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Cultural Issues in Response to Young Children's Illnesses, Chronic Conditions, Malformations, and Their Management

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Issues Related to Pregnancy

In previous generations, there was a great deal of uncertainty as the outcome of a pregnancy, and also about the condition of the baby in utero, starting with not knowing the gender, and then regarding the health status of the baby to be born. In many countries, with the advancement of technologies, disciplines like perinatology and maternal fetal medicine physicians are able to diagnose a number of health complications or alterations that may or may not be compatible with a "good outcome." Parents are faced with adverse health information much earlier than in previous generations, and at times with having to make decisions about whether an amniocentesis (Browner et al. 1999) or other procedures should be conducted to definitely diagnose a certain disturbance. They may face options like whether to continue with a pregnancy, and even about whether there should be surgery while the baby is inside the womb in order to correct some malformations. These decisions have a strongly cultural component and this issue would need to be taken into account in a health care system responsive to the needs of various groups.

A common contrast between cultural beliefs can be seen for instance when certain "bad news" are discovered, and "who should know" about such news. In the United States, it is a standard practice to tell adult or child patients that they have cancer, as it is thought they are entitled to "the truth" for multiple reasons, and patients themselves are assumed to want to know. In many cultures around the world, in the same situations, the patient is not told of an ominous diagnosis like that, and much less if it is terminal or if metastases have been discovered. Among other reasons, people fear the patient would get discouraged, lose hope, or be devastated on learning that news. In the United States and other countries, children are routinely informed about very severe diagnoses and their parents usually agree to this disclosure. In Mexico, Japan, and many other non-Westernized countries, parents would not want their child to learn of a severe diagnosis, among the reasons mentioned above because they could not make decisions about treatment.

In a similar fashion, not all parents might want to be told that their baby in utero has a major malformation, a severe syndromic condition, or that the baby is "expected to die" in utero or a short time after birth. Parents who belong to various cultures might resent such bad news, and may in fact not believe them, despite chemical evidence, images, and the like. If in one's world view "anything can happen" if it is God's will, even the scientific revelations of doctors might be put into question. We have encountered parents of Mexican or African origin who say that when

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they were advised of bad news during the pregnancy, and despite having been told the baby would die, they were hoping for a miracle to be bestowed by God and up until the last minute, they were hopeful that something different might happen, and only are faced with the reality until they see for themselves the baby once he or she is born.

One of the questions in the face of different attitudes toward ominous conditions is whether hospitals should have a "one policy" to be applied to everyone regarding a bad prognosis or whether at least their beliefs that the scientific evidence "could be wrong."

One further angle in connection with "not believing" or "not wanting to know" terrible news is what can be considered as a "healthy denial" or not losing hope. Many families in Latin America and of Mediterranean origin believe that "hope is what dies last" and therefore acting as though the bad news did not really register is an important coping device, then they have to face things as they happen, not before. Well-intentioned personnel from various medical centers in urban hospitals from modern cultures might worry that some families "do not really comprehend" or "do not realize" the seriousness of a disease or a fateful prognosis and see that as a sign of a pathological coping strategy. This is an open question: within different cultural worldviews, alternative coping strategies might be understandable. The quality of the doctor–patient or doctor–family relationship in different cultures is a determinant issue as well. In many traditional cultures, the doctor "gives orders" or "makes prescriptions" and the parents' opinions are not as determinant as it might be in a more "customer-oriented" society. The doctor may be seen as an authority figure, who decides what is to be done and prescribes a course of action. Parents from a non-Western culture who are immigrants in an industrialized country may see their clinician in that fashion, and feel that if the doctor recommends something, they really should not question the doctor, and even if they disagree with a procedure or course of action, they may not wish to offend the doctor, and agree to recommendations even if they really do not agree with it. The clinician in these cases may want to give time to the family to reflect, if possible, and to encourage them give their "true opinion" openly.

A further matter is to consider the parents' health care decisions from a cultural lens. To give one example, Mexican mothers in the United States who are offered an amniocentesis (after a high level of alpha-fetoprotein has been detected in the mother) tend to decline the procedure more often than other mothers (Browner et al. 1999). Alpha-fetoprotein is associated with a much higher risk of malformations in general, and trisomy 21 and spina bifida in particular.

Even among Caucasian and African American parents, if they have religious beliefs against abortion, they may not necessarily "want to know" or to have to make a decision regarding continuation or termination of the pregnancy in the case of conditions like Down syndrome.

A related issue is the "genetic counseling" that nowadays is non-directive in most hospitals in industrialized countries. A family may hear the statistical figures about the risk of having another child with autism, or with a certain syndrome after having had a previous child with such condition, and despite a high risk involvement, they may indeed go on to have another child despite a high risk of repetition of the illness. This may be rooted in the belief—which has a higher priority than the scientific advice—that each pregnancy is determined by the will of God and therefore He decides what the new child will be like. The parents may well accept another child with the same syndrome as tests that God gives to that particular family for unfathomable reasons. The same occurs with some very profoundly Christian families in Westernized societies.

There are also cultural factors as to "which conditions" or alterations are considered more ominous or unbearable. For instance, if blindness, deafness, a brain malformation, etc. are announced, they may be more or less acceptable or terrible for parents, who base their decisions on the perceptions of the quality of life their baby would have, and the social stigma associated with it, the availability of services for such a child, and the likelihood of leading a happy life in the future.

There are crucial cultural implications in what it means and what are the consequences for the child and the family, if a son or daughter has major handicaps or malformations in highly technological societies in contrast to conditions of rural poverty in a non-industrialized country. Having a child who chronically requires a respirator, who needs oxygen for a long term, or has a tracheostomy, who may require physical therapy due to cerebral palsy, or who is blind or deaf, all of those situations represent different challenges for a family in one condition or another. Parents who live in precarious circumstances may feel forced to make difficult decisions because of the sheer number of stressors they are already facing and because they might not be able to afford all the services the child wound need. Also, the needs of their other children may have to be taken into account.

In certain situations, parents also may face conflicting advice or "diagnoses" from the medical establishment, which may disagree with the prophecies or opinions of a fortune-teller, a psychic, a witch-doctor or other folk healers who may give a different prescription than the one offered at a hospital. Who should one believe? There is some suggestion that in urban Western hospital centers, parents who are perceived as less educated or less receptive, may not even be offered some prenatal diagnostic procedures; this was a finding in a study involving South Asian parents (Rowea et al. 2004). In some centers, pregnant Muslim women might be viewed stereotypically as "not wanting" prenatal testing in any circumstance. In reality, from an Islamic point of view, a termination of pregnancy is permissible if it is carried before a certain number of weeks, as in Pakistan (Ahmed et al. 2000). This involves the issue of "ensoulment" of the baby in uterus, that is, the time at which the fetus is considered to have a soul, which occurs around after the 120th day (Al-Matary and Ali 2014). Of course, official religious sanction may or may not agree with cultural traditions in different regions.

The Infant with Chronic and Other Health Conditions

The birth of a child with major health problems, such as a malformation, a chronic illness, or who is extremely premature provokes a number of reactions in the parents and the extended family. The responses may vary from a feeling of rejection and horror, to one of estrangement and thinking that the child is "too different," or to a complete acceptance of the child the way "he or she is" as well as many other emotions. When the condition is grave and requires special care and multiple or costly treatments, this adds further stress to the parents/extended family; moreover, the child may require repeated hospitalizations, surgeries, and complicated treatments which may be financially prohibitive for many families and drain their emotional and financial resources.

In such conditions, it is only natural that people from different backgrounds look for multiple possible explanations as to why the child has these difficulties and what should be done to help. There are historically a great number of traditions and beliefs, many of which have been disappearing with the progress of science. However, the basic issue of how one reacts to the birth of a "different" child, someone strange or unusual, is still a part of the human psyche, which is reflected clearly in the myths, traditions, and practices of many cultures. Nonetheless, even in the most industrialized countries and modern societies, there are similar reactions to the birth of a "different" child, even if no transcendental, supranatural, or magical beliefs are invoked.

Historically, when a child was born with a severe medical condition, the more severe or deforming the condition was, the more ominous the meaning for the family and the surrounding society. At times, these children were left to die or actually killed in some way. Often, the diagnosis of the problem was left to diviners, shamans, or religious figures, who gave the final judgment as to the nature of the condition dictated what was to be the fate of the child.

In many European cultures, as in many other parts of the world, infanticide of those born with significant malformations was commonplace.

This is said to have been a common practice in Sparta and others in which a child that had such a poor outlook was left to die through selective neglect (Scheper-Hughes 1990).

One of the most common responses to the birth of a child with a severe disease or unusual somatic features is a feeling that something went wrong from external sources, another is that the child represents a punishment for a transgression or an omission, or that the child might even be a message from higher beings such as ancestors or gods. These theories also apply in cases in which a child has unusual or difficult behavior, not just odd bodily features. The main groups of causal explanations could be described as: (1) the untoward emotional state of the mother during pregnancy which can have a negative effect on the baby. (2) A transgression or a sin by the mother, her husband, or a close member of the family, may lead to a punishment that impacts the baby. (3) The child has been changed, and instead of the normal child, there is now lying there an unusual baby who really belongs to another world, or has a different nature, such as fairies, demons, or spirits. (4) The child is the product of an unnatural liaison between the mother and an evil spirit, a fact of which she may or not be conscious. The child is a "mix" or a "hybrid" of human and nonhuman, a product of unwitting or willing intercourse with a fairy, a spirit, a *djinn*, or a wondering spirit. (5) The child is seen as born with problems as a result of God's will. In many traditional groups, it is thought that one's life course, events, and outcome are written at birth (in Arabic, *maktub* = written) in the person's life book, which may represent also a test of one's faith to be accepted and endured without question. (6) In "scientific" explanations (such as genetic disturbances, effect of natural causes in utero, etc.) the condition does not have to consist of physically visible malformations but can be invoked in the case of difficult behavior in the baby or small child.

A further consideration for parents is the cultural group's acceptance of children (and families) with disabilities. While in some social groups it is quite acceptable to take children outside, to a child care center or other public places where there may exist numerous accommodations for them, in others, there is much a stigma of having a "defective" child.

A Japanese family seen by us recently, had a preschool child with autistic disorder who slapped himself repeatedly on the head, and had to wear a helmet in order to prevent serious lesions to his head. The parents were immigrants into the United States. They appreciated all the services the child could receive (language, occupational, physical and behavioral therapies) but they dreaded to take him outside or to a park even. They were very worried about the impact that seeing a child "like their son" might have on other people. Seeing a young child hitting himself might feel onlookers feel uncomfortable and they tended to keep him inside the house as much as possible. They were not ashamed of him, but feared that others might be offended by looking at him, as it might have been the case in their country.

Parents, of course, generally wish their baby to be healthy, and if possible, beautiful. In many modern countries, there is now the expectation that the child should be perfect physically. An author has suggested that in the "new culture" in Israel, for example, there is a strong admiration for perfect, strong muscular bodies, and disabilities are considered almost unacceptable, at least from the emotional point of view (Weiss 2007). With globalization, the phenomenon may be more pervasive in various social groups that increasingly identify with "strong bodies" and "perfection" and are intolerant of "defects" in people, male and female.

We illustrate some of the above explanations with a few common beliefs in various parts of the world.

In rural Ireland, until recently, among some families, there was the belief that a newborn could be taken away by fairies or other supernatural beings, such as elves, wood spirits, underground beings and other non-human creatures (this was also true in Eastern Europe). These entities desire a beautiful child and take away such baby, and leave in place of the human, one of their own instead, that is, the good and perfect child is changed for a "defective one," therefore, the notion of changeling (Zhang 2013). An anthropological study found that this belief accounted as an explanation for children who behaved oddly, cried too much, or had a malformation. This is a traditional belief also in some areas of Germany where the term *wechselbalg*, and in Dutch *wisselkind*. Other signs are a large head, an odd facial appearance, and excessive crying in the baby.

In folklore, it has been described in Switzerland that children who had mental retardation due to "cretinism" were of good luck, because such son or daughter is like a repository of God's anger, which therefore is focused only on that child and thus spares the rest of the community or village (Eberly 1988).

One could say that often, below the surface conscious beliefs about the natural causes of illnesses and malformations, there is frequently a measure of guilt in parents, a suspicion that they might have done something wrong to bring about the negative outcome, or the fear that they somehow are under the influence of powers they cannot comprehend or control. However, at the conscious level, an external cause is a sort of protection, the child kidnapped by a fairy and taken away, while she left the "wrong child" on the crib, protects the family from any feelings of guilt.

An infant with hydrocephaly could be considered as a changeling due to the large head. One that cried excessively also revealed thus its "obstinate nature." If the child shows developmental delays, and does not move much and later on does not talk, this may be judged as evidence of the unnatural origin of the baby.

The Infant as a "Hybrid" of Mixed Being

In many societies, the birth of an infant with some sort of malformation was thought to be a "sign" of something, it could be ominous, frequently, or occasionally, a sign of good luck. Some characteristics such as webbed feet, or a peculiar facial structure, or a scaly skin (*ichtyosis)* often were considered as signs of the "hybrid" origin of the baby. The child would be the product of a relationship between a mother and an alien or supernatural being, who could not be seen, but whose presence is testified by the birth of the "mixed" child. The union between the mother and the supernatural being is often unknown to the mother, and the causality only assigned after the birth.

In the traditional British culture and in many others, there were beliefs that humans could cohabitate, often unwittingly, with supernatural beings and then a "hybrid" being would be produced. In Greek mythology, this often gave as a product, a semi-God with superior capacities or powers. In the British Isles, particularly in the coasts, it was thought that humans might cohabitate with mermaids and produce hybrid beings. Similar folk beliefs were also common in the Scandinavian countries. The mermaids were usually thought to be beautiful, while the masculine fish-like fairies were thought to be ugly, but they also could have intercourse with human women. In old times, children who were born with fusion of the legs (*syryngomelos*) were believed to be a product of such unions. A similar explanation could be invoked if the baby had "scaly" skin, or had webbed fingers or webbed toes (syndactyly). In the folklore of Scotland, it was thought possible for seals to have unions with humans, giving birth to children with similar malformations to the ones described above. Anencephaly was thought to be the "head similar to that of a seal."

In Scandinavian folklore, there were accounts of "trough backed women" called *ellewomen* (Briggs 1976), who were beautiful, and could correspond to disorders of the closure of the neural tube (rachischisis) in the spinal area.

Cretinism, a form of early hypothyroidism which, if untreated, leads to intellectual handicap and poor growth, used to be endemic in regions where iodine was not available in people's diet, such as some parts of Switzerland and Franconia, Germany (Persing et al. 1989). It used to be ascribed to the Devil impregnating maidens. It is said that Martin Luther advised the prince of Anhalt to drown a child like that in the local river, as it was only a "piece of flesh with the soul of the Devil."

Beauty, Malformations, and the Perception of the Baby

Malformations, particularly when they are severe, confront parents directly with the challenge of having a child who not only may not be "attractive" but may elicit contradictory feelings. It is natural for parents to have multiple and conflicting reactions to cleft lip or palate, a missing a finger or to have an extra one, or indeed or any other major morphological problem, from empathy toward the baby, to anger, worry about the future of the child and uncertainty as to what is going to happen. In modern societies, genetic testing may be available to diagnose and treat these conditions. However, we find that in the mind of many parents, despite all the scientific underpinnings and explanations, there is often the doubt as to whether they did "something wrong" or violated a hygienic precaution to have caused or contribute the condition in the child which might be "their fault" or a sign of such transgression.

In many cultures, there is an "externalizing explanation" for such a condition, particularly if it is severe, and the explanation may provide some relief to parents and relatives, for instance, if an evil spirit penetrated in the child and caused the malformation. In the case of Abiku (Ilechukwu 1990), a condition often diagnosed in families in Nigeria, the child with a malformation can be thought to bear the "marks" of a spirit that was mutilated in a previous life and now has reincarnated in this new body, carrying the scars or mutilations of previous maltreatment. In other cultures, like in various areas of India, a child with cleft lip may be ostracized by other children or adults, even by neighbors, who may avoid such a child, as the young person is thought to bear the mark of some transgression or impurity on the part of the family, that is, the malformation is a "punishment" for some misdeed, which makes the child and his or her family different from everyone else, and unacceptable. The family may themselves have that belief and the child in question grows as though he or she were the bearer of such shame. Many of these reactions and beliefs still apply in many areas of the world and in Westernized cultures as well, even though at a less conscious level.

If there is a perception of the family somehow being "at fault" when a child with a dysmorphic condition is born, the social reaction may also include ostracism of the child and/or family. Others around them may fear that the affected family might invite negative influences to occur also in a village or geographical area and it would be better if the family vanished or disappeared.

An additional complication may be the reactions of the extended family. On occasion, the families of origin of the child's father or mother, who have made a matrimonial contract "between families" start to argue or blame each other for having carried some kind of "hereditary taint," or from being of a bad stock, or for possible representations that the malformation is the result of being part of a bad family. The spouses also can blame each other, or one spouse blame the other as having caused the problem due to behavior or lifestyle issues.

A family treated by us, originally from China came for treatment, they had a set of twins with a chromosomal disorder that led the twins to develop developmental delay, cerebral palsy, and difficulties with sleep and disruptive behavior. In the course of treatment, much marital discord arose to the surface. One part of this was the mother's view that her mother-in-law had blamed her for "not being able to bear healthy children." Indeed, the mother-in-law had told the babies' mother that she should "throw herself from a building with her two useless kids." The children's mother was very offended because her husband did not defend her at the time, instead he acted deferentially toward his mother. His argument was that his mother "did not mean that" but only had said something in anger, and his wife should not be offended. This impasse had lasted about 12 years.

Among members of a tribe in Benin, the Bariba, witches are thought to be present at the birth of children. They can influence a negative outcome or cause the appearance of odd features, such as a breech presentation, a baby born with teeth, or with more fingers than normal (polydactyly), which indicates the evil influence in the child, who has been "born to die" (Sargent 1988).

The diseases of children with obvious malformations used to receive descriptive or mythical names such as "mongolism" or "moronism," and the child described with names such as cripple and spastic. which now are unacceptable in Westernized societies. Not many years ago, many syndromes still had such names such as "gargoylism," that is, the child looking like a gargoyle, which was given to the various mucopolysaccharidosis syndromes (Hunter, Hurler, Sanfilippo, Morquio syndromes).

Conditions like hydrocephalus, Cornelia de Lange syndrome, Kabuki syndrome, and many others challenge strongly the view of the "beauty" of babies, and force parents and relatives to "make room" in their minds to the baby they have in front of them and who may be quite shocking at first, and only gradually they may get used to the "new normal." In England and the US, not many decades ago, it was customary to "institutionalize" children who had major handicaps and malformations, keeping them away from the family, in part because of their needs, but also due to issues of social stigma, shame. These segregated children were hardly ever talked about or discussed in public.

It is also well documented that in the name of "Eugenics" the Nazi ideology in the 20s and 30s of the XX century advocated (and in many cases carried out) the "euthanasia," that is, the killing of children with handicaps as they had "lives not worth living." In many other countries, there were groups that feared the reproduction of "defective" human beings also in the name of preserving a "good genetic pool" and for decades the forced sterilization of many people was carried out in a routine manner in institutions for adults with mental and intellectual handicaps. These are events of the recent past, but they illustrate the challenge that it may represent for parents and societies to deal with children who have major medical conditions or malformations.

Several anthropologists have discussed the fact that in many traditional societies, the practice of "selective neglect" of children who have major malformations or diseases is still carried out. In most circumstances, this is related to the poverty of the family, the scarcity of resources, the enormous need of medical care of a child in social groups without supportive structures to provide such care, and the need to look after the other children (Scheper-Hughes 1990). It is important to understand that in some of these cases, the families may see as their only option to practice some form of infanticide, for instance, if the newborn is thought to be a "witch baby." As mentioned, among some Bariba in Benin (Scheper-Hughes 1990), the diagnosis of the baby being a witch may depend on physical signs and malformations, and even on whether the upper teeth appear before the lower (mandibular) ones which may be interpreted as the baby having its origin in the underworld.

Infanticide has been practiced all over the world for centuries, and in part this depended on the question on whether the child is considered as being "a person," in the first place, as in some of the scenarios already described. At times, a selective neglect of the baby is practiced, and if the baby is very small, weak, does not eat well, or shows signs of illness, the parents may interpret that the child "does not want to live." This obviously brings up many ethical dilemmas, but it is important to understand that from such frame of mind, the baby is assumed to not belong in this world, or it is thought he or she represents something dangerous and taboo. The baby may be thought to be an "embodied spirit" and if the spirit returns to its world, he or she will be more comfortable.

In the West, the dilemma of "personhood" is often seen on the question of abortion (when a baby in utero is already "a person."). It could be at conception, after the 12th week, the 20th week of gestation, or at birth. In many cultures, a recently born baby may not really be a person until a certain ritual is practiced to "admit" the child into a family or group. Infanticide was until recently more common in India and China. In India, because of the burdens of having girls and having to save money to pay for a dowry years later when the girl had to be married off; in China, because of the (now revoked) policy of "one child only" per family, paired with a parental preference to have a boy who may be able to take care of them when they become old.

Western health workers in some of the areas where these practices exist may try to intervene to prevent these killings, or come for a period of time to perform a specific corrective surgery, for instance, to correct cleft lip or palate. Even if for the Western mind the "defect" has been repaired, this does not necessarily erase or alleviate the "internal nature" of the child, who may be a spirit, or a witch in essence still, and may continue to be stigmatized, together with the family. The child can be the repository of the blame for all the bad things that may happen to a family or a community and may be perceived to have evil powers. Several anthropologists have cautioned against the assumption that the mere reparation of a certain defect in a concrete way means that the child's life is going to have a much better quality of life from then on, but more interventions may be necessary after the surgery to help the child "reenter" social acceptability in the long term.

In most countries where this has been studied, there is a higher risk of maltreatment and neglect in children with major deformities, chronic illnesses, or those who demand a lot of attention from their parents, such as the ones who have excessive and persistent crying or chronic illnesses (Stalker and McArthur 2012). The reaction of parents and other relatives to the birth of a child with a serious condition that will lead to a motor handicap, or who suffers some sort of accident that leaves the child in that condition, have primarily an individual dimension. Each person has their own reactions as a mother, father, sibling, etc. to the birth of a child with such conditions. There is, however, also a cultural realm.

A researcher in Algeria (Kouadria 2000) described common reactions: the pattern of guilt and overprotection on the part of the mother, the intense devotion of the mother to the care of the baby and her anxiety about the child's future. But there is also an experience of shame as exemplified by several words in the local lingo which describe the handicaps with negative connotations, such as "*mahboul*" crazy, *meskoun* (possessed), *meshour* (bewitched) or *aieb* (crippled). Faced with the condition, the parents have to deal both with the "medical explanations" and treatments, as well as the traditional ones, such as the influence of djins (evil spirits or angels) which, to be placated, require the intervention of a healer (*taleb*). In the West, there is less "shame" for the child and the family, but in many traditional societies the child is kept from the sight of others or from going out in public for fear that people might look down and consider him or her as inferior or feel sorry for the child and the family.

Cleft Lip and/or Palate

In many cultures, there are strong beliefs in the supernatural, magical and magic regarding the etiology of cleft lip or palate. This is changing in most of the world, as parents are increasingly aware of the biological phenomena associated with these problems. However, there is still a widespread belief in supernatural etiologies (Black et al. 2009). A recent study in Nigeria among the Hausa and the Yoruba in rural Nigeria found that a majority of parents attribute cleft lip or palate to "ancestor spirits," other evil spirits, or "the will of God." A great proportion of families with an affected child had consulted local folk healers before going to the hospital or for treatment with modern medicine (Olasoji et al. 2007). In some groups in Mexico, the problem is often attributed to the mother of the child having been exposed to an eclipse during the pregnancy, or to alcohol consumption by the father. In many cultures, there is the belief that if a pregnant woman is frightened by a rabbit, the baby can acquire the trait, which also can occur if she laughs or makes fun of someone with a malformation.

Dwarfism

In North America and Europe, people with "dwarfism" (individuals with these conditions often prefer to call themselves little people or of short stature as the term dwarfism has a pejorative connotation) have historically been portrayed in movies and stories as amusing, mischievous, entertaining, or ridiculous. A recent study of attitudes of college students regarding the stereotypes and cultural perceptions of people with "dwarfism" (Heider et al. 2013) found that common opinions of the stereotype were "weird," "amusing," and quick tempered. Other beliefs were more positive, such as "intelligent," "capable," and the like. Some responders reported feeling pity and compassion for such a person and thought that people with the condition often appear childlike. In many countries, people with unusual body features were at times employed as a part of exhibitions, such as the "freak shows" in Britain and the United States (McHold 2008). These spectacles could include people with dwarfism and other conditions such as gigantism, morbid obesity ("fat people"), and women with hirsutism among many others. The meaning of these spectacles is multifaceted, but one aspect is the general anxiety and fear of "being like them" and the comfort people may experience in segregating them and seeing these persons as "not me" or as "the other." In some of these folk "displays," people with deformities would verbalize that their condition was due to "disobeying their parents" or due to greed, intemperance, or a punishment from God. It appears that socially there was both an anxiety, fear, and at the same time a fascination with the "oddity in the other." Also, those explanations as the condition being a punishment for misdeeds were meant as a warning for children not to commit social transgressions lest they be punished in the same fashion.

In some aboriginal cultures of the American continent, like the Mayans, and Moche (Rodriguez et al. 2012) individuals with achondroplastic dwarfism were considered as "liminal beings," that is, in the border between this and the other word, or a mixture of the human and the divine and were thought to have great power. They often worked in the arts, playing music and assisted in governmental functions.

Asthma and Other Respiratory Diseases

In urban centers, (Smith et al. 2005) asthma is a medical condition which has an important ethnic/cultural/social determination, as it concentrates among the poorest children, who live in conditions of humidity, infestation with cockroaches, and pervasive smoking in the small dwelling units, with the worst housing (Rosenbaum 2008). Asthma is more prevalent in ethnic minorities in many urban centers (Forno and Celedon 2009). A cultural element described in some Asian families (Smeeton et al. 2007) is the belief that the drugs used in the treatment of asthma could be addictive and do more harm than good. In a small study in England, parents from India and Pakistan also tend to use preventive measures less, and as a result the children may have more hospital visits compared with other ethnic groups. Some communities use dietary restrictions to deal with the asthma, for instance, among Bangladeshi mothers, a precaution to avoid asthma is restricting foods like banana and others that "irritate the throat" (Cane et al. 2001) and asthma can be considered to be contagious. In traditional cultures, the remedies for asthma, learned from older generations, may include rubbing wax on the chest, and drinking infusions, such as of lemon and honey. Many parents may see asthma not as a chronic disease, which requires constant treatment, but only as an episodic event (Van Dellen et al. 2008).

Ambiguous Genitalia

After the birth of a child, one of the first questions asked is of the health of the baby and the mother, and immediately after what the gender of the baby is, a boy or a girl. This may be a difficult question to answer if the newborn has ambiguous genitalia. Obviously this situation, being born "hermaphrodite" or "intersex" or with ambiguous genitals is very difficult for parents, as there often is intense emotion and investment in the gender of the child. There are then dilemmas such as whether the child "should" be raised, as a boy or as a girl, and questions about the reproductive capacity of the child later on. With such intense emotional investment, it is common for parents to feel confused, baffled, and anguished, when the medical staff says that there is a need for further studies. It may be difficult for the parents to actually see the genitals of the baby, which may include a "micro-penis" or clitoris, and the presence or absence of testicles in what appears to be labia, etc. This state, ambiguous genitalia, also has a strong cultural representation. In many societies, historically, the decision as to what gender to assign the child, has been left to the physicians, who with the best intentions may make medical and surgical recommendations, such as clitoridectomy, reconstruction of a vagina, etc. the medical team then may recommend to raise the child as a boy or a girl. There are multiple reports of this approach being misguided, as the child him or herself may be dissatisfied years later with the decision, and even more so as an adult (Lee and Houk 2010).

In a study in Saudi Arabia (Abdullah et al. 1991), there were a number of complicating issues: the need to consult religious leaders as to what Islamic law permits, what is their opinion, and then the wishes and opinions of the parents. Additionally, parents had a bias toward having a "boy" and even the staff may feel pressured to say "it is a boy" (it is customary for the parents to bring a gift to the doctor or nurse in the hospital if the baby is a boy). Also, there is the issue of consanguinity, like marriage between cousins, which is a common practice, and this makes conditions like congenital adrenal hyperplasia more common. Some parents were angry when they were told that, after all, the baby was not a boy. There are worries about the correction of the female genitals, due to the concern with the preservation of the hymen, which required doctors to issue a certificate explaining why the hymen was not intact, a very important concern. Also, grandparents often had the "last say" in the decision to assign the baby, rather than the parents. The doctors resorted in some cases to "not telling everything" to the parents so they would accept what was best for the child. Additionally, parents expect to conduct a "naming ceremony" within 7–14 days after the birth, which the extended family expects. Delaying this event in order to conduct hormonal and genetic tests represents a major complication for parents. Clearly, there are multiple and overlapping considerations as well as ideological/cultural and religious factors that need to be taken into account, and not purely the "medical ones."

Other issues in the decision are the increased risk of developing malignancies in some of these conditions as well as "salt wasting," that is, losing sodium through the urine due to hormonal imbalance. The pressure to bias the decision toward a boy is also noticed in China, India, Pakistan, and the Middle East in general (Warne and Raza 2008); for economic reasons, the boy is more likely to be economically independent and to be of support to his parents in old age. Also, a girl who is sterile, as many of these children may turn out to be, would be more difficult to marriage, she may eventually attract a stigma because of this and the parents may have difficulty in arranging a marriage. Another concern is the "privacy" one. If a child has ambiguous genitalia, this may be difficult to conceal as the child is likely to take baths and showers with relatives, including cousins.

An additional issue in the diagnosis and treatment of these states is that in many poor countries, there is no infrastructure for laboratory tests, imaging studies, genetic assays, nor for hormonal treatment or even the various surgeries that might be needed, and this may expose the infant later on to ridicule or ostracism.

Nowadays, there are many clinicians and anthropologists in the Western world who advocate to abandon the dichotomy male–female (Fausto-Sterling 2000a), and to adopt a more flexible approach along a continuum of identities and possibilities (Fausto-Sterling 2000b; Kessler 1998). This would mean to separate in one's mind what the "genitals look like," what the person feels and thinks he or she is, man, female, both, or some degree of each, and to whom the person is attracted to sexually or in terms of stable partnerships. The permutations are multiple.

In some cultures, there are conceptions that approach the notion of a "third sex" or "neither man or woman," for instance, *hijra* (hermaphrodite or eunuch, in literal translation from Hindi) in India. The approximate definition is a group of people who live together or in a community and are neither male nor female, it may include a variety of people really (from transvestites, to homosexual, to transgender, and truly hermaphrodite persons). They are however, rather ostracized, somewhat discriminated or "tolerated" groups, who often survive by singing at weddings and other festivities, or begging. In India, most parents would be scared if told their child would become a *hijra*.

In Samoa, there is a term *fa'afafine*, which is not as shameful and allows a man to "live like a female," but technically the person is neither male or female and is a "third gender" and the person is thought to embrace both "masculine and feminine qualities." In some cases, the assigned gender relates to the parents "deciding" that a boy should be raised as a girl, because of the wish for a girl and to help her in domestic work. In other cases, it is thought that the boy has a "feminine spirit" and therefore is not considered gay, as the actual genitals are thought to be of secondary importance. In older times in Hawaii, also it was recognized that some children were not either male or female.

Modern Societies and Technological Advances

In technologically advanced societies and among the wealthier classes in poor or developing countries, there are more "scientific" explanations for malformations. These are often not consciously seen as punishments, or as the already written fate. At the preconscious level, a mother often worries about whether something she did or failed to do might have contributed to a malformation in the baby, however, and she may feel guilty.

However, modern technology, for all its advantages also presents new dilemmas to the mother. When an infant in utero is already diagnosed with a major health condition, the parents have sometimes to "decide" what they want to do about continuation of the pregnancy, the kind of birth that they desire, or what measures if any to take from the medical point of view, once the baby is born. Also, there is the feeling of being a "carrier" of a genetic code that is abnormal, and then having to struggle with whether the couple would wish to have more children.

There are few scientific studies of these "new problems." Mothers are presented with diagnoses and malformations about which they do not know anything, such as "Kabuki syndrome" "Mitochondrial disease" and the information will often be obtained from the worldwide web in detail. The parents at times are given the option of seeking a termination of the pregnancy and they have to decide what they want to do, often without full information of the condition and deciding on religious and ethical grounds, as well as extended family pressures. If a mother is told in the second trimester that her baby will have a trisomy 21 and is offered the possibility of an abortion, what should she do? This is a very difficult dilemma and there is no "totally perfect decision" that will cause no regrets of some kind. Many mothers decide to leave everything in "God's hands" and may request that the baby should not be heroically resuscitated if he or she stops breathing. But other mothers want the medical establishment to "do everything" to keep the baby alive.

Infant Prematurity

Dealing with a premature infant, the prolonged hospitalization, and the sequelae that often accompany the condition have an important cultural dimension. A study with Korean mothers of premature infants showed that the traditional attitudes and values colored the reaction to the status of the baby. One of them is the sense of responsibility or "blame" of the mother for the problem itself; another was the stigmatization of a premature child or one with special needs, and the fear of expressing any negative thoughts about the whole experience. In their frame of mind, negative thoughts could bring about adverse events in the real world (Lee et al. 2005). Among the main causes of prematurity, there is chronic and severe stress, in the United States, young mothers, those who experience domestic violence and are in very difficult environments have a higher frequency of early end to the pregnancy and having to deal with a premature child.

There is a wide difference between poor countries and highly technological societies regarding extremely premature babies. In the more "modern" countries, it is possible to save very small infants, who may spend many months in a neonatal intensive care unit, undergo several surgeries, and eventually have to be fed with total parenteral nutrition, have a tracheostomy and ventilation in the long term, etc. The technology may not exist particularly in less urbanized areas of poor countries and such babies would just not survive. On the other extreme, in very technologically advanced cities, infants of little more than one pound in weight will survive and may develop important sequelae, from learning disabilities and attention deficit problems, to cerebral palsy, blindness, seizures and need to be fed by gastrostomy. These infants also represent considerable stress for parents who may have to devote most of their lives to the care of a child with multiple handicaps and this represents also a challenge for siblings. Public schools may or may not provide the required accommodations to have the child in the school setting and the child often develops a great sensitivity to illnesses and may not be a good candidate to attend school. Caring for a medically very fragile taxes the family intensely and may lead to "carer fatigue."

Stillbirth

Although less frequent now than in the past, the death of a child whom the mother has carried through a 9 month pregnancy can be a devastating experience for the parents, leaving emotional scars such as unresolved mourning, fear of having another child, and intense anxiety in subsequent pregnancies, as well as fantasies of having a "replacement child" in the next pregnancy, sometimes giving the same name as the one who died. Also, in many cultures there is the problem of what to do with the body of the baby and where the spirit of the infant would go. In the Catholic belief system, a baby who has not been baptized may not go to Heaven and instead "stay in limbo." In France, there used to be occasional shrines where still born babies could be buried and they would "briefly would be brought back to life" by the Virgin Mary, in order for them to be baptized, such as the "Lady of revival" in French *Notre Dame de Recouvrance* (Simpson 2014).

Infant Death

Similar explanations as those for illnesses or malformations can be invoked when an infant dies, which is one of the most painful experiences parents can go through. Cultural and religious beliefs help to alleviate the pain of this event.

In many parts of Latin America, from Mexico to Chile, the death of an infant is often referred to as the death of an "*angelito*" (little angel) and the funeral rituals may be different than those for an adult. In Chile like in other countries, people may be dressed in white (instead of the usual black) and the dead baby may also dressed in white clothes, and adorned with motifs that resemble a small angel (Simpson 2014).

In many cultures, an infant that is very small is thought not to "feel anything" until he or she reaches a certain age, for instance, 3 months. Perhaps, due to the previously high infant mortality in many places, the mother does not experience, or may not manifest, much grief if such a small infant dies. The "personhood" is only achieved months later (Friedl 1997).

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