Artificial placentas, pregnancy loss and loss-sensitive care

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ABSTRACT

In this paper, we explore how the prospect of artificial placenta technology (nearing clinical trials in human subjects) should encourage further consideration of the loss experienced by individuals when their pregnancy ends unexpectedly. Discussions of pregnancy loss are intertwined with procreative loss, whereby the gestated entity has died when the pregnancy ends. However, we demonstrate how pregnancy loss can and does exist separate to procreative loss in circumstances where the gestated entity survives the premature ending of the pregnancy. In outlining the value that can be attached to pregnancy beyond fetal-centric narratives, we illustrate how pregnancy loss, separate to procreative loss, can be experienced. This loss has already been recognised among parents who have experienced an unexpected early ending of their pregnancy, resulting in their child being cared for in neonatal intensive care unit. Artificial placentas, however, may exacerbate these feelings and make pregnancy loss (without procreative loss) more visible. We argue that pregnancy is an embodied state in which gestation is facilitated by the body but gestation itself should be recognised as a process—and one that could be separable from pregnancy. In demarcating the two, we explore the different ways in which pregnancy loss can be understood. Our objective in this paper goes beyond contributing to our philosophical understanding of pregnancy towards practical-orientated conclusions regarding the care pathways surrounding the artificial placenta. We make recommendations including the need for counselling and careful consideration of the language used when an artificial placenta is used.

INTRODUCTION

Since successful animal trials of an artificial placenta in Philadelphia in 2017,[1] there has been considerable academic interest in technologies capable of facilitating gestation extra uterum. Partial ectogestation—the use of Artificial Amnion and Placenta Technology (AAPT)[2] to 'take over' gestation where a pregnancy ends prematurely[3]—is an increasingly imminent prospect.[4] Researchers in Philadelphia are anticipating that clinical testing on human preterm neonates will begin in 2024.[5] AAPT has the potential to revolutionise our approach to treating prematurity,[3] which is the leading cause of neonatal deaths across the globe.[6] This technology should be welcomed for its potential to address the morbidity and mortality of preterm neonates, alleviate the suffering of putative parents and limit the consequences of dangerous pregnancies.[3] There is a growing body of literature that examines the benefits and complexities of AAPT-facilitated partial ectogestation and we add an important and unique perspective. Drawing on parents' experiences of neonatal intensive care units (NICUs), we examine how the use of AAPT may contribute to feelings of 'pregnancy loss' even where there is no fetal/neonatal death.

Most discussion of pregnancy loss is focused on instances in which pregnancy loss is also procreative loss; the death of the developing human entity coincides with the ending of pregnancy. We explore the phenomenon of 'pregnancy loss' literally; meaning loss associated with the unexpected ending of a pregnancy before 'full term' even if the entity survives. We examine this potential experience of loss to consider the implications of AAPT for pregnant people.[i] We advocate for the importance of designing care pathways that are attentive to pregnant people's needs,[ii] including the provision of information, language and counselling surrounding the use of AAPT. This will optimise the care provided to, and minimise any negative mental health implications for, pregnant people.

In section I, we explain 'pregnancy loss' without 'procreative loss.' In section II, we highlight pregnant people's experiences of pregnancy loss where a pregnancy ends prematurely, and their child is admitted to NICU. In section III, we use AAPT to illustrate the distinction between pregnancy and gestation. In section IV, we argue that where AAPT is used, some (formerly) pregnant people may experience loss of their pregnancy where gestation is continued ex utero and that the feeling of loss may be more amplified than those described about NICU (section V). The normative implications, as we illustrate, are in how care pathways for AAPT are designed. We make no comment on who can or should be able to access AAPT, rather our reflections

[i]We use gender neutral language to describe people with the capacity to become pregnant. We do so in recognition of the fact that the term 'woman' is both under-inclusive (trans men and non-binary people can become pregnant) and over-inclusive (many women cannot become pregnant for a variety of reasons). See Ross and Solinger. *Reproductive Justice: An Introduction*, Oakland: University of California Press, 2017. This is particularly important to note in the context of loss because transmasculine and nonbinary people often have their experiences marginalised and, in this context, that could compound the difficulties of procreative loss: Riggs D, Pearce R, Pfeffer C, *et al*. Men, trans/masculine, and non-binary people's experiences of pregnancy loss: an international qualitative study. *BMC Pregnancy and Childbirth* 2020 20: 482.

[ii]On the insistence of a reviewer, we acknowledge that we use the term 'need' here deliberately. 'Need' should be taken to encompass individual preferences in some circumstances. It is a problem that in clinical spaces and ethical literature preferences and needs are understood to be dichotomous. See Romanis EC. Appropriately framing maternal request caesarean section. *J Med Ethics* 2022; 48:554–556.

are about how the process of AAPT is designed and managed for people who use it. This is important to minimise any potential harm to pregnant people by ensuring proper regard is paid to their experiences, physical and psychological health and to their reproductive needs. We conclude that, consequently, the development of AAPT care pathways must be attentive to potential experiences of pregnancy loss.

Pregnancy loss without procreative loss

A wanted pregnancy is often assumed to have one objective: to become a parent.[iii] However, Lindemann explains that there is more than one source of value in a wanted pregnancy: '(a) the fetus and (b) the pregnant woman's activity'.[7][iv] She explains that for the pregnant person a wanted pregnancy has value as a process of 'calling a fetus into personhood' in doing the work of creating 'a place in the social world for the developing child to occupy when it is born'.[7] While it is intuitive to recognise multiple sources of meaning in a wanted pregnancy, we suggest that Lindemann's approach fails to do this because it is fetal-centric. Even in describing the value of pregnancy work Lindemann bases the value of that work in the fetus (pregnant individuals work to make space for the fetus in their social world because they see the fetus as a part of their future). An account that also attends to the intentions and experiences of pregnant people, we suggest, goes further in understanding how and in what ways a pregnancy is valued.

There are two sources of value in a wanted pregnancy that we suggest should be recognised.

First, is a future of parenthood: this is the value that a pregnant person places in having a future parentable entity.[8] The fetus is valuable to the pregnant person as the potential of their future parenthood. This value is not something necessarily unique to the pregnant person and is something that is recognised by other persons who intend to parent (eg, a second parent). We believe this value to be uncontroversial in *wanted* pregnancies, even if it is not experienced by all pregnant people.[v]

Second, is the exercise of a creative power in pregnancy: this is the value the pregnant person places in the activity of pregnancy itself such as using one's bodily resources to create their future.[9–11] Every pregnancy is a 'physically innovative act'.[12] Yet, there is a tendency to treat pregnancy as a passive activity and pregnant people are often referred to as 'expecting' as if they are merely waiting. However, Young explains that:

> The pregnant woman experiences herself as a source and participant in a creative process. Though she does not plan and direct it, neither does it merely wash over her.[13]

As Woollard has argued, pregnancy is an epistemically transformative experience.[vi] One has first-hand knowledge about what it is to be pregnant only with/after being pregnant.[14] She explains, 'pregnancy includes: (1) multiple unexpected bodily sensations and physical changes to one's body (that occur in different people and different pregnancies in different ways); (2), having what will become another person growing inside one's body; (3) changes to one's relation to oneself and one's body resulting from (1) and (2)'.[14] These unique and interacting experiences are hard to grasp without also having the epistemically transformative experience of being pregnant. For some, there will be considerable epistemic value in obtaining this knowledge as a part of experiencing a creative power:[vii] having been pregnant means having knowledge about what it is to do the generative work of creating a new human entity using one's body.

There are some who value the experience of being pregnant—specifically undertaking the exercise of creation themselves—very highly. In qualitative studies, some pregnant people describe their embodiment as intrinsically linked to this creative power. For example,

> *'I was thinking; 'there is a human being developing here, and my body is doing it!' It is phenomenal! There is nowhere else that can actually incubate and grow a human being, that's what your body does. I was nourishing it, and it was just amazing … it's mind blowing.'*[15]

Some individuals may be unable to gestate but want the epistemically transformative experience of being pregnant to such a degree that they may seek out uterus transplantation to fulfil their wish not just to have their own child, but to have this transformative experience.[16–19][viii] Furthermore, there are people who find pregnancy to be a rewarding experience and describe a willingness to help people unable to gestate through pregnancy work (surrogacy).[20]

In describing these two sources of value, we are not speaking universally of all people, and all wanted pregnancies.[ix] As one of us has argued with others elsewhere, 'reproductive consciousness is individual, complex and corporeal and thus is difficult to generalise'.[21] The fact is that '(n)o woman [or person with the physiology to become pregnant] and no pregnancy is the same as all others'.[22] There is no one way of viewing and experiencing pregnancy. Indeed, we consider it an important feminist commitment that we make space for contradictory experiences.[23] Although not seeking to essentialise and fetishise pregnancy to the exclusion of different experiences, our objective here is to consider the value that *some* people do invest in pregnancy beyond the fetus and to use this to reflect on how people may experience partial ectogestation.

In Euro-American cultures there is a tendency to negate the value that some people find in pregnancy as a process of creation. The focus, instead, is overwhelmingly on the outcome of the pregnancy, as the fetus is centralised in culture, law and

[iii] There are many cases in which this is not true: for example, where a person intends to assist another person in becoming a parent by acting as a surrogate, or because they intend to pursue adoption after birthing.

[iv] NB: Lindemann is clear that neither of these sources of value are sufficient to deny a right to abortion; we strongly agree.

[v] E.g., people who carry pregnancies as a surrogate or to pursue adoption may see no value in the pregnancy as a source of future parenthood for themselves but may still see value in the pregnancy as producing a future parentable entity for others.

[vi] It is important to emphasise that whether it is a positive or negative transformative experience will depend on a multitude of external factors—including whether the pregnancy is wanted. Because of the fundamental impact a pregnancy has on a person (among other things), we support abortion for persons who do not wish to be pregnant.

[vii] We are grateful to an anonymous reviewer for encouraging us to think about the potential epistemic value for some people here.

[viii] This is even though pregnancy following a uterus transplant will not result in the same physical experience of a pregnancy undertaken in a non-transplanted uterus. For example, they will not experience fetal movements as no nerves are attached to the uterus, although they will still be subject to morning sickness and fatigue (see Robertson 2016). Importantly, however, there are many aspects of pregnancy that uterine transplant can deliver that a person may value, for example, there may be psychosocial benefits from being seen to be pregnant by others (reference removed for anonymity).

[ix] In the interests of reflexivity, the authors feel it important to acknowledge that neither have experienced pregnancy which in itself may or may not impact their own views on this topic.

contemporary medical practice.[13 19 21] Premature birth is often reported as a traumatic experience, however, there is a tendency for a multitude of factors to be discussed together including the physical difficulties of a premature birth, fear for the life of the fetus/baby and the stresses of a child being treated in NICU. What is often not acknowledged, and rarely made explicit, is how there may be traumas associated with the premature ending of a pregnancy based on what pregnancy means to an individual.

In taking a non-fetal-centric approach to the value of pregnancy we can begin to understand how pregnancy loss can be experienced without death of the gestated entity. Persons can and do experience 'non-death related' loss in other contexts, for example where they experience a life transition—even ones that are welcomed or happy—such as marriage or living organ donation.[24] By acknowledging that value can be attached to pregnancy separate from the gestated entity, we can give due attention to the loss suffered by individuals when their pregnancies cease unexpectedly.[x] Recognition of the different reasons why people place value in their pregnancy makes visible that morally relevant reproductive experiences encompass more than just the outcomes of these experiences. These experiences are important to recognise, acknowledge and potentially make some adjustments for to minimise the potential for harm to pregnant persons. Being cognisant of experiences of pregnancy loss is important to understand the implications of AAPT for pregnant people. In the next section, we explore accounts of pregnancy loss without procreative loss in the context of NICU.

Pregnancy loss in NICU

Premature birth can exacerbate the difficulties in becoming a new parent and is commonly associated with a greater incidence of postnatal depression.[25] The notion of loss in relation to the unexpected ending of a pregnancy has been recognised among parents who have found themselves in need of using NICU following premature delivery. Golish and Powell, for example, use the term 'ambiguous loss',[26][xi] to describe how the loss experienced by parents after a premature birth is related to a loss of experience rather than a loss associated with a death.[27] It is the loss of a full-term pregnancy, particularly for the individual who was undertaking gestation, that can exacerbate feelings of grief.[27]

Similar experiences have been reported for individuals who have undergone unplanned caesarean deliveries,[28] with disappointment arising from not being able to give birth naturally and resulting in individuals *feeling* that their bodies had failed them.[28] Individuals have often been encouraged to 'downplay' these feelings of loss and disappointment and focus on the positivity of having a healthy infant.[28] In being torn between the happiness of the child being born and the lost opportunity of a 'normal birth', formerly pregnant people can find it difficult to balance feelings of both joy and grief,[27] and as result they can experience loss 'clouded with contradictions'.[28]

In creating inadequate space to acknowledge their losses, individuals' experiences are further exacerbated by feelings of shame. Not only does an individual feel shame for 'failing' to take a pregnancy to term they then undergo a double dosing of shame as they worry that their sadness about the premature ending of the pregnancy is perceived as ungratefulness at having a child that survived.[29][xii] The shame felt by individuals is also linked to narratives of being a 'good mother', which derive from fetal-centric discourses.[8] In reporting on experiences of 'caesarean shame', Keglowitsch and Meagher report that individuals felt they had 'failed in their first task as a mother'.[28] With an incorrect conceptualisation of women becoming mothers as soon as they become pregnant[13] as well as 'natural birth' often considered the ideal,[30] it is unsurprising that individuals feel a sense of failure when the pregnancy is not taken to term and birth plans are interrupted. In Moraga's autobiographical account of premature birth, we can see how experiences of loss become connected to 'guilt' towards the resulting child:

> *'What is hardest to write about is the loss I feel not having brought Rafael to full term. At times, I think it is loss, then wonder if it's really guilt I feel that my son had to go through so much suffering outside the womb because I couldn't protect him inside'.*[31]

Kamata, reflecting on her premature birth, likewise writes: '*If you could will them back into your body you would*'.[32] In both accounts, we can see that an individual's loss of experience of pregnancy could be viewed as a loss of the perceived ability to provide for their future child/child in the way that human gestation sustained by pregnacy allows. Individuals' inability to describe their own loss separate from the impact of prematurity on their infants is further evidence of the fetal-centric narratives that encompass social scripts around pregnancy and birth. Systematic studies of the experience of parents in NICU similarly reflect that new parents often express feelings of helplessness when they are not able to care for their infant.[33 34]

The complex feelings of loss that are attributable to premature birth are also intricately tied to the technology that supports the premature infant. In her ethnographic exploration of prematurity and race in the United States, Davis spoke to several participants who made a connection between feelings of loss and the role of the incubator. One participant, explained:

> *'I felt like my baby should be in my body and yet the baby was in the incubator. So, it was overwhelming to be hit with the visual of babies, multiple babies, as well as my baby in this thing* [the incubator] *that is doing its job. But it was doing my job. I felt a little ashamed, like I was supposed to be doing what the incubator was doing'.*[35]

Similarly, Digregorio describes how she viewed her body becoming replaced by technology after delivering prematurely:

> *'We were parents hooked up to machines…. All of those machines were replacements for what our bodies would have been doing, under different circumstances. The technology breathed for my baby, cradled my baby, and kept her warm… Sometimes I closed my eyes while pumping and imagined my body still connected to hers by a cord, a tube, anything'*[36]

These accounts describe suffering a loss of the ability to provide for the gestating entity through pregnancy. Further expressions of shame then arise from witnessing technology 'doing the job'

[x] Although many people experience changes in mood following any ending to a pregnancy, including those that come to an end in a planned and desired way (eg, through vaginal birth or caesarean section at full term)- our focus here is specifically on the emotional and physical experiences of pregnancy loss.

[xi] This term, they acknowledge, was coined by Boss.[27]

[xii] We recognise that there might be some sense in which some people feel deprived of a choice of birth for example, a birth of their choosing including mode of delivery and/or place of delivery. This is because they must have a certain type of birth (a caesarean section) to maintain fetal physiology for transfer to an artificial placenta. However, in this paper, we focus on a loss of pregnancy as in the loss of the embodied experience of sustaining a gestation.

that the (former) pregnant person may believe, based on cultural narratives, that they should be doing. We suggest that observing AAPT undertaking the gestational process that was formerly performed by the (formerly) pregnant person may incite feelings of guilt/frustration or even envy, particularly for those who desired to gestate to term. Narratives of guilt are, overwhelmingly, indicative of the social messaging around 'good mothering' and pregnancy, which is deeply problematic for its metaphysical inaccuracy and harmful implications.[8] It is important that we continue to challenge fetal-centric conceptions of pregnancy and especially so with developments like AAPT on the horizon because of the coercive implications these technologies can have if fetal-centric notions (like 'maternal-fetal conflict') continue to be propagated by legal, clinical and social institutions.[21 37] While we do address the deeply engrained social scripts around pregnancy and maternal self-sacrifice in this paper, our principal argument is that care pathways in relation to the development of AAPT should be attentive to experiences of pregnancy loss (whether they result from negative social messaging or sadness of the loss of the feeling of creative power and control over it that we outlined) to minimise any negative consequences for pregnant people.

In exploring the different elements of loss experienced by individuals who have found themselves in need of NICU, it has been demonstrated that individuals do experience pregnancy loss, even when the gestated entity survives. There are often local support groups for NICU parents.[38] A new law in Great Britain also supports additional paid employment leave for parents of NICU children.[39] However, these (important) sources of support remain focused on the *outcome* of the pregnancy (the baby after birth), rather than opening up conversations about the loss/grief that can be experienced where there is no procreative loss, but a person still experiences pregnancy loss. Rather than having the space to acknowledge and process this loss, feelings of shame and guilt overshadow and complicate the experience. It is often suggested that NICUs should be family-centred to help parents establish their role in caregiving towards the infant,[34 40] however, we endorse the provision of judgement free space for individuals to express their feelings and have them considered during their own recovery separately from the needs of the infant. Family-centred help could be reframed as an opportunity to help individuals work through their sense of loss by regaining some essence of control over the care of their child. In the following section, we explore this further by focusing on how pregnancy loss may be experienced when AAPT is introduced as a form of care for a premature infant. We first explore what AAPT is, how it renders more visible the distinction between pregnancy and gestation and its potential impact on the phenomenon of pregnancy loss without procreative loss.

Aritifical placentas and the distinction between pregnancy and gestation

Preterm birth is associated with high neonatal morbidity and mortality.[4] Some entities are born too physiologically immature to survive in the external environment and there are innate risks to NICU interventions including lung damage, infection and heart failure.[41] Researchers have, therefore, sought to develop new technologies that embody a paradigmatic shift to care of entities delivered extremely premature: rather than trying to facilitate incubation of extreme premature neonates, researchers are attempting to develop technology that can facilitate gestation outside of the body.[2 3] Most specifically researchers seek to duplicate the way in which a fetus breathes through its umbilical cord in the placenta. Rather than the lungs emptying of fluid during birth, fetal physiology is maintained by keeping the fetal lungs in a fluid-filled state.[1] The fetus is then submerged in artificial amniotic fluid and its umbilical cord is attached to an oxygenator pump. The aim is to increase the chance of survival and decrease the likelihood of morbidities that result from current conventional methods[3] and relieve the pressure on underdeveloped lungs.[41] Devices have demonstrated proof of principle of AAPT in animal models,[1 42 43] and if some of the technical[44] and ethical hurdles[45 46] in clinical translation can be overcome, they potentially have the capacity to revolutionise the treatment of prematurity.

With the advent of this technology, careful 'conceptual separation of gestation from pregnancy is imperative to prevent excessive social and legal regulation of pregnant people'.[47] Recognising the distinction between pregnancy and gestation—that AAPT enables us to see more clearly—is not just about protecting the rights of pregnant people but understanding how they might experience AAPT if their pregnancy ends prematurely. Gestation is the generative process between conception and birth. In gestation, a conceptus transforms into an entity with fetal physiology that, where possible,[xiii] can become adapted to the external environment as the process ends.[45] The process of gestation takes place within humans, as a result of evolution,[xiv] sustained by a pregnant person in the *state* of pregnancy. Pregnancy is the state that the body is in when supporting gestation. Being in this state (pregnancy) is an active biological undertaking even if not conscious. The state of pregnancy may have ambiguous boundaries. Some people may consider themselves still to be pregnant when they have birthed their fetus, but the placenta remains in their body.[xv] Equally, the body may be in a pregnant state where there is no fetus gestating, for example, in cases of gestational trophoblastic disease.[xvi] These cases exemplify the distinction; gestation is the process, and pregnancy is a state of being.

While pregnant, a person undergoes significant structural and physical transformation to enable a successful gestation. Their body is in a different condition (sometimes described as 'an inflammatory state')[48] than when it is not pregnant. AAPT illustrates how the process of gestation, though intimately connected to the body by evolution, can be separated from the state of pregnancy. If AAPT works as envisaged, gestation could well be supported without the need for a human person to sustain the complete process by being in a pregnant state. The pregnant state of a human will cease when the process of gestation ends in the body and is continued in AAPT.

The distinction between pregnancy as a state and gestation as a process has implications for the understanding of birth. Both Romanis and Kingma and Finn have advanced accounts of birth as a two-stage process.[2 3 49–51] First, an entity is *birthed* when it is delivered from the pregnant person. Second, that entity is *born* once it is delivered from gestation and becomes adapted to

[xiii] E.g., where the fetus as has severe fatal abnormality, like anencephaly, that means it cannot survive after it is born.

[xiv] Evolutionary biologists have theorised that pregnancy-supported gestation was an important biological adaptation for early humans because it was a safer environment than extracorporeal environments. (Power and Schulkin 2012).

[xv] We are grateful to Professor Ainsley Newson for raising this point with us at the British Sociological Association Human Reproduction Study Group Conference in June 2023.

[xvi] We were prompted to this point by a presentation by Dr Emily Ross at the British Sociological Association Human Reproduction Study Group Conference in June 2023. Information about her current project is available: https://www.sheffield.ac.uk/ihuman/practices-gestational-trophoblastic-disease (accessed 28 June 2023).

the external environment.[2 3 49–51] These accounts have important implications if we consider them from the perspective of the pregnant person and other intended parent(s). Where the entity is birthed from the pregnant person, that person transitions from a state of pregnancy to a postpregnancy state (no longer being pregnant). This transition, in a conventional birth in which the neonate also makes the transition to neonatal physiology (adaptation to the external environment), marks for many a beginning, but for the pregnant person it is also an ending because of the physiological change within them. As Young explains:

> For others the birth of an infant may be only a beginning, but for the birthing woman it is a conclusion as well. It signals the close of a process she has been undergoing for nine months.[13]

The process that ends for the pregnant and birthing person may have been, for some, an important, powerful and moving experience.

There are significant physiological changes in a person's body when it transitions back to being in the non-pregnant state. The postpartum condition is distinct from the non-pregnant state before pregnancy. For example, rapid hormonal changes cause lactation.[52] Where the entity delivered from the pregnant person's body does not make the transition to neonatal physiology, adapting to the external environment, and is instead isolated to continue gestating ex utero in sterile AAPT, the pregnant person experiences an ending to their pregnancy, but one that is not simultaneous with the 'beginning' described. There, instead, would be a gap between the birthing a pregnant person undertakes (and their transition to the non-pregnant postpartum state) and their child being born.[53] In such an instance, a pregnant person may find the end of their pregnancy a more jarring experience because they do not, even when the gestated entity lives, synchronously have an entity with which they can have physical contact.

Some parents whose infant requires being cared for in NICU experience a 'gap' between the birthing of the child and their interaction with it. For example, parents have reported delays between giving birth to their child and being able to visit the neonatal unit.[40] Some parents wait only 1–2 weeks to hold their infant in NICU, while others have had to wait up to 8 weeks.[40] The longer durations before any physical contact are exceptional, especially since there is considerable evidence of the benefits of 'kangaroo care' in NICU.[54] Moreover, even where there is not the ability to hold an NICU baby, parent(s) are able to see it and talk to it. The 'gap' where an entity is translocated to AAPT for continued gestation will likely be of a much longer duration and involve (likely) no physical interaction between parent(s) and the subject of extra uterum gestation for an extended period. Even considering those extreme cases where there is no interaction in NICU until some weeks later, the visual interaction with an infant in NICU will still be significantly different to viewing an entity within AAPT (if such viewing is a possibility).[55 56] It is these differences that we argue could exacerbate feelings of pregnancy loss that we saw described in relation to NICU. This can fundamentally shift how the epistemically transformative experience of pregnancy is experienced and this must be recognised to meet pregnant person's shifting needs. We consider recognition and adaptations to care pathways crucial to ensure that AAPT is not governed by wholly fetal-centric narratives, which can compound some pregnant people's feelings around pregnancy loss. Gestation being continued outside the body, while the pregnant person transitions to the postpartum state without their baby being in their physical care, is likely to exemplify feelings of pregnancy loss.

Artificial placentas and pregnancy loss

De Bie *et al* (from the team building AAPT in Philadelphia) explain that, if the technology works as well as anticipated theoretically then it 'could also benefit parents by sparing them having to witness their premature infant supported on a ventilator with intravenous lines'.[57] This is a fetal-centric narrative: the machine benefits the gestating entity and thus benefits the parent(s). It is often the way of things that ethical discussion of novel technologies is framed 'mainly in terms of the value of prenatal life'.[20] We do not dispute that AAPT will be experienced as a benefit by many parents. However, we suggest that the experience of putative parent(s), and (formerly) pregnant people in particular need further interrogation. In this section, we consider the ethical issues that arise if we reframe our thinking about AAPT to not be wholly fetal-centric and instead consider the experiences of pregnant people including potential difficulties that might arise for them. How AAPT could be experienced is a matter in which there should be empirical qualitative inquiry, and this ought to feed into the design of the device and the associated care pathways. While the technology is specifically aimed at providing treatment to infants born prematurely, the way in which this treatment is applied requires planning while gestation is still being undertaken by the pregnant person. As such a pregnant person's bodily experience of and emotional engagement with the ending of their pregnancy is intricately linked to the provision of AAPT. As Segers *et al* have also acknowledged, for some people, partial ectogestation 'would take away the opportunity for her[/them] to experience her[/their] pregnancy according to her[/their] personal values and preferences'[37] with negative consequences for their sense of self and potentially the feelings of loss we have described. Evaluating pregnant persons' experience with the technology can lead to implementation of the technology in a way that ensures their psychological and physical care is attended to. What we explore here is our initial speculative interpretation and it should not be considered a complete or universal account.

While our purpose here is to focus on the experience of pregnancy loss, we will make one observation about design ethics. De Bie *et al*'s statement assumes certain facts about the design of AAPT and how parent(s) might respond to it. It is known that parent(s) struggle with the volume of machinery in NICU,[58] but alternative worries that parents may have about how their gestating entity would look in AAPT—suspended, floating in a dark, liquid environment—also need to be considered. The visualisation of the entity in a manner so unfamiliar, where they cannot see it in the same way or touch it at all, may have an equal or more detrimental impact on the parents' experiences.[46] Therefore, it is assertive to assume, setting aside the knowledge that the device is working and the gestateling (subject of artificial gestation)[3] is healthy, that putative parent(s) would find this less distressing than NICU. Design is an ethical issue that should be considered in more depth for its impact on parents.

As the experiences of NICU highlighted earlier demonstrate, premature birth can for some people result in a feeling of loss in not sustaining a pregnancy to full term. There are some factors that mean this loss could be exacerbated and/or experienced by more people where AAPT is used. The 'ambiguous loss' described by Golish and Powell[27] is at risk of becoming more ambiguous with the introduction of AAPT. Although their child is under the care of NICU, parents are often able to feel some joy at their child surviving birth and this joy becomes tangled with

the grief at the loss of a full-term pregnancy. With AAPT the loss of a full-term pregnancy will remain, yet the joy at the 'survival' of the child could become more ambiguous. While an entity that has left the human uterus and made it through the transfer to the AAPT may be considered to have 'survived' being birthed, it is not yet clear whether that entity would be considered a 'born child' or whether it would continue to carry the status of a fetus, in which case it might not legally be considered a born entity.[50] Alternatively, it may occupy a new 'in between' legal state—not a fetus, but not quite yet a born child.[50] Such legal definitions may have little influence over how the formerly pregnant person feels towards the entity, however, it's ambiguous legal status may impact whether parents consider the entity to have 'survived' and, therefore, whether they can take joy from this. With this ambiguity there is the risk that the pregnancy loss that the pregnant person may experience is side-lined as attention is focused on determining whether the entity has or will survive, although it is similarly acknowledged that visualisation of the entity could provide more reassurance for parents. The visual difference between a neonate in an NICU cot and an entity floating in fluid however does hold the potential to further stall any feelings of joy or relief at the survival of the entity until such time that it begins to look like a newborn or can be interacted with in the same way. Some might argue that this is only a temporary problem as medical technologies become normalised, increasingly visible and socially embedded. Nevertheless, this does not detract from the difficulties that may be experienced in the early clinical translation of AAPT.

If clinical translation of AAPT is successful, this could change decision-making in obstetrics. Where AAPT minimises the concern about prematurity, it could be that more people experiencing dangerous pregnancies are advised to end their pregnancy earlier to opt for AAPT to better preserve their health.[59] More people could consequently experience a two (rather than three) trimester pregnancy, and therefore, experience earlier pregnancy loss where the likelihood of procreative loss is decreased. Formerly pregnant people describe making the decision to prematurely end their wanted pregnancy as extremely difficult.[60] Such decision-making might, therefore, become more straight-forward with AAPT: they can preserve their own health/life and that of their fetus by opting for the machine.[59] However, for some people, this decision will not be so straight-forward, especially those who place a high value in pregnancy beyond just the outcome of that pregnancy. It is hard to predict how people will feel even where they are happy with their choice to opt for AAPT : '(e)very birth story only makes sense in retrospect'[61] and there are all sorts of cultural and social scripts that are projected onto birth stories and how they are self-interpreted.[xvii] Where people value their pregnancy and/or they are under considerable sociomedical pressure to 'perform' pregnancy well, grief and loss experienced in making the decision to opt for AAPT (because, eg, they deem it necessary in the circumstances even if it is does not match their preferences) should not be ignored because of how it might negatively frame the experience of AAPT for the pregnant person. There could be a significant impact on pregnant people's psychological health if these feelings are not acknowledged through adapted care pathways.

[xvii]E.g., there is much in European cultures encouraging shame in those who have or seek a technologically assisted birth (Keglowitsch and Meagher 2022).

How AAPT is understood and framed may also further exacerbate feelings of 'failure' in formerly pregnant people. As the quotes earlier illustrated, many people often describe shame at the incubator 'doing what their body should have done'.[32 34 35] AAPT, in 'taking over' gestation (in facilitating that creative process, rather than incubation),[3] may be thought of by pregnant people as more directly taking over the creative labour they 'should be doing'. Unlike NICU, AAPT could offer a more vivid visual representation of gestational work being replaced by technology, particularly as the floating entity may reflect how pregnant persons imagine their fetuses to be within their body and may look akin to the images that they have seen on ultrasound scans (unlike entities' presentation in NICU incubators).

We have not explained the phenomenon of pregnancy loss without procreative loss to say that people should feel this way when they experience a premature ending to a pregnancy. Rather, we are acknowledging that this is an experience that people *do have* and this will continue to happen—potentially with some escalation—with AAPT. That people may experience these feelings will have a significant impact on their procreation and affect their future and their sense of self, and thus it is important that they are considered.

Implications for care pathways: loss-sensitive care

With the technology specifically designed to improve the survival and morbidity of premature babies, the fetus will undoubtedly be at the centre of decisions as to whether to use AAPT. However, we suggest that the transfer of the fetus to AAPT should also be understood/framed as the premature ending of a pregnancy, in order to capture a pregnant individual's potential experience of pregnancy loss. This reframing creates space for the impact of the transfer on the pregnant person to also be considered. In designing the care pathways around AAPT, we must consider what pregnant people's experiences might be, and what can we do to make pregnant people feel supported and heard during and after these experiences. In this section, we reflect on some of the factors we consider important for a care pathway that recognises pregnancy loss without procreative loss. What follows is not to be considered as an exhaustive list of factors relevant to care pathways. There is also ample scope beyond this paper to explore the factors below in more depth. By raising these issues, we hope to encourage further and more in-depth discussion of how care pathways can incorporate the experiences of pregnant persons.

Information for decision-making

In many of the studies regarding parents' experiences of NICU, information was considered key to helping parents reduce the shock of their unexpected circumstances.[27 34 40] It will be essential for those who find themselves in need of using AAPT to understand the technology,[47 62] although not necessarily in its totality. Ideally, intended parents should be provided with enough information in relation to what the technology offers and how it works prior to the emergency situation in which they may need to consent to use of the technology.[62]

There is potential for information regarding reproductive options to become heavily fetal-centric (encouraging people to make decisions based on the safety of the fetus, rather than considering the benefit a person may take from pregnancy), particularly when these decisions are made at a later gestational stage. While a pregnant individual will most likely want to know the implications for the fetus, written and verbal information about the technology should also outline what a transfer of the

fetus from the individual's body to AAPT will mean for that individual and their body, regardless of fetal outcome. This should include the process of fetal extraction and explicitly acknowledge that the use of AAPT will require the premature ending of a pregnancy.[63] Information focused solely on the implications of the technology for the fetus can suggest that the fetus is all that matters in the decision-making and creates an opportunity for the pregnant individual to forget themselves, even when their body is immediately implicated in the decision they will make. An explicit focus on the implications for the pregnant person can encourage them to situate themselves in the options being presented and better allows for them to feel confident that their needs are being considered. This could further help them appreciate and acknowledge the loss and grief they may come to experience should they proceed with AAPT.

While we encourage the inclusion of information that is sensitive to the possibility of experiences of loss, this information provision should not minimise the process of the decision-making that the pregnant person is undertaking. Newton, in discussing information provision regarding whole genome sequencing, argues that the 'psychological properties' of the decision-maker need also be considered.[64] Patients should not just be bombarded with facts. They should be supported to understand relevant information in context so that they can engage in deliberative decision-making in line with their values. While it will be important for pregnant people to be informed about the physical implications of AAPT for them and the reasonable alternatives[65] so that a proper informed consent can be obtained, prolonged discussions of loss may not be suitable for all. We advocate for adequate space for individuals to critically reflect[64] on implications of loss if they so wish and as far as they wish to do so.

There is some literature about pregnant people's right to make the decision to opt for AAPT,[59 66] but it would be useful to also see more reflection on a person's right to refuse a transfer if they would prefer to continue a bodily gestation. While it is easy to see this an extension of a pregnant person's right to refuse unwanted bodily interventions (pregnant or not), the law in England and Wales has shown consistently its inability to respect refusal where medical professionals determine a course of action that is 'best' for the fetus.[67] Nevertheless, inclusion of loss-sensitive information should not be co-opted in such a way as to deter people from the use of AAPT. Rather its inclusion is to create a space whereby a pregnant person can consider the possibility of feelings of loss and know that should they have those experiences they are in an environment where those experiences and feelings can be expressed and shared. As such it is not just about what information is provided but also how that information is provided, and the language used in its delivery.

Language

An important part of how information is conveyed to pregnant persons is the language used to communicate key concepts.[63] Terminology around AAPT should be clear and easy for pregnant people and parent(s) to understand. Most importantly, the terminology should be accurate and precise to enable decision-making based on a sufficient understanding of how the technology works. However, there is also a need to consider the implications of the language used for the way that pregnant people feel about their bodies.

Kingma and Finn pointed out that AAPT/artificial placenta is the most accurate name for the devices in development based on their function.[2] Prior to this intervention, the devices had been termed 'artificial wombs' in the literature (this term is still used by the team in Philadelphia). Verweij and Kingma have explained that 'artificial placentas' is a preferable term, not just for its accuracy, but because artificial womb gives the impression that the device is 'a replacement for an entire pregnancy (or even for women!) as opposed to (in reality) a replacement for neonatal incubation at the edge of viability'.[46] In addition to misconceptions about what the device can do, there is also the issue that in terming the device 'a womb' a pregnant person may have a much more complex relationship with the device since the terminology is directly mimicking the language that would be used to describe their pregnancy. For those people who may experience pregnancy loss in the way we have described, language that has the potential to reiterate the notion that the pregnant person, and the role their body was playing in gestation, is being replaced, has the potential to exacerbate feelings of guilt and shame.

In addition to the name of the device, there is also debate about the appropriate name for the subject in AAPT. Often, it is referred to as the fetus or 'ecto-fetus'.[68] The defining feature of a fetus is that it is a part of a pregnant person,[69] and as such the term fetus for this entity is not accurate.[3] Moreover, calling the entity a fetus may also exacerbate the feelings of grief we have described because the entity is discussed in the same terms as it was during the pregnancy. Romanis has suggested the term 'gestateling'[3] which could better manage parental expectations—the entity is not in a state, like babies in NICU often are—where it can be held, touched, smelled.[4] Using a unique term might also help give parents an understanding of the ambiguity gap that results when the ending of a pregnancy and the entity entering the world postgestation do not coincide. Moreover, this unique term does not map onto our existing language in a way that might lead to pregnant people trying to shoehorn their experience of AAPT into the language and ideas we already have.

The debate about what to call the entity in AAPT continues[51xviii] and there is limited hope of a consensus soon. What we add to this discussion is that in thinking about how we name this entity we should also centre the experiences of pregnant people and parents by considering what the name means for them. We do not mean to suggest that everyone *must* use the same language, and compassionate care may require healthcare professionals to mirror the language that parents use (though there are strong reasons not to use emotionally laden terms as default).[8] Nevertheless, introducing a technical term that describes what the entity is, even if it is not then routinely used, is a way of ensuring understanding about the unique state of the entity and of their reproductive journey.

Psychological support

We have explained how the inclusion of supportive information that allows a pregnant individual to centre themselves in decision-making regarding this technology is essential to allowing feelings of pregnancy loss to feel seen and heard. Beyond simply paying lip service to these feelings in consultations and written guidance however, that support needs to be followed up with the provision of psychological support.

The psychological support we envisage, which acknowledges potential experiences of pregnancy loss, must be distinct from services that are currently provided to those who experience both pregnancy loss and procreative loss simultaneously. The loss of pregnancy is an ambiguous loss because it is the loss of

[xviii]The team developing EXTEND therapy in Philadelphia have started calling the entity the 'fetonate' and the team in the Netherlands have begun dubbing the entity partially gestating ex utero the 'perinate' (though recognising it as a sub-category of gestateling).

an experience as opposed to the loss of a person[27] and general bereavement counselling may not be appropriate to provide the psychological support necessary for pregnancy loss. Provision must be made for AAPT service-users to have access to counselling (so that space is created for them to share and process any difficult feelings about their pregnancy). It should also be clear that this counselling is not compulsory, but rather is available. How such a service would be structured, as well as organised, and funded, is something that requires further reflection—with the insight of psychologists.

In addition, psychological support need not necessarily present itself as a form of counselling or as a programme that the formerly pregnant person must use. Rather psychological support for experiences of pregnancy loss can be provided in more subtle ways such as in the behaviour of the staff caring for the individual. Cohen, an NICU nurse, has reflected on how her experience of having a child in NICU changed the way she interacted with NICU parents once she returned to work. She explains that little compassionate adjustments on the part of healthcare professionals, to make room for the acknowledgement of her feelings rather than their simple dismissal, were what she felt she needed:

> '*One of the neonatologists had seen me standing there and casually asked how I was doing. I responded by bursting into tears and telling her how guilty I felt for my son's early delivery. The sweet doctor who had worked side by side with me for many nights hugged me, but then she assured me that none of this was my fault and that I 'knew better' than to feel responsible for it… What did I need in that moment? … someone to let me talk and cry about how I felt without telling me to stop feeling that way, or telling me that it was wrong to think it*'.[58]

Accounts like this illustrate the missed opportunities for adequate support to be provided in the everyday interactions between healthcare providers and their patients. In terms of the information provision discussed earlier, if this information is to encourage pregnant persons to feel secure in the sharing of their feelings of loss, when those feelings are shared the relevant support must be in place so as not to lead patients into a false sense of security. In literature that considers how we best support individuals with processing grief and loss, it is often observed that acknowledgement of these feelings from another person is important to help them feel understood.[24] The dismissal of these experiences will only exacerbate feelings of guilt and shame and deny individuals the opportunity to process their loss. Healthcare professionals working with AAPT must be trained to be attentive to these experiences so that they can recognise and acknowledge them.

Conclusion

There is a growing body of ethico-legal literature that considers the complexities surrounding the use of partial ectogestation as an alternative to conventional NICU. However, the focus of this literature has been on the subject of artificial gestation ('the gestateling'),[3] for example, what this entity is,[2 3 70] or in what circumstances we should use AAPT experimentally.[45 46] There has been some reflection on the need to centre the pregnant person in the development of AAPT[49 71] since they are the person being experimented on in the first place (the subject of extra uterum gestation must first be extracted from them).[46] To our knowledge, however, the notion of loss we have explored in this paper, is novel. There are some papers that have hypothesised about the impact of gestation extra uterum on the psychological welfare of the future child.[44 72 73] Such questions exemplify a fetal-centric approach as, while somewhat alluding to the disruption in the embodiment of a pregnancy, they are asking about the experience of a non-conscious entity, as opposed to (formerly) pregnant people who may have attached value to their pregnancy beyond just the outcome of a healthy fetus. Our account is intended to reorient thinking from what it is felt that a resulting child may have 'missed out on,' to what a pregnant person may experience where partial ectogestation is used.

AAPT makes increasingly visible the phenomenon of pregnancy loss without procreative loss. Thinking about pregnancy loss in this context is conceptually useful because it enables us to work through the conceptual distinctions between gestation (the process) and pregnancy (the state) and the value that individuals place in pregnancy. We posited an account of the value that people may place in pregnancy that was not wholly fetal-centric to explain why people experience pregnancy loss without procreative loss. Our investigation has more than just conceptual significance. Experiences of pregnancy loss is something that we must be attentive to in designing care pathways for AAPT in various ways. We must consider, in addition to the availability and design of AAPT, how we can provide information about experiences of pregnancy loss that can help pregnant people make decisions about the use of AAPT in line with their values. To better understand how we can centre the experiences of potential service-users of AAPT, including understanding the phenomenon of pregnancy loss without procreative loss, empirical research with NICU parents will be critical.[74]

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