

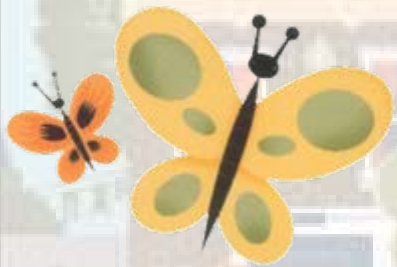
**EXPECTING A LIMB DEFICIENT CHILD:
HOW PRENATAL DIAGNOSIS CHANGES
THE NEEDS IN COUNSELING
AND SUPPORT FOR FAMILIES**



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CONTENT OF PRESENTATION

- Introduction: the mourning of the ideal child
- Precursors to parent-child attachment
- Patterns of mourning: limb deficiency discovered at birth
- Patterns of mourning: limb deficiency discovered in utero
- Main differences between the two patterns
- Conclusion: how can we help?



INTRODUCTION: THE MOURNING OF THE IDEAL CHILD

- Variety of timing: different starting points in life
- Different types of evolutions: abrupt or progressive
- Impact of rapid expansion of prenatal diagnosis on patterns of mourning
- Possibilities of resilience for attachment when challenged by the discovery of a limb deficiency



PRECURSORS TO PARENT-CHILD ATTACHMENT

- Desire for a child, conception and pregnancy, dreams about an “ideal child”
- Fantasies about losing the baby or giving birth to a malformed one as normal counterparts
- If pregnancy is unplanned
 - ✓ Dreams about an ideal child hindered by ambivalence or clearly rejected
 - ✓ Opportunity for attachment welcomed after all, emergence of the ideal child with some delay
 - ✓ Precursors to attachment fight their way through external sources of stress and fearful fantasies



PRECURSORS TO PARENT-CHILD ATTACHMENT

- Attachment to the fetus increases progressively as its movements are felt; fantasies about the ideal child mostly elaborated during the third trimester
- Attachment remains an abstraction until birth: the fetus is still a stranger, unseen, unheard and untouched
- At birth, the ideal child leaves the scene to the real baby. Patterns of attachment, separation and individuation can start and progress through a sequence of normal developmental stages and crises

PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED AT BIRTH

1- Acute and intense shock

- Parents might refuse to touch or even look at the baby
- Baby might be shoved away from parents, in order to regain "control" of the situation
 - ✓ Pediatric examination
 - ✓ Comforting care to distressed parents

PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED AT BIRTH

2- Confusion, guilt, anger and despair

- Rejection of the damaged baby who destroys the construction of the ideal child: parents feel guilty
- Parents feel responsible for the anomaly: more guilt feelings
- "Why our baby???"

PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED AT BIRTH

2- Confusion, guilt, anger and despair

- Baby's future seems shattered
- Parents feel unable to cope
- If readjustment impossible, attachment fails (placement in orphanage in other times or other countries)



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED AT BIRTH

2- Confusion, guilt, anger and despair

- Professional efforts to comfort
 - ✓ Minimising the situation, denying parents' right to their pain
 - ✓ Unrealistic promises
 - ✓ Leaving the parents alone, not knowing what to do
 - ✓ Empathic support and realistic information

PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED AT BIRTH

3- Sadness, guilt and anxiety

- Contacts with extended family and friends: support or supplementary burden
- Infant care claims realistic attention, distracts from the pain
- Parents start to pay attention to family characteristics in their child



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED AT BIRTH

3- Sadness, guilt and anxiety

- Awareness and anxiety about all bimanual activities
- Hypersensitivity to strangers' looks and comments
- Fear of future social exclusion and low self esteem
- Anticipation of grown up child's blame

PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED AT BIRTH

4- Efforts to repair or compensate, reconstruction of confidence

- Parents search information about possible surgeries, prostheses or other means to compensate
- Baby develops normally: parents' anxiety about adult autonomy decreases, focuses on specific details
- Recuperation of parental feeling of competence

PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED AT BIRTH

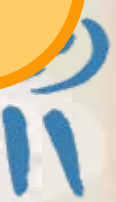
4- Efforts to repair or compensate, reconstruction of confidence

- Mourning resolved when parents renounce to make pain disappear completely
- No clear cut line for normal length of mourning: succession of normal crisis, one at a time
- Moving forward through healthy attachment process



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

1a - Diagnostic confirm in a single ultrasound: acute and intense shock

- Shock experienced more like a threat, or anticipation of an impending disaster, instead of a "fait accompli"
 - Ultrasound radiologist explains the limb deficiency; attitude and choice of words are reported to be a major factor influencing parents' initial perception of the severity of the deficiency
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PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

1b - Diffuse and growing anxiety: suspicion precedes confirmed diagnostic

- Anxious fantasies, parents trying to "prepare for the worst", but hoping that suspicion will be eliminated with next exam
- Intensity of shock varies with parental reactions and quality of support during the waiting period
- Parents will usually have discussed the possible anomaly, if suspicion was expressed clearly



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

1b - Diffuse and growing anxiety: suspicion precedes confirmed diagnostic

- Ultrasound radiologist will have more time to control emotional reactions and choose words
- Consultations with specialists often arranged in short delay





PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

2 - Confusion, guilt and despair, high level of diffuse anxiety

- Damaged fetus destroys parents' construction of their ideal child: parents feel guilty of rejection
- Parents search explanation in themselves, feeling responsible for the anomaly
- Anger with question "Why our baby???"
- Baby's future seems shattered
- Parents feel unable to cope



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

2 - Confusion, guilt and despair, high level of diffuse anxiety

- The appearance of the limb deficiency is still an abstraction: parents might imagine the worst, then hope it will not be so bad after all
- Unlike full term newborn infant, fetus is still an unseen, unheard and untouched stranger
- At 20 to 22 weeks, construction of ideal child still vulnerable



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

2 - Confusion, guilt and despair, high level of diffuse anxiety

- Medical termination of pregnancy might be chosen
- Choice to continue or terminate a desired pregnancy might depend upon the type of professional consulted
- Consensus in guidelines for practice about non directiveness in counselling, very difficult to achieve in practice



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

2 - Examples of different professional attitudes

- “I can’t see anything there, only a stump.” Hearing that statement, distressed mother reports feeling pregnant with a hand that wasn’t there. Ideal child destroyed, emerging construction must be reorganized in the middle of anguish and sadness
- “Your baby is in good health. One hand is missing, but her growth and everything else is all right. Your little girl, you’ll see, she’s going to do so many things.” Immediately talking about the baby prevents reduction of fetus to a missing body part. Emerging construction of ideal child challenged, but preserved



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

3 - Sadness, guilt and anxiety

- Telling the rest of the family is difficult when parents themselves have only a vague idea of what the limb deficiency will look like
- Sadness, guilt and anxiety are powerful obstacles to normal elaboration of the ideal child during the third trimester
- Parents are more focused on their painful thoughts: fetus' claims for attention are much more discreet than those of a newborn baby
- Difficulty in elaborating precursors to attachment might result in fear of not being able to attach to the baby



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

3 - Sadness, guilt and anxiety

- Anxiety about child's future won't be counterbalanced by actual development until birth and emergence from neonatal period
- Prenatal diagnosis might be an opportunity for parents to prepare themselves to greet a different child. Being actively involved in search for repair and compensation before birth might help to restore hope and reorganize the construction of the ideal child



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

4- At birth, reactivation of the crisis

- Parental perception of the limb deficiency might be worse than expected: a second wave of shock is felt
- On the contrary, if it is not as bad as expected: relief, instead of second shock, especially in cases of prenatal suspicion of other anomalies, even if eliminated before birth
- Second anxious waiting period, as neonatal tests are performed, fear of other "bad news"



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

4- At birth, reactivation of the crisis

- For parents who have started the reorganization phase between prenatal diagnosis and birth, resolution might come earlier
- When deep sadness and anxiety have characterised the last part of the pregnancy, there is a high risk of prolonged and difficult mourning. Knowing about the limb deficiency before birth puts on parents, especially mother, the burden of a deliberate choice to give birth to a child who might have a low quality of life



PATTERNS OF MOURNING: LIMB DEFICIENCY DISCOVERED IN UTERO

5- Efforts to repair or compensate, reconstruction of confidence

- At this point, parents already have some information about therapeutical options, but it is often incomplete. Therefore, they might have made choices without having all the elements needed
- However, the rest of the steps to mourning resolution are similar to what parents who discovered the limb deficiency at birth go through: baby's normal development is reassuring, feeling of parental competence is restored, normal patterns of attachment, separation and individuation follow their course



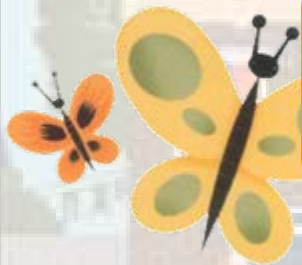
MAIN DIFFERENCE BETWEEN THE TWO PATTERNS

Discovery at birth

- Free elaboration of the ideal child during 3rd semester of pregnancy
- Destruction of the ideal child by the newborn "damaged" baby: in our culture, low risk of total rejection by family (placement)

Discovery in utero

- Construction of ideal child challenged when still vulnerable
- Non negligible risk of medical termination of a desired pregnancy if reorganization of ideal child construction is impossible



MAIN DIFFERENCE BETWEEN THE TWO PATTERNS

Discovery at birth

- Deep shock, limb deficiency is a "fait accompli"
- Newborn baby is present to show other characteristics: lower risk of being reduced to a missing body part

Discovery in utero

- Appearance of limb deficiency remains an abstraction until birth: diffuse sense of an impending disaster
- Fetus remains an unseen, unheard and untouched stranger: high risk of being reduced to a missing body part



MAIN DIFFERENCE BETWEEN THE TWO PATTERNS

Discovery at birth

- Reorganization facilitated by infant's realistic day to day claims for attention (distracters from parents' pain)
- Reassurance by normal psychomotor development comes soon

Discovery in utero

- Fetus' claims for attention much more discreet, not enough to distract from parental pain
- Long delay before normal development counterbalances parental anxiety about child's functional and social future



MAIN DIFFERENCE BETWEEN THE TWO PATTERNS

Discovery at birth

- No preparation to greet a different child
- Mourning starts abruptly at birth
- Parents might feel guilty for limb deficiency and attachment difficulties, but not knowing before birth means they had no choice

Discovery in utero

- Opportunity for family to prepare for greeting of a different child
- Impression of going through the crisis twice
- Some parents, especially mothers, feel the burden of their deliberate choice to give birth to a child who might live a miserable life



MAIN DIFFERENCE BETWEEN THE TWO PATTERNS

Discovery at birth

- Counterpart is anger for perceived medical incompetence to make or communicate prenatal diagnosis

Discovery in utero

- We have met some parents unsatisfied with professional approach to prenatal diagnosis, but none who questioned the pertinence of prenatal tests

CONCLUSION: HOW CAN WE HELP?

- Constant readjustments in guidelines for practice in an effort to keep up with new medical technology
- Peer support for professionals dealing with emotional crisis when communicating a neonatal or prenatal diagnosis
- Consultation with specialists (physiatrist, orthopaedist) in short delay: it's difficult to talk about the expected quality of life for a limb deficient child if you don't know much about it

CONCLUSION: HOW CAN WE HELP?

- Remember that professional approach and choice of words is a major factor in parental perception of the severity of the anomaly: realistic information is needed, but care must be taken not to reduce fetus or baby to a missing body part
- After medical consultation, psychosocial support should always be offered, preferably by specialists (to expecting parents as much as to new parents)
- As soon as possible, think about the whole family in your counselling, especially siblings

CONCLUSION: HOW CAN WE HELP?

- Don't presume that parents who met with specialists and had time to prepare themselves before the birth of their limb deficient child have integrated all the information available: check and offer more
- Even after resolution of critical phases of mourning, psychosocial help should remain available whenever pain is reactivated during normal developmental crisis



HOW ABOUT YOUR TEAM
EXPERIENCE ON THIS MATTER ?

Please, share it with us!

Thank you for your indulgence about my
eventual exotic use of English
phonology, spelling and grammar...



SOURCE OF THE TRANSLATED EXCERPTS FROM FRENCH SCIENTIFIC LITTERATURE (Slide 21)

- BEN SOUSSAN, Patrick et al. (2006).
*L'annonce du handicap autour de la
naissance en douze questions.*
Ramonville-Saint-Agne, Erès, pp 54-57

*(The announcement of a handicap
around birth in twelve questions)*





THANK YOU !

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LE CENTRE DE RÉADAPTATION MARIE ENFANT