Voices of experience in periviable decision-making and artificial placenta technology

Boer, A.H.A. de

Chapter 6

Capabilities and stakeholders – Two ways of enriching the ethical debate on artificial womb technology

André Krom; Angret de Boer; Rosa Geurtzen, Martine de Vries

American Journal of Bioethics, 2023

Commentary

The review by De Bie et al. (2022) provides an overview of the current ethical literature on artificial womb technology (AWT).[1] Two characteristics stand out, and provide the basis for our commentary. First, the normative framework used to structure the ethical issues of AWT largely aligns with the traditional four bioethical principles: beneficence, non-maleficence, respect for autonomy and justice. We believe that the debate can be enriched by viewing AWT through the lens of a broader normative framework: the capability approach, which focuses on the freedom to achieve wellbeing. Second, the existing literature upon which the review is based, is mostly theoretical. No empirical data on stakeholders' perspectives were included, although the authors acknowledge their relevance. We believe that empirical studies are crucial in responsible innovation.

Our focus will be *narrower* than De Bie et al's in one respect: while the authors cover 4 domains in which AWT could theoretically be used, we will focus on domain III (peri-viability), because the current development of AWT is aimed at potential treatment for extreme prematurity. We think it is important to take a concrete technology as the starting-point of co-creating responsible AWT.

Capabilities: enriching the normative framework for thinking about AWT

It is common to refer to the established four principles of biomedical ethics when identifying ethical issues in healthcare. In mapping the ethical issues of AWT, De Bie et al. consistently refer to considerations that largely align with the traditional principles of biomedical ethics, with "Potential Benefits and Harms" referring to beneficence and non-maleficence; "Decision-Making Authority of Parents" and "Legal Status and Protections'' signalling respect for autonomy, and "Fairness of Access" indicating justice.[1]

We believe that the debate on AWT ethics can be enriched by embracing a broader normative framework. Crucial is the fact that wide variety exists between people regarding the extent to which they are able to *convert* certain (healthcare) means into outcomes that they value most. This might for instance be due to personal or social "conversions factors". Examples of personal factors that influence the achievement of desired outcomes include our physical condition and literacy . Examples of social conversion factors include social norms, and power relations.[2]

The capability approach, highlighting the importance of conversion factors, is a particularly well-suited framework for normative reflection on developing technologies for the purpose of health and well-being,[3] such as AWT. It is a theoretical framework centered around two normative claims. First, it is of primary moral importance for individuals to have the freedom to achieve well-being. Second, well-being should be understood in terms of "capabilities" and "functionings".[2] Capabilities refer to the real choices or opportunities available to people in leading the life they desire, while functionings are the tangible forms

of "doing" and "being" that individuals actually realize, if they so choose. By focusing on what people can actually do and be, in addition to the distribution of goods and resources, the capability approach recognizes that people can differ greatly in their ability to convert those goods and resources into real opportunities and achievements, that is, the kind of life they can effectively lead.[2]

Table 1 provides an overview of capabilities that, according to Martha Nussbaum, are central for people to live a worthy life (as judged by themselves).[4]

Table 1: Central human capabilities established by Nussbaum (2011)4

Central human capabilities established by Nussbaum:
(1) Being able to live to the end of a human life of normal length; and not have one's life reduced to not worth living.
(2) Being able to have good health (including the possibility to reproduce).
(3) Being able to maintain bodily integrity.
(4) Being able to use the senses, imagination, and think and have the ability to express yourself.
(5) Being able to have emotions and emotional attachments.
(6) Possess practical reason to form a conception of the good; being able to plan your own life or form a conception of the good.
(7) Have social affiliations that are meaningful and respectful.
(8) Express concern for other species and being able to have relationships with the natural world and to care for other species.
(9) Being able to play or laugh; to enjoy recreation activities.
(10) Have control over one's material and political environment, being able to meaningfully participate in decisions concerning one's environment.

Capabilities are helpful to formulate what – from the perspective of human flourishing – is at stake in considering AWT. For instance, the risk of dying prematurely threatens the capability of being able to live a human life of normal length (1); potential complications caused by extreme premature birth might thwart the capability of being able to have good health (2); a caesarean is needed for AWT to succeed, raising issues concerning the capability to maintain bodily integrity (3); being separated as part of the AWT procedure raises issues concerning emotional attachment (5), et cetera.

Real freedom to achieve well-being requires more than providing people with goods and means and having them choose. *Figure 1* summarizes how conversion factors may prevent or promote our real freedom (capabilities) to convert resources into desired outcomes (functionings), if we so choose.

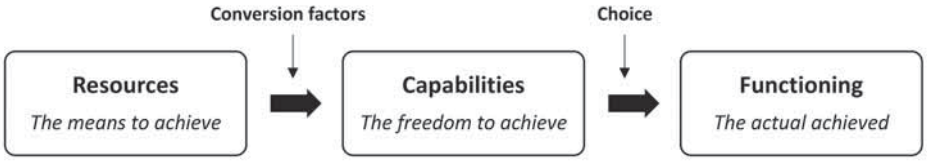

Figure 1. The relation between resources, capabilities and functioning; based on Robeyns (2005).5

This has direct implications for how to deal with the traditional four medical-ethical principles. First, it shows that caring about beneficence and non-maleficence, and an optimal

balance between the two, requires accounting for positive and negative conversion factors. That is also crucial for respecting autonomy and for acting justly. For even if equal access to AWT is guaranteed (justice, as interpreted by De Bie et al.)[1], this does not mean that only an informed choice is standing in the way of a person's wellbeing. The freedom to achieve wellbeing at the very least requires remedying negative conversion factors, also a matter of justice.

The following examples from domain III (peri-viability) show how the capability approach can complement the results of the review of De Bie et al.[1] Regarding justice, while the authors focus on fair access to AWT, broader considerations of justice also include questions like whether society should invest in improving antenatal care instead of developing AWT. If promoting real freedom to achieve wellbeing is our aim, AWT is one option among several others.

Beneficence and non-maleficence are mostly discussed in (narrow) medical-technical terms, focusing e.g., on the viability of the foetus and potential complications of extreme prematurity. The capability approach places these considerations in the context of human flourishing, providing a more comprehensive and nuanced perspective on the potential effects of AWT on the foetus and the mother. It also enriches the interpretation of pros and cons of the technology by thinking through conversion factors that could hamper our freedom to achieve well-being. For example, what if you survive with handicaps through AWT, but later in life medical and social support is insufficient (sociopolitical conversion factor). It shows that AWT is not a stand-alone solution but needs to be incorporated in a broader system of healthcare.

De Bie et al's discussion of "Decision-Making Authority of Parents'' focuses on the autonomy of the pregnant person.[1] However, the capability approach recognizes that social norms and expectations (e.g., about responsibilities), as well as power relations and pressure can be sociopolitical conversion factors that can hinder the pregnant person's freedom to achieve well-being. These are relevant ethical issues (e.g., in the context of the necessary caesarean), even if they do not preclude being able to provide informed consent.

In sum: the capability approach allows for a richer and more comprehensive normative evaluation of AWT, compared to the traditional four principles.

Stakeholders: enriching the ethical debate on AWT with empirical research

The ethical debate about AWT can also be enriched by including empirical ethical research. We believe this is a crucial element of responsible innovation. Constructively engaging various stakeholders in an early stage allows us to identify potential concerns, and to ensure that the technology is developed and used in line with relevant ethical values and considerations.

A Guidance Ethics Approach (GEA) is well-suited for investigating what is of moral significance in developing and using AWT according to directly affected stakeholders.[6] GEA recognizes that technology can have a large impact on society and individuals, and therefore seeks to ensure that its development is guided by ethical considerations and is aligned with stakeholders' values as much as possible.

The GAE typically takes the form of a stakeholders' workshop with representatives of patient groups, (medical) professionals, technologists and managers/policy-makers. Participants go through three stages, and provide the normative content. *Figure 2* provides an overview. .

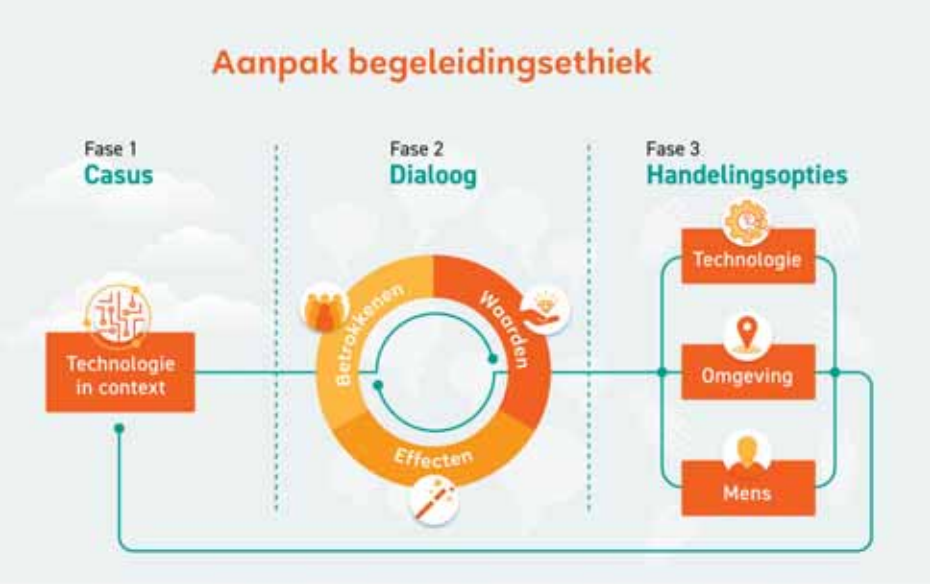

Figure 2 The process of Guidance Ethics6

A Guidance Ethics workshop results in:

- A clear description of a concrete technology and the context in which it can be used (Stage 1: Technology in context);
- A list of (a) actors whose viewpoint should (also) be taken into account, (b) potential effects of using the technology in this context, and (c) which values are at play (Stage 2: Dialogue);
- A list of options for action (Stage 3) that could support responsible innovation, by changing the technology (*ethics by design*), by changing the 'environment' in which the technology is used (e.g., issuing guidelines) (*ethics in context*), and/or by empowering those using the technology e.g., through learning new skills (*ethics by user*).[6]

Guidance ethics⁺: combining guidance ethics workshops with the capability approach

The capability approach enriches the ethical landscape of AWT. It invites us to look at relevant conversion factors, with the aim to promote the individuals' real freedom to lead fulfilling lives, as judged by themselves. The latter requires empirical ethical research. The GEA provides a structure for constructively including the viewpoints of stakeholders. This will help to examine which capabilities and functionings are particularly important in the case of AWT, and which options for action could promote the desired functionings as identified by the stakeholders.

We call the combination of the Guidance Ethics Approach with a substantive normative framework such as the capability approach: Guidance Ethics⁺. This approach will be taken in a project on AWT in which Leiden University Medical Center and Radboud University Medical Center cooperate.

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