionals' experiences and reflections on experiences in the field of reproductive medicine indicated that this was not always the case in practice. Two examples will be given which reveal a gap between theoretical ethical discussions and experienced ethical dilemmas - in short, between theory and practice.

A. Most interviews contained *narratives of progress* where the scenario was described as going from a worse state to a better state. Typically, the pre-PGD and pre-prenatal diagnosis era (when molecular screening was the only alternative) was pictured as "difficult" or "terrible," as a time when the women and men concerned had no or little choice (interviews 9, 10). Some women did not dare to become pregnant knowing that they might be carriers of genes for genetic diseases. Others chose to abort a male foetus if a recessive x-linked disease was present.⁴ Interviewees described the development of prenatal diagnosis and termination as opening the door to an important option. Prenatal genetic diagnosis implied the possibility of a more accurate diagnosis. However, interviewees explained, couples with experience of a number of terminations or couples who could not consider abortion for other reasons did not consider prenatal genetic diagnosis as a desirable alternative, and sometimes not as an alternative at all. The costs, e.g. in terms of personal trauma or infringed religious or ideological convictions, were considered as too high. The realism of prenatal diagnosis as an

alternative for these couples may thus be questioned. The development of IVF and PGD represented a further step in interviewees' narratives of progress. Use of PGD was described as making the situation "easier" for medical professionals and for the women and men. According to most of the interviewees, the possibility of using PGD meant that women and men at high risk regarding genetic disease could be given "secure information" on whether the embryo was unaffected, affected or a carrier of a disease (Interviews 7, 8). If implantation and diagnosis was successful, pain and suffering could be minimised for the women and men concerned in terms of less anxiety during pregnancy as well as less suffering and pain for the future child. Selection of 'healthy' embryos, before implantation, could take place. "It used to be no alternatives, just tossing a coin," one interviewee said. Now, couples for whom IVF/PGD worked as intended "are the happiest couples I've ever seen" (Interview 8).

Narratives of progress also had a reverse side. Whereas PGD was described as a step forward in terms of being one more (positive) alternative, this alternative also entailed certain kinds of possible trauma, which needed to be taken into account. Whether the alternative of PGD was perceived as eligible or not, depended on how the women and men concerned judged personal traumas – physical as well as mental. The alternative of IVF and PGD was described as physically and psychologically painful and risky (Interviews 1, 3, 4, 7, 9, 13, 15). As phrased by one interviewee, "to superstimulate, to take hormones... It's your life you're playing with, you prefer this [if you use IVF and PGD]" (Interview 3). Furthermore, some couples went through several IVF and PGD procedures in order to get a healthy child, without success. "Each time," one interviewee commented upon these situations, "it becomes more and more traumatic. They experience the first child's death again and again [when embryos do not implant]" (Interview 8).

Consequently, PGD may be understood as a means to increase the number of eligible alternatives for some, but not for all, and there are reservations to be made when it comes to PGD as a means to enhance reproductive autonomy. It can be seen as an alternative for some couples, namely for couples at high risk regarding a number of genetic diseases, who long for biological healthy children, who can accept the idea of embryo disposal, and who consider the personal trauma as acceptable. For these, there is an alternative to chance as well as to prenatal genetic diagnosis and termination. The possibility of using PGD cannot be understood as enhancing reproductive autonomy in general.

Returning to the elaboration of the definition of reproductive autonomy and the discussion of possible constraints on such autonomy, personal (physical, but primarily mental) traumas of different kinds can hamper the *ability to make autonomous decisions*. This is so if such traumas influence the will of the woman and/or man concerned.

B. Correct information is commonly put forward as a prerequisite for autonomous choice in general and for reproductive free choice in particular. Within the IVF and PGD context, I understand this as implying that physical/psychological risks as well as the low success rate are made explicit. Alternatives, such as donor insemination, adoption or neonatal surgery, need also to be verbalised and discussed. Risks of getting too much or too little genetic information need to be clarified. Whereas these elements of disclosure of information may seem obvious in theory, this was, again, not necessarily so in practice.

Interviewees recalled situations where undesirable information had been obtained, where too much or too little information had been obtained, as well as situations where alternatives had not been discussed with the same caution and care as in the case of IVF and PGD. Such sections within the interviews have been labelled *narratives of unease*, and interviewees expressed different kinds of unease (varying from vague mistrust to explicit fears). Unease within the interviews was sometimes present in the form of worries that certain kinds of reproduction technologies would be misused, resulting in a lessened genetic variation in human beings. Unease was sometimes ontological, as in sections where interviewees expressed their concern that the use of technologies would change the conditions of human life in a fundamental way, and stated that a specific use was “hubris” and a matter of “substituting” or “playing God.” An ontological unease, as I use the notion, was also present in sections where interviewees expressed their worry that there was “nothing beyond” a certain intervention (in this case germ line gene therapy), if interpreted as a worry that if there was nothing beyond, this would change our way of understanding ourselves. Of special interest for the present discussion is the epistemologically based unease: unease evoked by our present level or lack of knowledge, in different senses.⁵ Two specific examples of an epistemologically based unease will be explored.

First, such unease was evoked by actions or omissions of actions performed by interviewees themselves or by colleagues. Professionals at PGD units might have, unconsciously, a “vested interest” in performing and developing the technology or, as one interviewee put it, “we got caught up in the enthusiasm of PGD actually working” (Interviews 9, 8. Also interviews 1, 2, 13). Such unease was evoked and articulated when interviewees felt that too little or too much genetic information was obtained, as well as when alternatives were not clarified enough.

Second, an epistemologically based unease was evoked when little knowledge *could* be obtained about future developments and when couples nevertheless needed to make decisions concerning whether to wait for the diagnostic method to be available for them, or to abandon the idea and go on with their lives. Some couples, one interviewee reflected, risked living in a constant pause, a stage of waiting, which might

become a way of living, as a result of its taking longer than first anticipated for new therapies to emerge. Couples put their “lives on hold:”

We’ve had couples wanting Huntington’s testing for five years and we keep saying we’re nearly there, we’re nearly there, and we’re not there yet. I think they’ve put their lives on hold until it’s available, so I think that the prospect that PGD might be there is more harmful for those couples because they can’t get on and decide to have a family or do prenatal diagnosis and termination. (mm) They can’t move because PGD’s not there for them yet (Interview 8).

This unease concerns the limits of knowledge, the present level of knowledge, and the uncertainty in terms of how to judge the latter.

Interviewees’ narratives of unease indicate the existence of a gap between theory and practice, due to lack of correct information in different senses. In theory, correct information was understood as a prerequisite for autonomous choice. In practice, correct information was not easily obtained or given.

Again, reservations need to be made when it comes to PGD as a means to enhance reproductive autonomy. If reproductive autonomy can be said to be enhanced, this is only so in certain situations. Correct information is not always given and cannot always be given – because of e.g. technological failures – even though the possession of such information is presupposed in theoretical discussion of autonomy.

When correct information is not given, or when too little information is given, this also has consequences regarding whether couples can be described as having the ability to make autonomous decisions. Lack of knowledge can thus be an internal constraint on the *ability to make a decision*, just as was the case in the discussion of personal trauma.

The analysis of interviews presented here shows that the ability to make a decision can sometimes, for some people, be understood as constrained. For these couples, under these conditions, reproductive autonomy cannot be said to be present.

Empirically-based Criticism No 2: The Paradox of Increased Choice

The assumption that increase in choice, if offered without coercion, is desirable, may seem plausible at first sight. However, increased choice, in the sense of more and different alternatives to choose among as well as choice that must be made in an earlier stage than prenatal diagnosis, may also have negative consequences. Depending on how serious such consequences are considered, increased choice may be considered as undesirable (compare Dworkin 1988; Hildt 2002).

In the interviews, negative consequences of increased choice were typically framed as constraints on couples’ free choice not to choose. Constraints were also

described as due to structures, due to medical professionals' desire to help, due to pressures in society and due to technology as such. Five examples of constraints will be given:

A. Some interviewees stated that information *as such* biased a given situation. Information about a medical technology led to unfreedom. "It sounds so good," one interviewee explained, "you don't hear this unfreedom when you speak about it. You are just informing, and it is their choice" (Interview 13). Information about choices, this interviewee explained, forced couples to make choices. Should they listen to the information? How should they judge the information and should they base their decisions on it? Increased choice through the availability of IVF and PGD could not only have negative consequences for couples who did not want to decide whether to use PGD or not, but also for other family-members. Information about genetic diseases not only said something about the genes of the person concerned, but also about the genetic disposition of siblings. Their possible choice not to know could also be rendered more difficult.

When it comes to information as such, which forced couples to make certain choices, references can be made to the previous discussion of lack of knowledge as a constraint on the power of self-government and, more precisely, on the *ability to make reproductive autonomous choices*. If a couple do not wish to take a stand, do not wish to decide, this in itself can be an autonomous choice. However, if information as such forces them to do what they don't want – to explicitly decide whether or not to use PGD – then this is an example of how information hampers the ability to decide not to decide. Paradoxically, increased choice, through the availability of IVF and PGD, may (not only have negative side-effects for some persons, but also) result in constraints on free choice.

B. Interviewees also described autonomous choice as constrained as a result of the *structures* in which PGD was offered. PGD units in Britain and Sweden are centralised and only a few such units exist. This, interviewees explained, had not only consequences for how regulations were handled, but also for what took place in the clinical encounters. Normally, interviewees explained, when a couple wanted to use PGD and when the medical professionals at their local hospital considered this as appropriate, the professionals got in contact with the PGD unit and made sure that PGD was available for that specific condition. In practice, these structures (though important with regard to having national control over what was offered, under what circumstances, and by what means) hampered the possibility of free choice. Couples needed to be very verbal and convinced that they wanted PGD in order to be sent to PGD centres in the first place. They could not articulate their possible concerns or

worries, because if they did, they might not be offered PGD (Interview 8). Whereas the possibility of IVF and PGD increased choice (in terms of more alternatives), autonomous choice in terms of what worries couples could express was hampered.

If couples do not feel free to express their possible worries (even though they want to use IVF and PGD), this results in a lessened *opportunity to make thought-through, autonomous choices*. Consequently, this kind of constraint, which may force couples to sound as if they are convinced of what they want, is a constraint on the power to make autonomous choices.

C. Interviewees also described the process of IVF and PGD as complex. Medical professionals needed to be reassured that the woman and man concerned knew what they wanted. This, one interviewee explained, might lead professionals at PGD units to “push” couples, to make them sound more convinced than they were:

We are almost supporting them ... pushing them towards it. Of course, they're going to be, if they want something they're going to be very vocal about it, because they have to have been quite vocal and persistent to have got as far as us (Interview 8).

Constraints in terms of being “pushed” in a certain direction were, in this excerpt, described as due to the actions of medical professionals themselves. Again, the need to be persistent and vocal had consequences for how PGD was discussed. The interviewee continued:

So they're never going to say to the doctor, 'I think I want to have this.' You know, they might not turn up for treatment but they are going to have to say, 'We really want this, we must have this now,' and so then we end up saying 'Yes, you must have it now.' Before you know it, we've done the treatment. Well ... we never stepped back to say, you know just because they wanted it, was it the right thing to do for that individual (Interview 8).

If medical professionals push couples (even though indirectly and unconsciously), as described by the interviewee, this can be understood as an example of a constraint on the power of self-government. As in scenario B above, this is a constraint on the *opportunity to make autonomous decisions*. Such constraints do influence the process of decision-making.

D. Constraints on increased choice may also be due to changes in societal attitudes. This view was expressed by some of the interviewees, and described as problematic. The decision made by the couple to use PGD or not was seen as embedded in other

human beings' representations and ideas, and in "attitudes in society." Few women who had given birth to children with genetic diseases or impairments managed the feeling of guilt, of having done something that "society does not approve of," according to one interviewee (Interview 13).

The view that responsible parenthood consisted in parents' taking the responsibility to make sure that children were not born with genetic diseases, when this was preventable, was not articulated as a view from medical professionals themselves, but as a reflection coming from the couples. This view is also articulated and discussed by some bioethicists in terms of whether this results in less social help – individuals should not complain, but face the consequences of their actions. According to Henk ten Have (1997), society's moralising of the individual's responsibility will lead to further emphasis on the importance of genetic testing - and in that case also, I would add, to further constraints on choice.

If societal attitudes are understood as constraints on reproductive autonomy, they are so to the extent that they hamper couples with regard to *making a certain decision* (e.g. when couples see a certain decision as being too difficult to live with in a certain society). Societal attitudes, if influencing the legal system, may also hamper couples with regard to executing certain decisions. If so, they do not have the *opportunity to exercise* their power of self-government.

E. Finally, interviewees described pressures and demands on couples as a consequence of the very existence of the technology. One interviewee explained that some couples seemed to feel that they should use IVF and PGD, since the technology existed. Probably, the interviewee said, some couples could have accepted not having more children, or having gamete donation, or adopting if their condition allowed them to adopt, but "because a technology is offered to couples, and there is support of the doctors offering it, couples start to choose options that they might never have wanted." "Simply," the interviewee continued, "because this technology is there, many couples seem to feel that they must take it, that they are denying their future children [something] if they don't take it" (Interview 8).

The technological imperative, the view that a certain technology should be used since it is available, is commonly attributed to certain researchers who develop technologies (see e.g. Hottois 1998), but this interviewee described it as a part of the couples' reflections. In this description, the value of technology seemed to have been internalised by some of the couples concerned. It was not only an option, but something that should be used. If not, PGD might even be guilt-engendering: couples denied their future children something. In this sense, free choice was experienced as constrained.

Interestingly, this interviewee described the use of IVF and PGD as therapeutic, even when PGD did not result in the birth of a healthy child. Some couples who had tried PGD felt then that “they’ve done everything. They can’t say they didn’t try” (Interview 8). The feeling was described as one of relief. Couples could go on with their lives. In this reflection, the question seemed not to be whether the development of PGD as such should be questioned due to this consequence - rather, PGD was considered as positive since it was the last resort. Having tried this last technology, couple could relax. They had faced and tried the available alternatives, they did not need to make any further choices. Choice, it seems, has become a burden.

The internalised technological imperative could be understood as an internal constraint in a psychological sense. It is internal - internalised - as a moral imperative, and couples feel that they need to, or should, follow it. In this sense, an internalised technological imperative may hamper the *ability to make autonomous decisions*.

As can be seen, increased choice in terms of the further possibility of choosing to use IVF and PGD sometimes transforms itself into a constriction. Choice is increased in terms of there being one more alternative, but this increased choice also hampers certain choices. This is the *paradox of increased choice*. Additional alternatives enhance the range of possible choices. Though positive at first sight, this increase in choice may be psychologically stressful for couples concerned, choices may as such be morally difficult, and choices may be illusory (in the sense that choices presented are not real choices, structures hamper choice). The notion of reproductive autonomy needs, again, to be qualified if the empirically based criticism is to be taken seriously. Vague and sweeping uses of the notion need to be avoided, and reproductive autonomy can only be understood as plausible in practice to a limited extent. As can be seen, examples can be given where either the ability or the opportunity to make a reproductive autonomous choice is hampered, as well as examples where the opportunity to realise such a choice is hampered.

How serious are the criticisms?

As shown, there is a gap or a discrepancy between theory and practice, between ethical analysis when kept on a theoretical level and the experienced ethical dilemmas as perceived by medical professionals. In theory, it is easy to hold that respect for autonomy is one of the most important bioethical principles. In practice, the possibility for couples concerned of making autonomous choices can be questioned (even though such a possibility is a prerequisite if the principle is to be realised). Increased choice in terms of one more option may also, paradoxically, result in constraints on free choice. Couples become obliged to choose whether or not to use the technology, and they may be constrained in their discussion with the medical professionals, in terms of what they say (even if it may be held that saying no to the use of IVF and

PGD can be done early on in a genetic counselling). These kinds of criticism – the gap and the paradox of increased choice – show that reproductive autonomy can only be understood as plausible to a limited extent, i.e. under certain conditions, when neither ability nor opportunity to come to a decision and to realise the decision are hampered. The empirically-based criticism also show that talk of autonomy within reproductive medicine in general can be misleading. The notion of reproductive autonomy needs to be used with care and caution.

Criticism of the gap between theory and practice can be understood as an argument for trying to improve the conditions for choices in reproductive medicine. If this argument is accepted, efforts are made to change practice and to make it resemble theory. (Likewise, to some extent, constraints on couples may be lessened through changes in structures, through an enhanced awareness of the complexities in the clinical encounter etc). Criticism of the perceived gap can also be understood as an argument for changing the ethical analysis on a theoretical level. This could be done if referrals to autonomy are performed in a careful dialogue with practice.

The constraints on reproductive autonomy, which showed that ability and opportunity to make certain decision and the opportunity to exercise the decision could be hampered, may be understood as an important impetus for further discussions in genetic counselling, on a clinical level as well as on the level of policymaking. Within bioethical reasoning, the principle of respect for autonomy seem either to be understood as a right that should be respected, or as an ideal, that should (ideally) be respected. In both cases, this presupposes that reproductive autonomy is possible. As shown, this is not always the case.

Summary

Is autonomous choice in preimplantation genetic diagnosis mere rhetoric, is it a difficult but important ideal, is it a long-cherished illusion, is it a viable possibility or even an existing, substantive element in most uses of PGD?

Reproductive autonomy, it was held, can be understood as power and as exercised power. Reproductive autonomy as power (to make decisions) presupposed ability and opportunity of the person concerned. This was also the case if reproductive autonomy as exercised power was to be possible. Through an analysis of performed interviews, two kinds of criticism emerged. Criticism was directed at the gap between theory and practice, and at what was called the paradox of increased choice. It was argued that, at least, reproductive autonomy as power and exercised power could not be understood as present in reproductive medicine in general. It was also held that empirical research could be important in the theoretical discussions.

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- ¹ Cf. Buchanan *et al* explicitly refer to Robertson's definition and state that reproductive freedom is equivalent with procreative liberty (Buchanan, A., D.W. Brock, N. Daniels and D. Winkler: 2000, *From Chance to Choice*. Cambridge: Cambridge University Press p.206).
- ² It is argued that the promotion of reproductive autonomy as a right veils the existence of privileged positions, which still belong to men, as a group, to a larger extent than to women, as a group. The right to use any reproductive procedure and any means involved in such a procedure, as stated by Robertson, through reproductive contracts, is also criticised for hiding the existing individuals who become the means. Within reproductive medicine, the means are often women's bodies (Raymond 1995).
- ³ Interviews are performed within the project *Lifeviews, Human Nature and Genetics*. Semi-structured qualitative research interviews have been performed with six Italian, six Swedish and six British medical geneticists and gynaecologists. Medical professionals that work at PGD centres and professionals that work at departments of gynaecology or medical genetics in general (and not at PGD centres) have been interviewed.
- ⁴ In these cases, the specific genetic disease would affect all boys being born, whereas girls being born would be carriers of genes for the disease, but not necessarily affected.
- ⁵ My use of distinctions is inspired by Åkesson's (1997) use of different kinds of fears evoked by cloning (e.g. biologically based fear, philosophical fear). (Åkesson. L.: 1997, "Klona skapelsens krona?", *Klona skapelsens krona? Forskare kommenterar kloning av djur och människor*. Stockholm: Forskningsrådsnämnden).

References

- Beauchamp, T.L and J. F. Childress: 1994, *Principles of Biomedical Ethics*. New York/Oxford: Oxford University Press.
- Dworkin, G.: 1988, *The Theory and Practice of Autonomy*. Cambridge/New York: Cambridge University Press.
- Ten Have, H.: 1997, "Living with the Future: Genetic Information and Human Existence", in R. Chadwick, M. Lewitt, and D. Shickle (eds.), *The Right to Know and the Right Not to Know*. Aldershot: Ashgate.
- Hildt, E.: 2002, "Autonomy and freedom of choice in prenatal genetic diagnosis", *Medicine, Health Care and Philosophy* 5/1.
- Handyside, A.H; Pattinson, J.K; Penketh, R.J; Delhanty, J.D; Winston, R.M and E. G Tuddenham: 1989, "Biopsy of Human Preimplantation Embryos and Sexing by DNA Amplifications", *Lancet* 1.
- Hottois, G.: 1998, "Regard rétrospectif d'un philosophie", *Journal International de Bioéthique* 9/1-2.
- Nordenfelt, L.: 2000, "On the Complexity of autonomy", *Action, Ability and Health. Essays in the philosophy of action and welfare*. Dordrecht: Kluwer Academic Publishers.
- Raymond, J. G.: 1995, *Women as Wombs. Reproductive technologies and the battle over women's freedom*. North Melbourne: Spinifex Press.
- Dahl Rendtorff, J. and P. Kemp: 2000, *Basic Ethical Principles in European Bioethics and Biolaw Vol I: Autonomy, Dignity, Integrity and Vulnerability*. Copenhagen and Barcelona: Centre for ethics and law and Institut Borja de Bioètica.

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- Robertson, J.: 1986, "Embryos, Families, and Procreative Liberty: The Legal Structure of the New Reproduction", *Southern California Law Review* 59.
- Robertson, J.: 1994, *Children of choice: freedom and the new reproductive technologies*. Princeton: Princeton University Press.
- Tong, R.: 1997, *Feminist approaches to bioethics: theoretical reflections and practical applications*. Boulder, Colorado: Westview Press.