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WHEN HEARTLESS BABIES ARE DISPOSABLE TISSUE

MATERNAL REACTIONS TO ACARDIAC TWINNING

This article explores the rare fetal condition, acardiac twinning, within the cultural context of loss. Acardiac twins are identical twins in which one twin develops with normal physiological characteristics while the co-twin, or «acardius», develops severe malformations rendering it incompatible with life *ex utero*. In many cases this condition, left untreated, leads to the demise of the otherwise healthy twin. To treat this condition some women undergo *in utero* fetal surgery, or «fetoscopy», to ligate the acardius from the placenta, thus improving the survival rate of the co-twin. Here I explore the variations in meanings associated with the acardius and demonstrate how women carrying these pregnancies vacillate between objectifying and subjectifying this entity. These vacillations suggest that the acardius challenges notions of personhood and humanness which are often thought of as existing along a spectrum. By recognizing this varying meaning within an amalgamation framework women and their caregivers may be better prepared to face these extraordinary pregnancies.

DEBORAH BLIZZARD

This article investigates maternal reactions to the rare fetal condition, acardiac twinning, in which one identical twin develops properly while the other twin develops without a fully formed heart and, at times, without arms or a head. Unfortunately the existence of the malformed twin (the *acardius*) endangers the co-twin (here also called *fetus*) because the two are unable to exchange blood in the appropriate proportions through the shared placenta. In essence the viable co-twin's heart acts as a pump for the two which leads to the deterioration of the fetus. If the condition is not abated, the likelihood of the demise of the co-twin is increased[1]. To save the viable twin physicians use fetoscopy (*in utero* fetal surgery) at the mid-gestation stage to ligate (tie-off or otherwise separate) the umbilical cord leading to the malformed twin[2]. Following surgery, both twins remain *in utero* until their eventual birth. Based upon my eleven month fieldwork at a US hospital developing fetoscopy (for acardiac twinning as well as other rare fetal conditions) and on interviews with patient-mothers who underwent surgery, I reached the conclusion that it was not always clear what an acardius meant to the patient-mother[3], to her family, and even to the ethnographer.

ACARDIAC TWINNING: AN AMBIGUOUS CONDITION

Of all the conditions that I studied during my research, acardiac twinning proved to be the most emotionally traumatic and intellectually challenging to understand. I initially thought these cases would be straight-forward to analyze and that the meanings associated with them

[1] Although statistics may vary depending upon the centre offering treatment, at the time of the study it was found (based upon frigures from a non-profit organization affiliated with the physician who performed these surgeries) that if these pregnancies were not treated approximately 50-75% ended in the death of the viable twin. If they were treated, approximately 70-80% of the viable fetuses survived.

[2] In general fetoscopy can be identified as one of two general techniques: diagnostic fetoscopy and operative fetoscopy (Quintero 2002). Diagnostic fetoscopy offers visualization (and in some cases fetal blood sampling) to an ongoing pregnancy (see, e.g. , Reece 2002; Reece et al. 1997). Operative fetoscopy utilizes the visual capabilities of diagnostic approaches and combines them with miniaturized surgical tools to offer *in utero* therapy through tiny incisions in the woman's abdomen. Acardiac ligation requires operative fetoscopy.

[3] In this article I use the hyphenated term patient-mother to highlight two of the roles by means of which pregnant women with acardiac pregnancies were frequently identified. This identification was both through self selection (i.e., «I am a mother») and by medical professionals (i.e. «she is a patient»). By underscoring this dual identity I further allude to the multiple fractured identities that all of these women experienced as they worked through their pregnancy experiences.

would be relatively clear. I assumed that a woman who carried a twin pregnancy in which one entity was viable and one was not would find the decision to ligate the non-viable acardius in an attempt to save the viable co-twin a clear-cut one. I assumed that the lack of viability of the acardius would make this decision-making relatively non-problematic. Over the years my naiveté lessened allowing me to recognize that these highly problematic pregnancies were perhaps the most difficult of all to analyze. The fact that the acardius was incompatible with life in many ways often proved to be the very aspect of the pregnancy that led to difficult decision-making. Put succinctly, a pregnant woman had to negotiate seemingly disparate characteristics all of which, nonetheless, formed part of the acardius: it was a product of conception, non-viable, and perhaps non-human while it was simultaneously a potential child, twin, and sibling. Through interviews with, and observations of, these women and their caregivers it became clear that acardiac twinning was a lived «ambiguous loss» in which both the loss of the fetus and the hope for the pregnancy was never clear nor stable (Boss 1999; Blizzard 2007). The loss was ongoing and difficult to reconcile because it was not clear what was lost – a son, a tumour, a daughter, a mass. This ambiguity transpired to leave many pregnant women and their caregivers at a loss for words, searching for meaning, and having to deal with the possible loss of a potential child. The diagnosis of an acardius and the subsequent decision of whether or not to ligate it, often entailed patient-mothers culturally rethinking what the acardius meant within their pregnancies. These reconstructions both affected how patient-mothers saw themselves in relation to the world around them and how they viewed any surviving or deceased baby.

As I note elsewhere (Blizzard 2007), in some cases the acardius appeared as a subjective entity, such as a brother or son, while in other cases the acardius was positioned as an objective entity, such as a tissue or mass[4]. Here I explore these vacillations and argue that the acardiac twinning experience is best understood within an amalgamation framework in which the acardius can exist as both a subjective and objective entity simultaneously, rather than by adopting the more prominent linear approaches often advanced in explorations of fetal personhood (and potential humanity) in which movement toward personhood, for example, suggests that there is movement away from objective status (e.g., a tumour, mass, or growth)[5]. This complicated act of being both subject and object defies a definition merging subject and object, reflecting instead a more complicated framework in which the acardius, depending upon the situation, may be both fully subject and fully object. In this article I highlight some of the tensions brought on by describing or understanding what the acardiac pregnancy entails (i.e., an overlaying of vacillations of objective and subjective qualities of the acardius) as experienced by particular women and suggest that this amalgamation of multiple identities may be necessary for patient-mothers as they develop their pregnancy narratives. However, while this vacillation accurred for the acardius, the co-twin was always a subjective entity with traits of humanness and potential personhood. The experiences that lead to this vacillation included how women reacted to ultrasounds following surgery, how they negotiated competing definitions of what the acardius is, whether or not they saw themselves as «killing» one twin to save another, and how they viewed the acardius in relation to their wider family and kinship roles. The remainder of this article explores some of these cultural quagmires and the ways in which women-patients and their social networks find ways to make sense out of these higly problematic pregnancies.

The acardius is intriguing in that it is both in the process of attaining «humanness» and potential personhood simultaneously, and at any point can demonstrate the characteristics of human, non-human, person, non-person, subject and object. Because of this, the acardius is less a new subject–object hybrid (i.e., merging of A and B), than a varying socio-physical amalgamation read *at once* (i.e., over-laying of A, B, C, ...) in which multiple identities of subjectivity and objectivity continually overlay one another

[4] For further discussion of subject / object vacillations in twinning pregnancies and comparisons of different kinds of twinning pregnancies (e.g., twin to twin transfusion syndrome) see Blizzard 2007. In this article I stress how the amalgamation framework highlights the apparent indeterminacy of acardiac twinning, in particular.

[5] The opportunity for an entity to exist as both subject and object is not only an attribute to acardiac twinning. For example, the newly deceased may also be spoken of in ways that are both subjectifying and objectifying. For grieving families it may be helpful to speak of a deceased relative in highly subjective terms (e.g., «Grandpa looks so peaceful») and objective terms (e.g. «Yes, you can take the kidney»). Where acardiac twinning differs from this is in that when the acardius is objectified it may entail thinking of it in ways in which it was never human or never achieved any form of human agency or personhood. For detailed analysis of this issue when compared to other forms of subjectifiying and objectifying individuals see Blizzard 2007.

as women make decisions as to whether or not to undergo fetoscopy to treat their condition. Further I suggest that such amalgamation of the acardius as subject and object may be inherent due to the subjective relationship of «twins». A complete object (e.g., the acardius) may not be able to culturally exist within a subjective relationship (i. e., the twins). It must, therefore, show some signs of subjectivity (cf. Boltanski 2004).

To illustrate the ambiguity felt about these pregnancies, when citing interviews with patient-mothers I underline the times when they and others in their social networks claim subjective and objective qualities for the acardius. A close examination of this apparent indeterminacy helps to illustrate that the acardiac pregnancy and the acardius held within it represent a variety of cultural meanings about what constitutes a person, a baby, or a tumour, and that the local context in which the pregnancy occurs must be taken into account when considering how to discuss the pregnancy and the possible treatment options. Importantly, when considering the acardius within an amalgamation framework it becomes possible to view apparent confusion concerning the ontological status of the acardius on the part of patient-mothers as changing certainty (Blizzard 2007). Examination of the above issues and their multiple answers are essential in order to deliver optimum care to women who have to endure such a difficult and emotionally complex surgery as necessitated by this severe fetal malformation. Further, by exploring when and how patient-mothers use subjective and objective terms for the entity that they carry, it is possible to examine how anthropological studies of what constitutes a person and what constitutes a human can be utilized to demonstrate that one entity may be both person and non-human at different points in a patient-mothers experience and that the two identities are not mutually exclusive when identifying an *in utero* entity.

METHODOLOGY

From September 1997 until July 1998 I conducted ethnographic research at a small hospital located in an urban centre in the United States. During this time I observed twenty operations, interviewed eighteen fetoscopy patient-mothers and ten patient-mother companions as well as numerous medical professionals representing a variety of specializations. In this article I use interview material from two patient groups: women who underwent surgery while I was conducting the research at the hospital and women who had surgery in the approximate five year period prior to my arrival at the hospital. Patient-mother interviews typically lasted thirty minutes to one hour, were conducted in their hospital room, and took place within the forty-eight hours following surgery. I used a semi-open-ended interview approach, asking them to tell me about themselves and their experiences with fetoscopy. If consent was given I also attended when surgery was conducted.

Following the research I interviewed twenty-four patient-mothers who had fetoscopy before I began the ethnography[6]. To offer as much confidentiality as possible, the surgeon's office sent letters to former patient-mothers asking if they would be willing to take part in my research. Out of approximately 150 packets sent, thirty-five consents were returned to me. Not all could be interviewed, however, due to incomplete information on their informed consents. During the following year and a half I conducted the interviews. Throughout this experience I met and interviewed seven women who underwent ligation for their acardiac pregnancies. Two of these women had surgery during my research while the other five underwent surgery preceeding my time at the hospital. To help ensure confidentiality all informant names are pseudonyms.

ACARDIAC TWINNING AND MATERNAL DECISION-MAKING

Women with acardiac pregnancies challenge our notions of fetal personhood as well as an *in utero's* potential to be identified as human. Some feminist anthropologists argue that fetal personhood is a constructed trait created within a social and cultural milieu which includes hospital practices and individual desires (e.g., Landsman 1999, 1998; Layne 1999). These analyses show that fetal personhood is created over time – patient-mothers and their social networks (including medical care-givers) give and withhold aspects of fetal personhood throughout the period of gestation. Within the context of fetal politics, it becomes clear that an *in utero* entity can be positioned as baby-like, that is, similar to and morally like a born baby or, in other cases, an *in utero* entity may be objectified as a bio-

[6] Since this time I have returned to the project and interviewed patient-mothers who underwent fetoscopy since my departure from the site in 1998. These interviewees underwent fetoscopy between the spring of 1998 and the spring of 2005.

logical growth and positioned more as a developing entity that is intellectually and morally separated from claims of personhood and / or viewed as not like a born baby or even human[7]. How much subjectivity and objectivity is ascribed to a fetus or other *in utero* entity is particular to the individual claiming it and depends on their cultural background and moral assumptions (cf. Casper 1998). Unlike pregnancies in which a single fetus may or may not develop into a baby, acardiac pregnancies hold two *in utero* products of conception: a fetus that may or may not develop into a baby that will be born and another entity that may or may not be considered a fetus at all.

Although each pregnancy was unique, patient-mothers, their families, and medical workers used at least three perspectives or ways of thinking about the acardius in relation to the rest of the pregnancy:

1. An acardius was a malformation. In these cases the acardius was understood to be a tumour or mass. Its existence was detrimental to the continued development and future existence of the otherwise healthy fetus.

2. An acardius was a separate individual killing the co-twin. In these cases, the acardius was understood to be an individual whose activities had to be stopped.

3. An acardius was a sick baby that would not live. In these cases, the acardius was understood to be an individual that was dying and whose death threatened the life of another. Its existence was a threat to the continued development of the co-twin, but it was not «killing» the co-twin, *per se* (i.e., by choice).

Although these readings imply different statuses for the acardius, they are not mutually exclusive and in most cases its identity shifted between these seemingly disparate attributes.

The shifting ontological status of the acardius is further problematized when physicians use ultrasound to diagnose the existence of the condition. Ultrasound has long been critiqued in the literature relating to the anthropology of reproduction for multiple reasons including (but not limited to): making a fetus appear more like a baby to a pregnant woman; for placing more emphasis on the fetus than the woman; for entrenching notions of maternal bonding; and for making the fetus a public icon. A common theme within these critiques is that ultrasound visually separates the fetus from the patient-mother (on ultrasound and the public fetus see Petchesky 1987; Taylor 1993; on ultrasound and erasing the woman see Rothman 1986; Stabile 1992). While the fetus has become an object of popular culture and cultural narrative, the technology to create it, the ultrasound, has also crept into the flow of daily life for many. Today, it has largely become an unquestioned part of Western prenatal care (especially in the US). Unfortunately, when paired with anomalous pregnancies, the ultrasound problematizes an already complicated medical and cultural event (cf. Taylor 1998; Blizzard 2007). As women shifted their descriptions about what they were carrying inside them meant to them, the ultrasound offered visual confirmation of the anomaly and further justified (medically) that treatment would necessitate separating a developing entity from the nutrient rich placenta. Furthermore, separating one *in utero* entity from a shared placenta would only take place if a patient-mother consented to surgery to save the viable fetus. Therefore women who consented to surgery to save one twin necessarily made the decision to end the further development of the other (i.e., the acardius).

One patient-mother, Sarah, was particularly troubled when making sense of her ultrasound. In the autumn of 1995 when Sarah went to her ultrasound appointment she was unaware that she was carrying twins. When hearing of the acardiac condition and the possibility of ligation she returned to the assumption that most pregnancies involve a single fetus, not twins. Earlier that day she had believed that she had only one fetus and the fact that she had more than one was in itself an anomalous event. Part of reconciling her decision to ligate the acardius relied on what she already imagined her pregnancy to entail. Furthermore, as she explained how she came to understand that she only had one, she moved between aspects of subjectivity and objectivity. She explained: «In my mind it was only *just one baby* the whole time because *the other one* was just kind of written off and besides when I went in – it was like – you know, I didn't even know I was having *twins* until the sonogram that day, so it was – you know, I was going in to see *one baby* in my mind anyway, maybe that influenced me?»

In her description of the ultrasound the acardius (which she did not anticipate existing) was both subjectified and objectified within the same breath: as an object she referred

[7] Examples of these differences are highlighted later in this discussion.

to it as «the other one», careful not to attribute too much agency (if any) to it while only a few words later she put it into a subjectified twinning relationship. To be clear, it is possible that «the other one» may infer the «other baby» because it follows on from her first description of the baby that she anticipated; however, it is intriguing that she does not use these words, instead leaving the ambiguity open as she refers to the «other one». Sarah's selection of terms suggests the possibility of less subjectivity offered to the acardius when she stresses the subjectivity of the one baby that she always had in her mind. Importantly, Sarah spent little time reflecting on the acardius and stressed the importance of seeing the baby that she had anticipated. Although the acardius was also present in the ultrasound, Sarah was able to distance herself from it by overlaying her anticipated vision of the pregnancy and returning to the belief that she was carrying a single, subjective fetus.

All women who underwent ligation for fetoscopy had at least three ultrasounds: an ultrasound to identify the condition, an ultrasound during surgery, and a follow-up ultrasound after surgery (in most cases women actually had multiple ultrasounds at each stage). Once the surgery has taken place, women must face the follow-up ultrasounds through which they are made acutely aware that a non-viable entity that was potentially hastening the death of a co-twin has been separated from the placenta. Requesting to tie-off an umbilical cord to a non-viable (yet still developing) acardius can prove traumatic; however seeing its effects through the ultrasound may be equally painful as the image offers visual confirmation of a wilfully changed pregnancy (Blizzard 2007).

One patient-mother, Janice, found the decision to ligate her acardius and view her follow-up ultrasound to be traumatic events. Although I interviewed the then 26-year-old Janice in 1999 and her ligation had taken place over two years prior to this, she still had difficulty explaining the event. Her vacillation illustrates how an amalgamation framework may help to express some certainty within an unstable context: «I mean I guess the reason why we have such a hard time is because we electively decided to disconnect *it* and basically kill *it*. I mean, I don't know. I don't know». She continued a short while later: «I mean this *baby* had no head, no heart, no – you know – nothing. [...] I guess I just took from what, how, you know [...] [the doctor] explained it and I guess that's where I sort of made my opinion or my [...] [mind] up – [...] *it* was just really a *tissue* that was forming, and not really a *human being, per se*, I guess, I don't know [...]». Janice's explanation of the ultrasound experience and her decision to ligate (as well as its emotional aftermath) show amazing flexibility in terms of how she understands her acardius. Within a short explanation the acardius exists as an «it», a «baby», «tissue», and as «not a human being». Janice's ability to use all four terms suggests ontological variation within her thoughts: the entity is an amalgamation of all four. At the same time, while she uses these terms she retains a conflicted context demonstrated by the repeated use of «I don't know». The conflict is also borne out in her desire to find a single statement to describe what her acardius «is» as she draws from her physician's explanations as well as from the different ways in which the media reported such cases. Indeed, Janice looked to many experts to try and give her *in utero* a label. Her case, however, appears to defy such a stark single categorization. Although Janice vacillates in how she feels about or understands her ordeal, tragically the one area where she shows certainty is her responsibility for the death of her «baby». As demonstrated by Janice's case, maternal grief and maternal blame can collide in cases of acardiac ligation when a woman has to consent to tying-off or otherwise separating a developing *in utero* entity from the placenta (see Blizzard 2005; Blizzard 2007). She explained her grief and potential blame in light of the ultrasound image, again utilizing terms such as «baby», «tissue», and «it» to describe the entity that she consented to being tied-off from the placenta: «After I had the surgery done and came back for the very first time to do the sonogram, it sort of really struck home even though the other baby wouldn't survive – it sort of struck home to me that I just decided *then*, you know, that I had, you know, that I had disconnected that umbilical cord and everything – and this other tissue – , that was forming in there was, you know – *I had killed it, you know, essentially, even though it would never live*».

Abortion politics and symbolic artefacts confounded some of the experiences of patient-mothers who struggled to understand what they had done and to whom. Abortion politics laid the groundwork for potentially explosive decision-making experiences should the woman and her social network disagree over aspects of treatment. At the same time the umbilical cord is a symbolic artefact representing the link between a woman and her fetus. Cultural narratives of nurturing motherhood and social patterns of related behavioral changes (such as the reduction in alcohol consumption or smoking as well as the improving of overall nutrition during pregnancy) all build the foundations for an interpretative system in which the short cord that attaches a developing fetus to «its mother» is highly

symbolic. For some individuals it is the physical manifestation of the emotional link between mother and child. To cut it, tie it off, or otherwise keep the developing fetus from receiving nutrients from its «nurturing mother» is counter-intuitive. Ligating this symbolic artefact invites accusations concerning, or a questioning of, the other cultural narratives of abortion politics and one's decision to end a pregnancy.

THE TWINNING RELATIONSHIP

Although it is difficult to identify exactly when women might subjectify and objectify the acardius as an amalgamation of multiple identities (as demonstrated in the illustrations above) and how they might reconcile feelings of indeterminacy over the implications of their actions, what remains clear is that patient-mothers often show a tremendous amount of flexibility when defining the acardius as, and making it, kin. Some insight may be gained by considering the Western kinship role of twin (Blizzard 2007). In many cases it is assumed that twins are closer to each other than to other siblings. This narrative is particularly powerful in the case of identical twins. The closeness and likeness of identical twins may make the decision to ligate difficult even if one twin is not able to survive post-birth. Further challenging is the fact that a twinning relationship relies on two entities that often exist as just one thought: *the twins*. If one twin is always subjective (i.e., the viable co-twin) it may be possible that total objectification cannot occur with regard to the acardius. The cognitive disconnection between having an object in a subjective (*the twins*) relationship may help to enable women to subjectify the acardius as they come to understand, know, and build a relationship with the viable twin[8]. In fact, in some interviews with patient-mothers undergoing fetoscopic ligation of a twin (not acardiac) a common concern about ligation was that by «killing» one twin they might also damage the emotional or psychological development of the survivor. Since the acardius can be subjectified it is possible that similar concerns may exist in these cases. Again, the cultural assumptions concerning twins may be deeply embedded within these patient-mothers leading to serious concerns and confusions over what is held within their wombs and how to treat this potentially lethal condition in a manner that retains their identities as women with wanted pregnancies.

The difficulty shown above of identifying what an acardius is, subject or object, was not just an issue for the patient-mothers; in some cases, physicians, laboratories, the ethnographer, and previous reproductive experiences were constructive forces making the acardius more or less subject or object. This demonstrated what kinship ties may be used to assure an acardius a place within a family structure. As an ethnographer, I too formed part of this social network and my assumptions, rhetoric, and approach to interviews could unintentionally conflict with a patient-mother's narrative and views on kinship. In an interview with Lucy, a woman who consented to ligation in 1992, I tried to follow how she identified with her acardius[9]. During the interview, it appeared clear that she had two daughters and that one was acardiac. When I asked if they had had a funeral or cremation ceremony for her (acardius) daughter, her response chilled me. Lucy explained: «[We had neither] because *it* wasn't even formed. *It* was *just a mass of tissue*». She continued: «Actually, really nothing. Because it was at that point I didn't – it was just like, I can't even explain it. *Just a mass*. It wasn't a form of anything. You know what I mean? I didn't really have a finality there». My question invoked a subjective notion of kinship, including how her family dealt with the death of her daughter. I deeply regretted my question and its possible implications. Her response, labelling what I had interpreted as a daughter as an «it» and a «mass of tissue» was antithetical to my understanding of her situation. It was later, when reviewing the interview, that I realized what had happened: just before this interaction she had spoken of the acardius as a «twin sister» to her «daughter». So important was this kinship tie that Lucy wanted her surviving daughter to know about her dead sister. Years after surgery, she sat down with her young daughter to tell her about her sister. Lucy explained: «[...] I didn't tell her the whole story of what happened. In time, when she's older, I'll tell her, but I just – I don't remember [what I said but] [...] that she had *a sister that looked just like her, a twin sister*». In a matter of minutes Lucy had invoked contrary notions of identity for

[8] I would like to thank Saskia Walentowitz for bringing French sociologist Luc Boltanski's concept of «Condition Foetale» to my attention and suggesting that it may be useful in determining the subjectivity and objectivity within an anomalous twin gestation.

[9] To be clear, although the physician's office assistant sent Lucy's packet out with the acardiac pregnancy group of informed consents, Lucy refers to her fetus as having «acarnia». I use Lucy's experience in this article because in both cases the lack of a fully formed head and anomalies associated with it leads the anomalous twin to be viewed as «other». Furthermore, I wish to follow the office assistant's decision including her experience within the ambit of other acardiac experiences.

her acardius: an «it» and «mass of tissue» was also a «twin sister» who «looked just like» her surviving daughter. Utilizing an amalgamation framework in which a mass of tissue may also be a surviving sister allowed Lucy to construct her pregnancy narrative as needed. At one point the acardius was a *malformation* at another she was *a sick baby that would not live*. One state did not preclude the other.

Another example comes from 1995. Amy was twenty-six years old when she underwent ligation of her acardius. Years later she reflected on the experience and the traumatic event of sending and retrieving her acardius from an autopsy laboratory. Amy explained that after the autopsy the laboratory contacted her requesting permission to «discard» the «specimen». Immediately Amy was thrown into incommensurate worldviews in which the autopsy laboratory viewed the acardius as an object while Amy continued to vacillate between subjectifying and objectifying her acardius / baby (cf. Kovit 1978). Her acardius was both an «it» and her «baby» depending upon the precise moment within her reflection and narrative. Amy explained the painful experience in detail. As I listened to her I felt increasing horror as she told me about her desire not to have her «baby» thrown out with the «garbage»: «I was home about a week from the hospital [...] still very emotional about everything, and had gotten a letter in the mail from [...] [the lab] saying, ‹Please sign this so that we can discard of the specimen›. [...] They wanted to just throw it away. And, I was just nuts. I said, ‹I am not letting them throw my baby away!› And you know [they] are going to throw it in the garbage or incinerate it, or what ever, and so I called the pathologist [...] and [...] [asked], ‹Do I have a right to get this back?›»

Clearly Amy does not view her acardius as a specimen, but she does use obectified terms such as «it» and «this» to refer to the acardius. At the same time she «was just nuts» at the prospect of her «baby» being thrown out or incinerated. She continued by explaining how she struggled with the idea of whether or not asking for the body was «something odd». She desperately wanted her «son» back, but felt awkward about asking for his body, given the laboratory's protocols. When the laboratory did return the acardius the grieving family buried him next to deceased family members (they named him as well). Now Amy takes her surviving children to the cemetery to visit their deceased brother.

To further illustrate the abilities of others in the social network to affect how a patient-mother comes to know her acardius in both subjective and objective terms (and by extension their role as potential kin), it is helpful to consider the interaction between Lucy and the sonographer. One day during her pregnancy Lucy was undergoing an ultrasound when she confided that she felt «bad» for the ligated «baby». The sonographer assured her that her grief was reasonable and «perfectly normal» because «you still have that loss». Later in the pregnancy she returned for another ultrasound. Immediately after the examination she went to the restroom where, depending upon one's point of view, she either expelled the acardius or gave birth to her dead baby. Her explanation of the experience demonstrates that *she did both* and importantly that the words and actions of her sonographer may have affected how she viewed the birth / expulsion. She explained that the sonographer told her that «Baby A» came out while a Lucy saw a «mass of tissue»: «I didn't know exactly what was happening, but then when...[the sonographer] came in, she looked and she said, ‹*That's Baby A*›. It's like, ‹Oh, I didn't want this›, because I didn't want to deal with that part. I didn't want – because it was *just a mass of tissue*, so of course [...] she pulled *it* out. She had to put it in a jar. Took it down to the lab and everything». As shown above, like Lucy, the sonographer also demonstrates vacillation. Prior to the birth / expulsion of the acardius she agrees that Lucy should grieve a lost baby, but post birth / expulsion the acardius becomes a laboratory work object to be placed in a jar and taken to the laboratory (cf. Casper 1998).

The abilities of others in a patient-mother's social network to affect how women view their pregnancies cannot be overstated. A comparison of Amy's and Lucy's birth experiences demonstrates the point. Similar to Lucy, Amy also faced a traumatic birth experience; however, Amy was able to determine if she wanted to see the acardius and her physician clearly subjectified the entity. Amy explained the birth: «[When the living baby] was delivering his head came out and the other baby shot over the doctor's shoulder, across the floor. And just kind of squirted out. And um, my physician had the nurses clean off the *other baby* and then bring it to my husband and ask if we wanted to see *him*». Her explanation demonstrates far more subjectivity than objectivity, as does her physician's reaction to the birth. After determining that she did want to see him, Amy showed a remarkable ability for finding aspects of humanness and ultimately personhood in her acardius. She stated that, even without integral body parts, she still saw him as «an identical boy». She explained: «But we got to see him and he was like I said, perfectly healthy from – you know – it didn't have arms, but from the trunk down, it had toes, it had a penis because it was *an identical boy*». Although Amy does use the term «it» in both explanations, these

represent an overwhelming case of subjectifying the severely malformed baby. And, as will be discussed later, although Amy does show the characteristics of the amalgamation of the acardius, more than others, she desperately constructs the subjective over the objective. The differences separating Lucy's and Amy's births are dramatic and demonstrate the variety of ways that individuals react to acardiac pregnancies. While Lucy's sonographer objectified her acardius at the moment of birth / expulsion, Amy's physician subjectified hers. Although individuals will inevitably bring their own assumptions as to what is appropriate care for an acardius post birth / expulsion it is imperative that they recognize that their actions will continue to affect how mothers see themselves and their children in the future. Furthermore, it is important to note that years later these women still vacillate between objectifying and subjectifying the acardius (to varying degrees), but that even with the vacillation both construct strong kinship ties to their lost acardiacs. Lucy's surviving daughter is told that she has a dead twin sister, and Amy's children are likewise told that they lost a brother.

DISCUSSION

The women in this article demonstrate ontological vacillation with regard to the acardius as both subject and object during and after pregnancy. Acardiac pregnancies are physical and cultural states that are continually reconstituted throughout gestation. As noted earlier, although variations existed, in general patient-mothers tended to think of their acardiuses in one of three ways: an acardius was a malformation; an acardius was a separate individual killing the co-twin; or an acardius was a sick baby that would not live. Although patient-mothers continually vacillated over these readings of the acardius, patient-mothers who struggled to understand their experiences were often able to speak of their acardius in ways that were «black and white» within an amalgamation framework: when the acardius was a subject, it appeared *fully* a subject; when it was an object, it appeared *fully* an object (see Blizzard 2007). However, as the amalgamation suggests, being subjectified or objectified is a matter of cultural context.

Unlike current notions of fetal personhood that see it as constructed and deconstructed in gradations, the case of acardiac twinning shows that the subjective fetus *qua* person and objective mass *qua* tissue exist concurrently to describe the same entity and that patient-mothers may invoke either reading throughout their pregnancy experiences. Analyses that position fetal personhood as something constructed over time explore the fetus as an entity that can accrue and lose its subjective attributes (see, e. g., Morgan 1996; Layne 1999; Landsman 1998). Unlike models which suggest a singular linearity to constructed personhood upon which a fetus moves towards or away from «personhood», this work shows that acardiac pregnancies are better understood as events experienced concurrently as both object and subject: moving towards and away from personhood while simultaneously moving towards and away from humanness.

The vacillation that women undergo may hint at a number of cultural nuances playing out in their lived experiences. Perhaps the most difficult aspect of the acardiac twinning cases is the rhetoric itself. Medically, the *in utero* entities are identical twins. They are the outcome of a fertilized egg splitting into two separately developing entities that share a placenta. Yet twinning is more than a physiological experience, it is also a cultural relationship. Many patient-mothers, and other actors in the larger context in which they live, have given particular cultural significance to twinning. Often the notion exists that identical twins share a special relationship – they tend to look alike, are at times mistaken for one another by others, and share an *in utero* environment during gestation. With this closeness, it is possible and probable that «the twins» take on an identity as a pair. With this, complete objectivity of the one (i.e., the acardius) may threaten the complete subjectivity of the developing fetus. Simply put, if the subjective fetus is always seen as a potential child it is culturally challenging and perhaps impossible to think only of the acardius as object. The acardius exists within a twinning relationship thereby perhaps leading to a psychological need to, at times, subjectify it in relation to the co-twin (cf. Boltanski 2004).

Beyond the complications of the rhetoric it is also important to examine the ways in which ultrasound visits and medical interactions limit the ways in which women may view their pregnancies. Both before diagnosis (or at diagnosis) and following surgery, patient-mothers continue to gestate a pregnancy (albeit an altered one). As such they continue to assume a Western patient-role (at least in the US) in which it is anticipated that she continues to be monitored medically until and shortly after birth. As she continues in this role she will have to come to terms with the images that she sees and the discus-

sions, or lack thereof, that surround her troubled pregnancy. Supportive and painful words offered in these context will effect how she sees herself as a mother and to what or whom. As demonstrated above, the ultrasound visit and medical reactions to it must be taken into account when understanding how an acardius is positioned within an amalgamation framework.

Also, when analyzing how patient-mothers came to understand the possible kinship ties between the twins and her own personal relationship with both it is helpful to consider issues of biological disposal. Each of the patient-mothers who appear in this article had vastly different reactions as to how to dispose of the acardius in a proper manner. Yet the crucial act of physically separating themselves from their acardius/twin illuminates current and future kinship roles created for the twins. As noted above, in Lucy's case, the sonographer immediately took the acardius to the laboratory in a specimen jar. Lucy was unable to dispose of her acardius. This becomes particularly problematic since her narrative is in vacillation: at one point the acardius is a mass and at another it is an identical twin sister. Without the ability to select how to dispose of the acardius, it is possible that neither of the two readings will ever prove stronger than the other. Amy, after receiving the acardius from the autopsy laboratory, buries it with other dead family members. Furthermore she tells her children that they had a brother who died. While the acardius shares both attributes of objectivity and subjectivity in Amy's narrative, her desire to name it, bury it, and keep it within the family unit suggests a stronger tendency to subjectify than to objectify. Unlike Lucy and Amy, Sarah never saw her acardius. Although her physicians asked if she wanted to see it, she declined. They took the acardius away and she does not know what happened to it. Though her case also reflects vacillation, it appears that the desire not to see or dispose of the acardius leads to more objective qualities in the entity than subjective ones. Janice proved to be the one who experienced the most difficulty in determining what was the preferred method for separating the twins through the disposal of the acardius. Like Sarah, Janice did not want to see the acardius and, sadly, her co-twin died as well. When asked what she did with the entities she explained that she buried her dead baby and also placed the acardius in the same casket. While Janice never knew how to feel about the acardius, her action of placing it in her dead son's coffin may suggest that the twinning relationship was clearer to her than the individual relationship she had with the acardius. Now, to visit her son's grave is, in effect, to visit them both.

The patient-mothers whom I met all experienced their pregnancies differently; however, many displayed similar themes relating to personal trauma evolving out of the difficulties of ultrasound experiences, the indeterminate ontological status of the acardius, wondering what it means to ligate an umbilical cord, and determining when and how an acardius is kin. The patient-mothers in this article all faced anomalous pregnancy experiences and all worked to come to terms with what the pregnancy held for them and how they could think about the developing entities that they carried. At first glance, one may consider the shifting rhetoric stressing subjective and objective qualities of the *in utero* to be suggestive of confusion. Indeed, as the women's narratives and experiences show, there is ample confusion surrounding these anomalous pregnancies. However, reading this shifting rhetoric as only confusion is too simple. It may suggest that these patient-mothers create *in utero* entities that are both potential subjective kin (e.g., a son) and biological tissue (e.g., a physiological mass). Depending upon the context (cultural and emotional) she may need one reading more than the other at a particular point in time. Also intriguing is that even the patient-mothers who express most strongly subjective or objective qualities with regard to their acardiacs also appear to need to be able to express the antithetical identity as well. As suggested earlier, twins may offer a particular subjective identity as a single theoretical unit that may disallow one from being wholly objective all the time (cf. Boltanski 2004). If this is the case, particular care must be taken when treating these pregnancies and caring for the women who carry them. If others in their social network, including care-givers and family, only wish to objectify or subjectify the acardius it may prove emotionally distressing for a patient-mother who experiences her body and her pregnancy in a more complex manner. By framing these experiences as amalgamations in which subjective and objective attributes of *in utero* entities co-exist, patient-mothers and their social networks may be better prepared to accept the uncertainty inherent in these pregnancies and to develop or recognize flexible ways to accept difficult decision-making and contrary notions of personhood, humanity, and kinship within the Western experience of pregnancy.

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