MEDVET - VET PROGRAMME FOR MEDICAL PRACTITIONERS SUPPORTING PARENTS OF BABIES WITH DISABILITIES AND COMPLEX NEEDS

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PREFACE

Over the years, the improved medical care and increasing more advanced paediatric intensive care units have increased the survival chances of children with severe health conditions. At the same time however, among the surviving children, the effect was inevitable in terms of brain and neurodevelopment. Especially in European countries, the increases in children born with congenital anomalies have increased significantly. Medical professionals are the first to meet parents during the diagnosis in prenatal, delivery and postpartum period. Obstetricians, neonatologists, paediatricians, neurologists, nurses, midwives, physiotherapists and other health professionals constantly communicate with the parents of babies who are at risk to develop disability or whose disability was already diagnosed in the foetus.

The relationship between medical professionals and the family begins with sharing the diagnosis of the atypical developing baby to the family, explaining the required medical care for the baby, the consequences of the baby's disability or health condition and the possible problems that await the newborn and the family in the future. In order to address the difficulties that the baby and their family will encounter throughout their life, the family needs guidance on behalf of professionals in their common efforts to find solutions. To achieve a good collaboration, efficient yet human communication us required between medical professionals and families regarding how to care for a baby with disabilities, and how to deal with the envisaged difficulties.

Specialized training courses for health professionals how to communicate and interact with parents with congenital disabilities have not been widely implemented so far. Equally, insufficient information is given to professionals during their formal education on how to properly communicate with parents.

This book, which we prepared within the scope of our MEDVET project, consists of a vocational training program prepared for health care professionals and medical doctors in order to contribute to the learning of appropriate communication principles and their usage in clinical practice. It was developed by experts and is divided in ten different modules. The educational content has been enriched with LiveBooks (available at https://medvet-project.eu/livebook/en/index.html) which offers different narratives for a better and easier understanding of the training material.

We hope that this book will be beneficial for all healthcare professionals working with newborns and their family, enhancing their communication skills, and gaining a new perspective.

MODULE 1

INTRODUCTION TO THE INTERACTION WITH THE PARENTS OF NEWBORNS WITH CONGENITAL DISABILITIES AND PREMATURE BABIES

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    1.1.3. Taking On Parenting Role
        1.1.3.1. The Infant’s Needs
        1.1.3.2. Difficulties in The Case of Neonatal Intensive Care Units
    1.1.4. Parents’ Needs and Support by Medical Staff

The purpose of this module is to offer support to parents of children with congenital disabilities or born prematurely in dealing with emotions and problems, in the first days after finding out about the diagnosis or while waiting for it.

The learners will be able to find out what are the emotions that parents go through, the losses they experience, how the mind and body reacts in these situations, what are the risk factors which can transform an event into a traumatic experience and the unfolding stages of the traumatic process, in order to better understand which is the best approach to the parents in these situations.

The learners will find out:

- **what are the needs of the parents** while the baby is hospitalized and after being discharged,
- **the difficulties in assuming the parenting roles** while the baby is in the neonatal intensive care unit (NICU),
- **how the medical staff can help the development of the parent-child relationship.**

They will understand which are the specific signs of anxiety, post-partum depression, panic attacks, or traumatic stress disorders and the importance of recognizing them in the hospitalized mothers, in order to advise seeking specialized help and offering support while in the hospital.

And last, but not least, which are **the basic principles of assertive communication by medical staff.**

1.1. EMOTIONAL ROLLER-COASTER

1.1.1. LEARNING THE NEWS

During the pregnancy the parents have a lot of hopes, dreams, expectations regarding the moment when they are welcoming the baby into the world. Parents attach to their child a projection into the future through fantasies and dreams. It is a psychological preparation for them as future parents.

These positive assumptions give them confidence and mobilize them to make future plans.

The child may be seen:

- as a psychological and physical extension of their parents, a combination of their characteristics
- as a person to fulfil the wishes of his/her parents
- as a way to achieve immortality, carrying on the name to the next generation
- as a gift of the mother to the father
- as someone who can strengthen the family relationships

In addition, **the parents must cope with stress, grief, sadness, fear, disappointments**, and unexpected challenges that can lead to a crisis or even disruption of family life.

When their newborn child has a congenital disability or prematurity, the parents are confronted with the possibility that their future would be different from what they had imagined.

The probability of future impairment and disability shatters all these/their precious dreams and fantasies. The joy of becoming parent may be diminished by the realization that the child could have a lifelong illness or disability.

The parents have to face and raise the child they have, letting go of the dreamed future.

They have to continue their lives and generate new attainable dreams. Before that however, they have to go through the process of grieving.

1.1.2. COPING WITH THE LOSSES

1.1.2.1. PARENTS' LOSSES

The parents may lose:

- dreams, fantasies, projection of the desired child
- the image they made of themselves as parents
- expectations related to the child's achievements in various stages
- belonging to the community
- the understanding of the partner or the family
- beliefs/ vision about life, safety, health, power, control

In addition, mothers with premature babies lose:
- few weeks or months of their pregnancy and preparation for the arrival of the baby
- the faith in their body's ability to carry the child to term
- the type of delivery that she wants
- moments after birth: cuddling, nursing, meeting with the extended family
- sense of community, because other members of the family and other mothers don't know what she and her baby experienced

What mothers perceived that their babies lost during hospitalization:
- the safety of the womb, her arms, her voice
- the touch
- parental affection

1.1.2.2. COMMON PARENTAL REACTIONS

There is no right or wrong way to grieve, and in this process the parent may experience a wide range of feelings and physical symptoms after they hear the news / diagnosis: shock, denial, incredulity about the diagnosis, numbness, emptiness, fear, anxiety, sadness, sorrow, confusion, anger, frustration, desperation, hopelessness, guilt, envy, anger, longing, depression, agony.

These emotions are related to the experience of loss and grief, and they depend on factors such as personality, perception and feelings about the disability, cultural norms, family beliefs etc.

These emotions change in a cyclical manner "like a roller-coaster", where happiness of being a parent interspersed with distress and sadness.

Understanding common reactions of parents and the process of their grief can help healthcare professionals offer appropriate **support over time.**

1.1.2.3. THE GRIEF PROCESS

Grief is a fluid and complex reaction with the loss of the expected normal child and the necessity to develop a new role of attachment to the real child.

The process of grief and adjustment is similar for parents with newborns with disability, prematurity or parents with perinatal death or loss and broadly follows the stages of the Kübler-Ross grief elaboration theory: **denial, anger, bargaining, depression and acceptance.** There isn't a linear process and the stages overlap.

Working through grief in the case of a child's disability is an ongoing process with periods of greater and less intensity of feelings, an alternation of hope and despair.

Adjustment and healing happen gradually over time, reaching a point where the parent can accept what happened and the child as he / she is.

The coping process is dynamic, a constantly changing cognitive and behavioural effort by the parent to overcome external and internal stress factors.

Families can adapt flexibly and mobilize into effective action or can freeze in various degrees of maladaptive, ineffective, rigid reactions.

Parental Reaction to disability

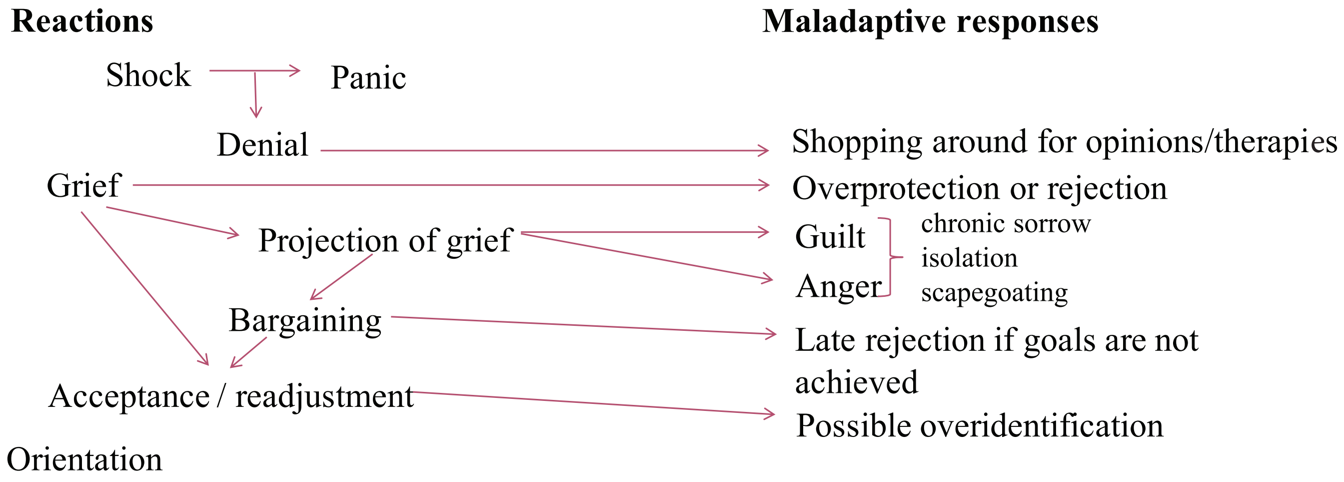

Figure I - **Model for parental adjustment following disclosure of disability.**

1.1.3. TAKING ON PARENTING ROLES

For parents, pregnancy is an adventure. For mothers the entire period is a very challenging time, both physically and psychologically and for the baby the birth is a huge event when everything changes.

After birth, the children are totally dependent on their parents' love and on caring for their physical and emotional development.

The parents who are glad for the birth of their baby and who can offer protection, love and caring for the infant, create an emotionally different environment compared to the situation where the baby is not wanted or accepted as s/he is.

The baby's harmonious development (social, emotional, but also physical and cognitive) depends on the state of mind of the parents and especially of the mother, because babies are in symbiosis with their mothers even before they are born.

The concept of attunement of Daniel Stern, a modern psychoanalyst, and "mirror neurons" explain how attitudes and the emotional state of the mother are unconsciously transferred to the baby and understood without words.

Mirror neurons form the neurological base of our capacity to resonate with others at emotional level, to understand intuitively, and proof that we are biologically pre-programmed to interact with each other.

Attunement is the key to attachment and represents the parent's ability to offer an attuned response to an infant's cues. **Thomas Brazelton, an American pediatrician, thinks that this ability is the most important aspect of parental competence.**

Allan Shore, a neuropsychologist, says "We are born to form attachments, our brains are physically wired to develop in tandem with another's, through emotional communication, beginning before words are spoken".

The baby's brain will grow within the relationship to the mother, synaptic connections between neurons are experience-independent, experience-expectant and experience-dependent.

*See **Module 6** for detailed explanations.*

In conclusion, an emotional nurturing relationship with another human being/ mother is a vital need.

All the moments when the mother interacts with her infant are opportunities to learn about the baby as a person, to accept the baby as a special human being and to discover the complexity of motherhood.

For the infant the shared intimacy with the mother leads to the association of the mother with feelings of protection, satisfaction, the pleasure of the contact; those moments transform into opportunities for the baby to learn about him/herself and the world.

Negative experiences of attachment occurring in the early developmental stages, along with anxiety and stress generated, leaves deep lasting traces , which can exert long-term effects.

1.1.3.1. THE INFANT'S NEEDS

Each baby has needs which can be accomplished through normal and permanent interactions with the parents, especially with the mother.

The need to be accepted as a unique human being:

- At birth the infant is able to recognize the mother's voice and smell, but the mother needs to see the baby in order to recognize him/her. Further, the pleasure she experiences when she interacts with her infant and takes care of him/her is extremely important for the baby to feel accepted and loved.

The need of safety:

- **John Bowlby's attachment theory says that a newborn child is biologically programmed to seek the proximity of its caregivers and this behaviour is naturally selected, because a baby can't survive otherwise.**
- Researches about baby's development highlight that the proximity and the quality of care serve in the regulation of internal functioning of the child's body and subsequently in the stability of its nervous system.
- **The quality of the attachment relationship between a parent and its baby (secure or insecure) influences the way in which the infant feels the experiences on a physical level and reacts to them.**

The need for physical contact:

- The cuddling and the caresses are very important for the baby and remind him/her of the safe intrauterine environment. The physical discomfort and pain will be easily endured if the child is in contact with his mother. Even later, when they feel restless or scared by potential danger, the children cling to their parents to soothe.

The need to be soothed, comforted:

- **The infant can't manage the stress and tension, which can be overwhelming by him/herself and needs his/her parents to help in the transition from tense moments to calm ones.**

The need to be permanently cared for with affection:

- The parents can reduce the baby's tensions through communication in a caring bodily language, a language that conveys the pleasure of human contact and security in the proximity of the parents to their infant.

The need for familiarity:

- It is accomplished by an interaction between the infant with the mother, by recognition of her voice or smell.
- **The exposure of the mother's voice is important too for future acquisition of the language and for the baby's soothing.**

In order for the mother to be able to soothe her infant and attune to its emotional needs, it's necessary that in the moment of interaction she's not anxious or depressed. This offers her the opportunity to be fully present in the interaction, to be calm in every situation, conveying safety and trust to her baby.

Caregivers/parents who are preoccupied by themselves, struggling with their own significant stressors such as depression, a chronic illness, addiction, trauma, poverty or lack of social or familial support can be overwhelmed, have reduced sensitivity to infant cues and are unable to respond adequately, potentially undermining the secure attachment relationship.

This is the case for **parents with a premature or a newborn with a congenital disability.** For them, it's difficult to be „a good-enough parent" without being supported in their turn.

The **mother can receive this support from her husband, her mother/ family, friends, other parents** and during hospitalization from medical personnel and psychologists in individual sessions or support groups.

1.1.3.2. DIFFICULTIES IN THE CASE OF NEONATAL INTENSIVE CARE UNITS

The parents with a premature child experience an emotional stress and challenges beyond those experienced normally by parents.

The prematurity exerts an additional pressure on the parental identity and their ability to establish a relationship.

For the **high-risk premature,** underlying vulnerability and adverse early-life experiences are characteristic and may ultimately lead to divergent **developmental pathways that compromise future health and well-being.**

The reduction in parental interaction or even total deprivation that is often experienced by them during the time spent in NICU (Neonatale Intensive Care Unit), may be a significant factor in determining the severity of the outcome.

Separation due to the medical procedures of a preterm baby could be a barrier to the secured attachment and a painful experience; attachment disorders are more common among this group of children when they grow up.

The literature suggests that involvement of parents in neonatal care and in baby's pain care (through family centered care, skin-to-skin contact, family rooms, increased visiting hours) has immediate and long-lasting effects, for both babies and parents:

- It can compensate some of the disadvantages of premature birth
- **The early and attuned interaction between parents and the infant lay the foundation of a secure attachment relationship**
- **It can decrease the infant's cortisol levels and pain responses through the physical and emotional closeness**
- **It can diminish the parents' stress and a**nxiety
- It can reduce the time spent in hospital.

Skene et al. followed couples of parent interacting with their infants in neonatal intensive care units and their conclusion, similar to other researches, were that:

- there are five stages of learning to parent, that facilitate parental involvement in the infants' comfort and pain care
- there are three stages of gradually handing over caring responsibility from nurses to parents.

5 stages on learning how to comfort and learning how to parent

1. Parents are afraid to touch their infant:

- Most of the parents are scared and anxious about the possibility to harm or create a discomfort to their infant and are preoccupied by medical equipment, searching information or reassurance.

2. Parents observe the infant:

- Through the possibility of gazing at the infant for hours the parents slowly familiarise with the child and become able to detect their infant's behavior suggesting comfort and discomfort.
- The written information about pain and comfort help parents understand their infant's behaviour in conjunction with their own observation.

3. Parents touch the baby:

- Because touch is so important in co-regulation and attachment the parents are encouraged to touch their infant and see that different kinds of touch produce different effects.
- They recognize the infant cues of discomfort and respond with a gentle touch and subtle tone of voice that comfort the baby.

4. Parents begin to participate in caregiving

- Parents are involved in providing care under the observation and guidance of the nurses.
- They apply all the information learned by observation until that moment and are aware of their ability to comfort the baby.

5. Parents become confident in caregiving

- Parents develop confidence in their knowledge and are eager to engage in more activities.

The encouragement offered by medical staff for the parents to get involved in comforting and caring of their prematures and the applying of family centered-care facilitate:

- the parental physical and emotional proximity
- the detection and understanding of the infant's cues and giving attuned answers
- the development of secure attachment
- the development of parental identity and sense of responsibility

Transferring responsibility

1. Comfort Provided by Nurse

- In the first few days, the parent/nurse relationship is one in which the nurses provided information to the parent and physical care for their infant while the parent listened or observed

2. Comfort Provided by Nurse and Parent

- As parents gradually become more involved in caregiving, they work together with nurses, and this increases their confidence to comfort their infants.

3. Comfort Provided by Parent

- Once parents are confident in comforting their infants, the nurse generally remains in the background, observing from a distance. This means that the parent is able to enjoy some privacy with his or her infant while knowing a nurse is nearby.

1.1.4. PARENTS' NEEDS AND SUPPORT BY MEDICAL STAFF

The event of a newborn with congenital disability or prematurity can impact negatively the family, but early support and interventions can help them to adjust and become positively involved in the care and development of the baby.

Helping parents adjust their expectations to their baby's actual situation allows them to develop a different and better relationship with him/her.

Parents expect from the healthcare professionals to approach them as individuals with unique experiences.

To support the parents to go through this process successfully, it is important to implement programs for emotional intervention, where they will be assisted at the time of diagnosis and throughout the process of raising their child.

Other measures that can be implemented by healthcare providers in a hospital may be:

- **anticipating the emergence of the parents emotions,**
- **carry out individual sessions to facilitate their expression,**
- **and creating groups to help the parents discuss the difficulties they face.**

After discharge from the hospital, trigger events can be anticipated (anniversary, lifespan events or developmental milestones that they will miss) to prepare the parents and to offer them support and guidance through these challenging periods.

The literature reveals some helpful strategies which healthcare providers can apply to alleviate the grief of parents.

When receiving the news during hospitalization:

- Recognizing their feelings as normal
- Allowing them to express their feelings of weakness and sadness
- Manifest empathy and compassion
- Offering care that is emphatic and respectful and empowering the parent
- Displaying kindness and developing a relationship with the mother
- Partnership rather than paternalistic relationship
- Providing holistic, individualized family-based emotional support and care

When receiving the news during hospitalization:

- Providing more explanation about the baby's condition, treatments, procedures
- Emphasize positive information/ aspects, whenever it's possible
- Giving parents positive feedback
- Allowing parents to make decisions
- Encouraging parents to be strong
- Providing appropriate referrals when it's necessary
- Offering equipment and assistive devices

When receiving the news at home:

- Providing information regarding available services and sources of funding
- Displaying interest in the baby and his condition
- Acknowledging the parent's efforts
- Raising community awareness about children with disabilities
- Helping parents find an online community
- Maintaining relationship

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1.2. STRESS AND TRAUMATIC POTENTIAL

1.2.1. DEFINITIONS

Exposure to stress, especially traumatic stress such as one experienced by the parents when they find out their newborn has a congenital disability, prematurity or other chronic illness, can have deep and long-lasting effects on their mental and physical health.

There are three approaches to handling stress:

- Stress as stimulus like a demanding job
- Stress as a response – the person's reaction to physiological stressors (tension, heart pounds, dryness of the mouth) and psychological stressors (anxiety, anger, fear, etc.)
- Stress as a process that includes stressors and reaction.

Psychologically, we use the term stress to refer to demands or pressures that create an acute tension to the organism, imposing the mobilization of physical and mental resources to adapt or to adjust.

Distress is a state of physical or mental pain or suffering.

Stressors are sources of stress . They can be:

- psychologically challenging events (traumatic and non-traumatic): a natural disaster, an accident with a serious injury, a very sick child, death of a friend or a loved one, a divorce, problems in relationships, exams, life changes (the birth of a child, leaving the parent's home, retirement, etc.)
- physical environmental circumstances: noises, extreme temperatures
- daily hassles.

A small amount of stress is useful, and keeps us attentive, active and motivated.

But if the person faces continuous challenges, without relief or relaxation between stressors, or if the perceived stress is very high, the body's autonomic nervous system which has a built-in stress response can become chronically activated.

Low level of stress

- Registering for classes
- Rushing a fraternity or sorority
- Making new friends
- Commuting to work or school
- Going out on a first date
- Beginning a new semester
- Dating someone steadily

- Getting sick
- Maintaining a stable romantic relationship
- Living away from home for the first time

Medium level of stress
- Being in a class you hate
- Getting involved with drugs
- Having difficulties with a roommate
- Cheating on a boyfriend or girlfriend
- Changing jobs or having hassles at work
- Missing sleep
- Having conflicts with parents
- Moving or adjusting to a new residence
- Experiencing negative consequences from using alcohol or drugs
- Having to talk in front of a class

High level of stress
- Death of a close friend or family member
- Missing an exam because you overslept
- Failing a class
- Terminating a long-standing dating relationship
- Learning that a boyfriend or girlfriend is cheating on you
- Having financial problems
- Dealing with a serious illness of a friend or family member
- Getting caught cheating
- Being raped
- Having someone accuse you of rape

1.2.2. HOW THE BODY AND MIND REACT TO STRESS

Prolonged activation of the stress response or chronic stress overwhelms our abilities and leads to:
- physiological changes: immune suppression, cardiovascular and endocrine reactivity and **physical symptoms** such as headaches, dizziness, upset stomach, elevated blood pressure, chest pain, sexual dysfunction, insomnia, increase or loss of appetite, tiredness, exhaustion, etc.
- psychological reaction or emotional distress: rumination, depressed mood, depression, panic attacks, anger, anxiety, worry
- health-compromising behaviours: drinking alcohol, smoking, sleep deprivation, bad diet, no exercise, etc.

1.2.2.1. BODY'S REACTIONS

Hans Selye, an endocrinologist, sees stress as an unspecific response of the body to any pressure or demand.

He describes the general response pattern of the body under excessive or prolonged stress, naming it General Adaptation Syndrome (GAS).

The GAS has three phases:

1. **Alarm reaction**
2. **Resistance or adaptation stage**
3. **Exhaustion stage**

1. Alarm reaction

- **this is the first line of defence**
- the perception of an immediate stressor (e.g. a person who threatens you, the death of a close friend, a car speeding towards you) mobilizes the body to prepare for challenges
- the body's autonomic nervous system has a built-in stress response that causes physiological changes to allow the body to combat stressful situations
- the body reacts by activating the hypothalmic-pituitary-adrenal (HPA) axis and/or sympathetic nervous system, which increase bodily arousal and triggers the release of stress hormones by the endocrine system (the adrenal glands, controlled by the pituitary gland, pump out cortical steroids and stress hormones that help mobilize the body's defences)
- the physiologist Cannon Walter named this kind of response the flight-or-fight reaction. **This reaction is activated in case of an emergency and helped our ancestors to cope with the perils they faced, either fleeing quickly or fighting off**

Changes occur in alarm reaction stage

- Corticosteroids are released
- Epinephrine and norepinephrine are released
- **Heart: beats faster and harder**
- Lungs: quick, deep breathing occurs
- Blood vessels: blood pressure increases as major vessels dilate
- Blood shifts from the internal organs to the skeletal muscles
- **Muscles: become more tense; trembling can occur**
- **Eyes: pupils dilate**
- Skin: blood vessels constrict chills and sweating
- Saliva: flow decreased
- Stomach: output of digestive enzymes decreases, digestion is inhibited

If the threat is eliminated, the body reinstates a low level of arousal again. But the persistence of a stressor makes us to advance to the next phase.

2. Resistance or adaptation stage

- responses from endocrine and sympathetic nervous system remain at high levels, but not as much as in an alarm reaction stage
- the body tries to renew spent energy and repair damages
- If the source of stress persists longer or another one appears, we advance to the final phase

3. Exhaustion stage

- the parasympathetic branch of the autonomic nervous system (ANS) dominates and the heart and respiratory rate decelerate
- If the stressor prolongs, we may develop adaptation disorders, ranging from allergic reactions to a heart disease, depression, burnout, and sometimes even death

1.2.2.2. MIND'S REACTIONS

The third approach of the stress as a process is based on the Transactional Stress Theory by Lazarus (1991). This model includes:

- stressors – that are demands made by the internal or external environment that upset the balance
- psychological and physiological reactions to restore the balance
- transactions between the person and their environment, where the person, through behavioural, cognitive, and emotional strategies, is seen like an active agent who can appraise and influence the impact of the stressor differently.

In this model, the same stressful life event is evaluated differently by each person, depending on the cognitive and emotional appraisal meaning they attribute to the event, leading to different reactions and impacts.

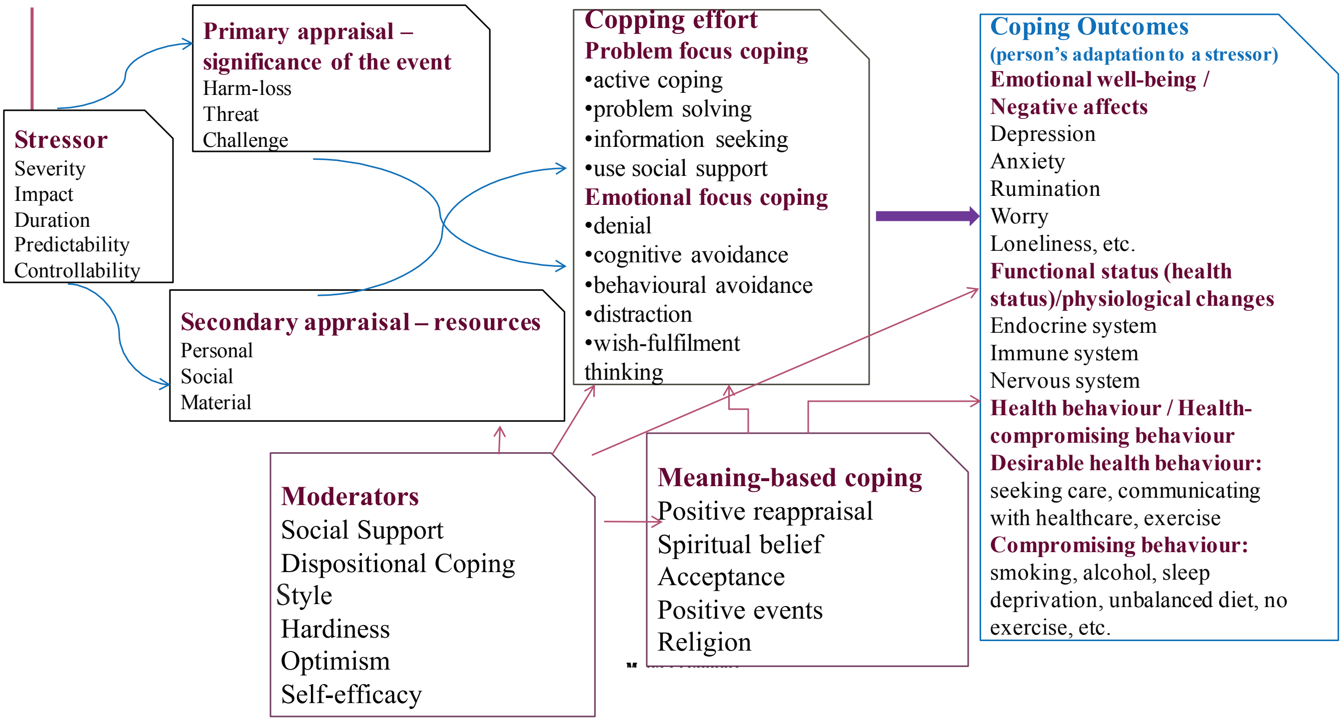

Figure 2 - **Transactional model of stress and coping**

Characteristics of stressful situations: unpredictability, low desirability, ambiguity, low controllability and life transitions (passing from one life condition or phase to another, e.g. moving to a new community, becoming a parent, and retiring from a career)

In a **primary appraisal** the **person judges the significance of the event** as stressful, positive, benign or irrelevant and their further implication: harm-loss, threat, challenge.

- harm-loss: damage has already occurred: injury or loss of valued persons, important objects, self-worth, social standing, etc.
- threat: the person perceives danger, expecting physical injuries or blows to his self-esteem
- challenge: the person may see an opportunity to prove himself, anticipating gain, or personal growth from the venture
- this appraisal can influence how we feel stress even when the stressor is not related to us directly, as in the case of a vicarious transaction, when we empathize with the other people in stressful situations
- health problems are usually evaluated initially as threatening or as negative stressors

In the second appraisal the person assesses his resources available for coping (personal, material, social) and his options (what he can do about the situation?).

- The outcome of this second appraisal often influences the stress we experience; for example, when we think that our resources are sufficient to meet the demands, we may experience la ower level of stress.

Coping effort:

- Problem-focus coping/engaging coping: Strategies directed at changing a stressful situation. People scrutinise the stressor and involve strategies directed to reduce its harmful impact such **as seeking information, planning problem solving, active coping, using social support**

- Emotion-focused coping/ disengaging coping: Strategies aimed at changing the way one thinks or feels about a stressful situation

  People try to diminish the impact of the stressor immediately by denying its existence, **withdrawin**g - cognitively, behavioural - from the situation, using wish-fulfilment fantasies, distraction

Coping effort:

- Those actions **don’t eliminate the stressor and its effects**
- The attention shift initially may allow the person to reduce their initial distress by avoiding feelings and thoughts related to the stressor
- Ultimately avoidance and denial may lead to intrusive thoughts that can amplify the distress over time
- This model predicts that p**roblem-focused coping strategies will be more adaptive for a changeable and controllable stressor,** but emotion-focused coping are most adaptive when the stressor is perceived as unchangeable or when this strategy can be used together with a problem solving strategy

Coping effort:

- When the stressor is perceived as uncontrollable and highly threatening, the person is more probable to use a disengaging coping strategy (denial, distraction, wish-fulfilment thinking, cognitive and behavioural avoidance, avoiding others, hiding feelings, refusing to think about the illness). Initially, these strategies allow the person to shift his attention from the stressor, minimizing the initial distress by avoiding disturbing feelings and thoughts. But avoidance or denial are considered maladaptive strategies, because over time the may lead to intrusive thoughts that can increase distress.
- When the stressor is seen as controllable and the person believes he has self-efficacy, s/he is likely to use engaging coping strategies (active coping, problem solving, information seeking, social support).

Another coping response to health threats is meaning-based coping:

- This coping involves the interpretation of a stressful situation in a personal and meaningful way.
- The aim is to generate a positive emotion, which in turn sustains the coping process by allowing the re-enactment of a problem or emotion focused coping.
- This includes a **positive reinterpretation, acceptance and use of religion and spirituality.**

1.2.3. WHEN STRESS IS TRAUMATIC

Emotional or psychological trauma:

- It is the result of a vital discrepancy between a highly stressful event and individual abilities to master it that shatters a person's sense of security, making her/him feel helpless, abandoned without any possibility of defence in a dangerous world.
- This leads to a lasting shaking of the understanding of the self and the world.

Traumatic experiences often involve a personal or loved one's threat to life or safety. In fact, any situation that leaves the person feeling overwhelmed, afraid, horrified, or helpless can be traumatic, even if it doesn't involve physical harm.

What determines whether a stressful situation is a traumatic one or not are not the objective facts, but the person's subjective emotional experience.

Common causes of trauma could be:

- One-time events: personal exposure to a natural disaster, accidents, surgery intervention (especially in the first three years of life), traumatic childbirth, violent attack, sudden death of a loved one, witnessing other people experiencing the trauma, or learning about a violent or accidental traumatic event experienced by a close friend or family member.
- Ongoing persistent stress/ a series of stressful events: a life-threatening illness, personal or of the child; a toxic environment in a family, negligence, repetitive physical and psychological abuse.

There is no right or wrong way of feeling or thinking, all emotional and physical reactions are normal responses to abnormal events.

The response of a traumatic event may be embodied by an acute stress reaction. Your nervous system has become overwhelmed by stress, triggering a wide range of intense emotions and physical reactions.

1.2.4. PHASES OF TRAUMATIC PROCESS

M.J. Horowitz and then G. Fischer and P. Riedesser described the development of the psychic traumatization process in four phases:

1. Shock
2. Invasion
3. Action phase
4. Completion

1. SHOCK PHASE

Begins immediately/moments after a traumatic event.

Characteristic are sensations of numbness, astonishment, often followed by denial, with the purpose of defending the body and mind of overwhelming emotions, a kind of "shut down" emotionally.

People often can't believe what is happening to them, feel empty, confused, are stupefied/ dumbfounded, emotionally disconnected.

Sometimes, people even deny that they feel scared or threatened, and may behave as if nothing had happened; the others may believe that they are powerful and untouchable or that they don't let it affect them or simply don't care, but these are only self defence mechanisms .

It can last from one hour to a week, but the state of shock and denial gradually fades, giving way to other emotions and thoughts.

The **behavioural reaction** is characterized by immobilization, restlessness or acting-out behaviour.

The body is likely to react with tensions, headache, stomach ache, nausea, tremor, and rapid heart beat.

The dissociative forms of experience – **depersonalization and derealization**- can appear too, as an attempt to protect the psychic, as well as alteration of living time (acceleration or deceleration) or perception mode (tunnel vision).

2. INVASION

In this phase the traumatized person can feel:

Anxiety and fear of being alone in a frightening situation, of danger to self or loved ones, that (s)he will lose control or break down, that something similar could happen again. These are the most common emotional reactions to a trauma, absolutely normal in the face of a scary event.

- The parents are concerned about the future development of their children, worrying whether they will be capable of having a normal independent life, if the diagnosis is accurate and its consequences, if they can manage the entire situation.

Anger about what has happened, whose responsibility it is, what caused the event, the meaninglessness of things, often asking "Why me?"; the anger can be directed at healthcare professionals or/ and can be directed toward her/himself, blaming for what has happened.

Helplessness, vulnerability, emptiness - because something bad happened and (s)he couldn't do anything.

- The parents can feel that they could not improve the situation of the child themselves and lack the ability or resources to deal with the child's disability.

Sadness, sorrow - for the losses suffered, for the world that temporarily lost its meaning and became frightening.

Guilt - that (s)he couldn't foresee or impede the event, "let these things happen", act differently or because (s)he survived, or feeling responsible for another person's death or injury.

- **The parents could feel guilty** about the causes of the disorder and their possible implication in its aetiology, or because they failed to prevent or recognize the warning signs earlier. **A part of them can blame the healthcare providers who assisted and consulted them during pregnancy and delivery.**

Shame - that (s)he has these feelings and reactions, that (s)he cannot control them or that (s)he needs the support of other people.

- **Feelings of shame can appear when parents discuss or transmit to the other members of the family the diagnosis.** Sometimes they don`t want to inform others in order not to anguish them or cause them problems.

Slightly irritable - which can lead to strained interpersonal relationships, increased conflicts and disagreements with family members or others.

The person could:

- Lose interest in common activities.
- **Rememorating the experience / replaying the memory of the traumatic experience** - the mind returns over and over to the event, trying to understand what happened or to realize if it had to react differently .
- **Cry - a way to calm down from the flight-or-fight response is crying;** crying is associated with the parasympathetic nervous system which calms the body and mind.

All these emotions and thoughts, which can be very intense, affect the person on the physical level too, leading to a series of physical symptoms of traumatic stress:

- Sleep problems, ranging from insomnia to dreams or nightmares about the traumatic event
- Muscle tension, dizziness, tremors, headaches, sweating, tiredness
- Restlessness and agitation, knot in the throat
- **Increased sensitivity to environmental factors**
- Changes in appetite and libido
- **Difficulties in reasoning, concentrating, memorizing, remembering certain things** (especially aspects of the traumatic event).

People can experience all or few of these emotional and bodily reactions, and it's important to know that everyone's reaction is different.

3. ACTION PHASE

It's a stage of personalized processing of the traumatic information that invades, in which the affected person faces and accepts gradually, in their own rhythm and style, what happened to them, the feelings of loss, the pain.

There is a process of modifying the cognitive-emotional patterns of the understanding of the self and the world.

In this phase, previous described emotional, mental and bodily reactions gradually diminish.

Nevertheless, in the presence of similar stimuli, the person can be disturbed by painful memories or emotions, but they don't overwhelm her/ him as before.

4. COMPLETION

The person can remember her/his traumatic situation, but without feeling overwhelmed or compulsively thinking about it.

(s)he accepted what has happened and begins to orient her/ himself towards the future.

(s)he integrated the traumatic experience into her/his life history and sees it as a part of her/his life experience.

There is voluntary access to information, (s)he knows what happened then, can differentiate between the traumatic event and the present, having appropriate emotions.

A traumatized person needs to go through all these four phases of the traumatic process successfully. Otherwise, (s)he can experience only the first two phases, resorting again to mechanisms of denial and avoidance, and subsequently developing even a pathology like traumatic stress disorders (acute stress disorder or posttraumatic stress disorder) and depression.

In phase 1, the shock, the best way to support the parent is to be there physically, listen if (s)he wants to talk or remain silent together and helping with everyday tasks.

In phase 2, the invasion, it is necessary to be kind, listen to the person thoughts and recognize all her/his feelings as normal and understood.

In order to overcome the grief and face the difficulties of their infant, premature or with a congenital disability, parents need to remain open to all those painful, negative emotions and not to deny them or be overwhelmed by them.

Their recognition, experience and expression of those emotions, trying to cope with their complexity and intensity, allows them to gradually blur.

It is a process that takes a long time, sometimes even months, but by raising awareness and facing their painful emotions, parents gradually give way to positive emotions, love and develop a strong connection with their baby, which benefits both the baby and his parents.

The attachment relationship becomes a source of healing for the parents, which gives them hope and skills in overcoming the problems and raising the baby as a subject.

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CONTENTS

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    1.3.1. Anxiety
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1.3. ANXIETY, PANIC ATTACKS, POST-PARTUM DEPRESSION, TRAUMATIC STRESS DISORDERS

Some parents can respond to stressful events in a period of time with a complete recovery, but some, according to DSM-5 (diagnostic and statistical manual of mental disorders), can present emotional distress often associated with experiencing stress: anxiety disorders, panic attacks, depression, postpartum depression in case of new mothers, traumatic stress disorders.

During hospitalization, it is vital to show empathy with the parents' struggles and remain open and non-judgemental to all their emotional reactions, knowing that they are normal responses to a very stressful or traumatic situation.

Recognizing these signs of disturbance is an opportunity to offer support, guidance and make referrals to other specialists. The most important thing that predicts the quality of a mother-infant relationship and their attunement is the mother's mental and physic sanity.

1.3.1. ANXIETY

Anxiety can be an offshoot of episodic or chronic stress.

Anxiety is a normal emotion and most people will experience occasionally fear, nervousness or even panic as an answer to a fearful situation.

But in anxiety disorders, anxiety is a persistent and disruptive towards aspect of daily lives.

The person with an anxiety disorder typically manifests:

- Emotional symptoms: fear, nervousness, jitters, agitation.
- Physical symptoms: dizziness, insomnia, muscular tension, tachycardia.
- Cognitive symptoms: permanent worry, derealization, sense of doom.

1.3.2. PANIC ATTACKS

A panic attack is characterized by a period of intense fear accompanied by the abrupt onset of several somatic and cognitive symptoms.

Physical symptoms are frightening, and people seek urgent medical care for this reason.

Somatic symptoms may include racing heartbeat, sweating, choking sensation, chest pain, nausea, shaking, numbness, feeling detached or unreal.

Cognitive symptoms may include rumination with health concerns, racing thoughts, catastrophic misinterpretation of somatic symptoms, believing that you are going insane.

Panic attacks are quite common among people exposed to negative traumatic experiences.

1.3.3. POST PARTUM DEPRESSION

Postpartum depression or peripartum / postnatal depression is a major depressive episode with onset of symptoms during pregnancy or in a period of 4 weeks after birth (according to DSM-5), and up to one year (according to the World Health Organization).

According to the common scientific evidences and claims the post partum depression lasts between a couple of days till four weeks. In case it doesn't fade, then we start thinking about Endogenous and Exogenous depression.

It's different from baby blues, which are common symptoms, of medium intensity, that occur in the first 2 weeks after birth, determined in particular by hormonal changes. Globally, postpartum depression ranges from 10-19%.

Symptoms may vary, depending on the severity but include: anxiety, irritability, loss of energy, insomnia or hypersomnia, feeling overwhelmed, sad, and hopeless, changes in appetite, cries "for no reason", excessive concern about the baby's health or lack of interest in the child, fear of hurting the baby, thoughts of self-aggression or suicidal ideation, loss of interest or pleasure for the most part of the day.

The consequences of postpartum depression for both mother and baby are quite well known. **A meta-analysis of the rates and risks of postpartum depression shows that women suffering from postnatal depression are 2 times more likely to experience depressive episodes in the next 5 years.**

Another major negative consequence of depression is the deterioration of the relationship between the mother and the child, an important predictor of insecure attachment, cognitive, emotional, physical and social delays in the development of affected children.

Other meta-analyses highlighted the risk factors for postnatal depression, indicating that the most important predictors are depression and anxiety during the pregnancy, lack of or poor social (or family) support and stressful or traumatic life events.

Another analysis by A. Bell and E. Andersson in 2016, **"The birth experience and women's postnatal depression: A systematic review",** targeted research from 2000-2015 on the association between the birth experience and postnatal depression. It highlighted the fact that there is a significant correlation between the negative birth experience and the post-natal depression, despite the fact that the study presents a number of methodological limitations.

The birth experience is a very personal experience, but certain topics are universally valid.
A focus group on the significance of a positive birth experience highlighted 2 factors:
1) confidence in the power and personal ability to give birth
2) the safety felt and the presence of supportive people at birth.

Another study lists among the critical aspects of the labor experience: supportive care, information, decision-making in agreement with the mother, respect for dignity and pain relief. **It seems that no matter how complicated or difficult the birth is, as long as the mother perceives the medical staff to be careful and supportive, long-term memories related to the birth experience will be positive.**

The birth experience is impacted by the mother's personal expectations, the hospital environment, the maternity care policy, and the amount and quality of support and care received during the birth. Even though the medical staff have a limited control over the events during the birth, in order to support a positive birth experience and to increase the mother's sense of safety and confidence, the interactions must be respectful, the mother must be informed and involved in the decision-making process and she must receive an attentive and reassuring care.

The study **"Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review"** shows that the risk of mothers with a premature baby to develop postpartum depression is a factor 1.6 bigger at 8-12 months after the child's birth.

In the particular group of mothers that give birth under 33 weeks or have babies with very little weight (under 1500 grams), the prevalence of a postpartum depression is 25-26%, even 52 weeks after birth.

The conclusion is that premature birth is a risk factor for developing postnatal depression, and depression can persist if gestational age or/and the weight are little, if there are any disabilities or conditions of the premature baby, and if the mother perceives the social support as absent.

1.3.4. TRAUMATIC STRESS DISORDERS

If the stressful event is traumatic, some people can develop traumatic stress disorders (acute stress disorder or/and posttraumatic stress disorder), which are characterized by maladaptive patterns of behaviour that involve pronounced personal distress or important impairment of functioning.

The person may have been directly exposed to trauma, witnessed other people experiencing the trauma or learned about a violent or accidental traumatic event, experienced by a close friend or family member. In **acute stress disorder** the person has acute maladaptive behaviour in the days or weeks following exposure to a traumatic event (three days to one month).

In posttraumatic stress disorder the person has the same maladaptive behaviours but these are lasting more then one month after the traumatic experience.

Common features:

Avoidance behaviour

- The person may avoid thinking about the traumatic event or avoid people, places or situations associated with it (all being triggers for painful memories).

Reexperiencing the trauma

- The person will reexperience the traumatic event in the form of intrusive memories, recurrent disturbing dreams, flashbacks (which bring back powerful emotions and vivid memories and feel like the trauma is happening all over again).

Emotional distress, negative thoughts, and impaired functioning

- The person has persistent negative thoughts and emotions (worry, fear, anxiety, sadness, guilt, blaming herself, feeling weak or inadequate), feels detached or estranged from others, or has difficulty functioning effectively

Heightened arousal. The person will experience signs of high arousal such as:

- feeling constantly on guard (becoming hyper vigilant); because the nervous system was in a terrifying shock, and it couldn't settle down immediately, remaining vigilant, alert
- having difficulty sleeping and concentrating - because the brain remains very active searching for possible further danger and processing the event, the sleep could be seen as a vulnerable state; the nightmares are common and also interfere with sleep
- having outbursts of anger, becoming irritable easily
- having exaggerated startle response like jumping at sudden noise.

Emotional numbing

- In posttraumatic stress disorder the person may feel numb inside, losing the ability to have loving feelings.

The mother's access to psychological support and counselling, during the hospitalization period, and also later, is very important in recovery and may prevent the onset of postnatal depression or even posttraumatic stress disorder.

Participation in support groups organized by psychologists in the hospitals, offer a safe space in which she is listened to, understood and where she realizes that she is not alone.

She can identify, understand and accept all her conflicting emotional states more easily and discover functional ways of managing them.

In this way, the mother will be able to integrate the traumatic event in her life story and connect emotionally with the baby, respond adequately to her/his needs, with confidence that (s)he will be able to overcome the difficulties that arise.

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PART
4

CONTENTS

1.4. Assertive communication techniques

1.4. ASSERTIVE COMMUNICATION TECHNIQUES

Assertive communication is a core ability and implies expressing yourself effectively and standing up for your point of view, needs, personal boundaries, and rights while you respect and have consideration for the rights and opinions of the interlocutor.

All **communications unfold verbal and a nonverbal** through gesture, tone, body language, facial expressions, and eye contact. It is important to align the two forms.

There are three **major** styles of communication: passive, aggressive and assertive.

Assertiveness is a style between the aggressive communication (when someone wants to impose, and disregard the needs, feelings and opinions of others) and the passive one (when the person agrees with everything the interlocutor says). Being passive or aggressive reduces the impact of your message, because people react to how you transmit the information.

In a conflict or scary situation, people naturally behave and communicate in a passive or aggressive manner, corresponding to the two primary reactions - to flee or to fight-.

Assertiveness is a skill that can be learned and practiced.

Assertiveness is a skill, that promotes an open attitude and the fact that all people are equally important. You respect yourself standing up for your own rights, needs, viewpoints, boundaries, but you are aware of the rights of others and willing to achieve a win-win solution to problems.

Assertiveness implies:

- **being able to say "no" without feeling guilty**
- express clearly and effectively your opinions and point of views
- being able to ask for what you want
- **express authentically, but not aggressively, your positive and negative feelings**
- request favours
- **being able to initiate, continue and make a conclusion during a general conversation.**

Assertive communication:

- **implies to express your rights, thoughts and feelings clearly, directly and with honesty while you respect and have consideration for the rights, opinions and feelings of the interlocutor.**
- creates opportunities for open discussion where all opinions and choices are heard and considered in order to resolve anypotential disagreements.
- can reduce stress, anxiety, depression, strengthen your relationships, improve your self-image and provide social support in difficult times.
- **is a diplomatic communication style, an effective adaptation to conflicting situations.**
- is direct, but respectful, and **offers you the chance to deliver your message successfully, because how you say something is just as important as what you say.**

Steps to achieve assertive communication:

1. If you don't like something in a person's behaviour, stick to factual description, and do not affix value judgments or labels.
   - Inappropriate: "You're rude!", "You are disrespectful, you are always late"
   - **Assertive communication: "The meeting is supposed to be at 3 o'clock, but now it's 4."**
2. Keep the description accurate, don't judge:
   - Inappropriate: "You ruin the meeting/ the day!"
   - **Assertive communication: "Now you have to reschedule the meeting, because I have to come back to work".**

Steps to achieve assertive communication:

3. Use "I" statements:
   - The use of "I" statements lets you focus on what you are thinking and feeling. If you start the sentence with "You...", it could be perceived accusatory. **Keep your requests specific and simple.**
   - Inappropriate: "You are wrong", "You must stop doing this"
   - **Assertive communication: "I would like you to tell me", "I would feel better if you didn't do that"**

Steps to achieve assertive communication:

4. Use following formula: "When you (their behaviour), I feel (your feelings)". This provides a non-attacking, honest and responsible way of letting others know how their behaviour affects you.

   "When you arrive late, I feel frustrated/ irritated/ that you don't care about me".
5. Another more comprehensive formula is to list their behaviour, the results, and your feelings:

   "When you (other's behaviour), then (the result of their conduct), and I feel (how you feel)".

Tips for assertive communication targeted to medical professionals

“I understand that you are overwhelmed by the negative emotions and experiences, but we need to try to think lucid.”

“It becomes difficult for me to communicate sensitive medical facts when you are raising the tone of your voice”.

“I understand your distress and the fact that you feel overwhelmed at the moment, because of the news and all the details. I suggest a meeting in a couple of days, in order to answer the questions emerging in the meantime.

It is understandable that you feel angry and aggrieved right now. Some time should pass to calm down and to discover together the best option for this situation.

“I assure you that we all do our best to make sure John receives the best treatment.”

“We have tried all treatments considered to be efficient for your child’s condition/Mary/John. Unfortunately, nothing seems to work. We wish things were different.”

“John/Mary is lucky you are her/his parent. I know it is very hard for you, but we will overcome this together.”

“I can assure you we all fight together with John/Mary, so that (s)he feels as best as (s)he can.”

“John is a strong boy/Mary is a strong girl fighting for survival. (s)He needs you be there and also to enjoy every little success.”

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MODULE 2

EARLY CHILD DEVELOPMENT – TYPICAL AND ATYPICAL

PART 1

EARLY CHILD DEVELOPMENT (TYPICAL AND ATYPICAL)

This section describes the motor (motor) development of children aged 0-3 years. The development of children from 0 months is given monthly. These stages of motor development can sometimes be one to two months early or late in infants.

When exploring skills under this heading, if the child is premature, it should be assessed using the corrected age*.

To better understand this information, we would like to explain some of the commonly used terms below.

- Premature baby: According to the World Health Organization (WHO), preterm means that babies are born alive before 37 weeks of pregnancy.
- Typical development: Normal development is the change that progresses continuously from fertilization to the final stage of the organism with certain physical, mental, language, emotional and social aspects.
- Atypical development : Atypical development can be defined as a condition that causes various disabilities in children and cannot be evaluated within the known developmental structure.

https://www.who.int/news-room/fact-sheets/detail/preterm-birth

- Red Flags: Clinical indicators of a probable critical underlying situation.
- Postnatal age: Elapsed time after birth, also known as «chronological age»
- Corrected age: Corrected age, or adjusted age, is the premature baby's chronological age minus the number of weeks or months the baby was born early.

https://www.who.int/news-room/fact-sheets/detail/preterm-birth

Ramanayake, R. P. J. C., & Basnayake, B. M. T. K. (2018). Evaluation of red flags minimizes missing serious diseases in primary care. Journal of family medicine and primary care, 7(2), 315.

- Gross motor development: Development of the skills which are need for the entire body movement and which include the large muscles of the body to perform everyday functions.
- Fine motor development: Development of the skill that coordinates small muscles in movements with the eyes.
- Social development: The process by which a child learns to interact with others around them.
- Language development: The process by which children learn and communicate language during early childhood.

https://www.scanva.org/support-for-parents/parent-resource-center-2/social-development-in-children/

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*Corrected age, or adjusted age, is the premature baby's chronological age minus the number of weeks or months the baby was born early.

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2.1 Typical development (month by month)
    2.1.1 Gross motor development
    2.1.2 Fine motor development
    2.1.3 Speech and language development
    2.1.4 Social, emotional, cognitive development

2.1.1 GROSS MOTOR DEVELOPMENT

Newborn
Using reflex movements like sucking and frightening
Uncontrolled extremities

1ST MONTH

Brings his hands to the eye and mouth
While lying on tummy, moves head from side to side
Head tips backward if unsupported

0-3 MONTHS

Pushes up on arms and lifts-holds head up while lying on stomach
Capable of moving fists from closed to open
Capable of bringing hands to mouth
Moves extremities off of surface when excited
Follows a thing with eyes from one side to the middle, but not all the way around

0-3 MONTHS WARNING SIGNS

Motor
Difficulty when lifting her/his head
Rigid legs with barely or no movement
Lacking arm movement and holds hands fisted
While lying on dorsal, pushes back with head

3-5 MONTHS

Hops on stomach; may be capable to roll from stomach to back
Puts weight on lower extremities when feet are flat on the floor
Transfers objects from hand to hand
At 3rd month, (s)he can stand up on her/his elbows and maintain this position for a while.
At 5th month, (s)he can stand up on her/his hand.

4-6 MONTHS

Uses her/his hands to support her/him while sitting down
Rolling from back to stomach and stomach to back
While standing up with support, lifts entire weight with legs
Attains for nearby toys while on stomach
While lying on dorsal, reaches both hands to play with her/his feet

4-6 MONTHS WARNING SIGNS

Motor
Sits with a rounded back
Poor head control and unable to lift head
Difficulty bringing arms forward to reach out
Arches back and stiffens legs when pulling to a sit
Holds arms back and has stiff legs in a supported stand

7 MONTHS

Rolls either way (front to dorsal, dorsal to front)
Sits with no support - support from hands
Does push-up position and starts to try to move forward
Supports her/his whole weight on her/his lower extremities
Starts to move with other extremities e.g. creeping
Raises her/his head up and pushes through elbows during Tummy Time (placing baby on her/his stomach to play)

9 MONTHS

Gets in and out of a sitting position but may require help
Starts scooting, creeping or crawling
May stand with support
Sits without support
Sits and reaches for objects without falling down
Starts to move with leg and arm movement e.g. crawling
Demonstrates more control while rolling and sitting

7-9 MONTHS WARNING SIGNS

Motor
Uses only one hand effectively
Rolls back while sitting, can’t put her/himself back straight
Poor use of upper extremities in sitting position
Difficulty when crawling
Uses only one side of the body to move
Cannot take body weight on lower extremities
Does/Can not transfer objects from one hand to the other

10-11 MONTHS

Creeps with the hands and knees while the hands and knees support the trunk
Standing and walking, while holding furniture
Going in and out of various positions to explore the environment and reach the desired toys

12 MONTHS

Creeps with the hands and knees while the hands and knees support the trunk
Standing and walking, while holding furniture
Going in and out of various positions to explore the environment and reach the desired toys
Stands alone and takes a few independent steps
Could take a few steps alone - Can walk two or three steps without support
Gets into sitting position without any assistance
Gets from sitting to crawling or prone position (lying on tummy)
Pulls her/himself up to stand
Keeps balance in sitting when throwing objects

10-12 MONTHS WARNING SIGNS

Motor
Difficulty to stand because of rigid legs and pointed toes
Only uses upper extremities to pull up to standing position
Sits on one side with weight
Strongly stretched or tightly extended arms
Must use hands to maintain sitting position
Weak head control in upright position

13-18 MONTHS WARNING SIGNS

Walks independently and rarely falls
Squats to pick up an object

13-18 MONTHS WARNING SIGNS

Motor
Can't step independently
Poor posture balance, often falls
Walks on toes
Doesn't pull to stand
Can't crawl and climb on things
Doesn't use pincer grasp to hold small objects (pincer = coordination happens via the index finger and thumb to hold an item)

BETWEEN 18-24 MONTHS

Stands alone and walks, holding on to a parent's hands
Sticks upper and lower extremities out to help to get dressed and undressed
Walks without any help
Starts to go up the stairs
Can squat to get a toy and stands again

2 YEARS OLD

Walks, runs and starts to learn how to jump with both feet
Pulls or carries objects while walking
Can throw a ball and kick it
Stands on tiptoes and maintains balance on one lower extremity
Climbs onto and down from furniture without support
Walks up stairs, holding on to the railing; may alternate feet

3 YEARS OLD

Walks backwards and climbs stairs in a row
Shoots a smaller ball; often catches a bigger ball
Starts tricycle or bicycle pedalling

2.1.2 FINE MOTOR DEVELOPMENT

1 MONTH

Keeps turns in tight clenched hands

0-3 MONTHS

Handles and shakes hand toys

3-5 MONTHS

Reaches out and gets objects

4-6 MONTHS

While lying on back, moves a toy from one hand to the other hand
Can raise hands to be picked up by parents

7 MONTHS

Picks up little things with thumbs and fingers
Gets things with one hand
Moves things from hand to hand
Uses raking grasp (wherein the fingers, but not including the thumb, do all the holding) to hold objects (not pincer)

9 MONTHS

Grips small objects, using thumb and index finger (pincer grasp)
Gets little items with thumbs and fingers

10-11 MONTHS

Can drop objects into a container with a large opening
Uses thumb and index finger to pick up little objects (pincer grasp)

12 MONTHS

Uses pincer grasps
Starts to bang two cubes together
Puts things into a container
Removes objects from a container
Releases objects intentionally
Pokes (objects) with the index finger
Tries to imitate scribbling
Claps hands
Points to the objects (s)he is interested in

13-18 MONTHS

Stacks two objects or blocks on top of each other

13-24 MONTHS

Drinks from a sippy cup (or standard cup with assistance)
Uses a spoon clumsily and tries to eat something
Gets objects like raisins with thumb and one finger (“pincer handle/grasp”)
Points, pokes and maybe even pinches someone or something
Puts things into a can or a bucket and takes them out again
Scrawls with a thick coloured pencil or marker

2-YEAR-OLD

Starting to brush own teeth and hair
Can pull pants up and down
May be able to turn on the faucet alone and wash hands
Builds a block tower with at least four blocks / or more
Starts practicing snapping and zipping
Holds utensils and coloured pencils with fingers, rather than with a clenched hand
At this age, toddlers enjoy turning over containers to pour out their contents

3-YEAR-OLD

Draw a circle with a coloured pencil, leads pencil or marker
Plays with toys with little moving parts and buttons
Turns the pages of a book, one by one
Builds something with blocks and creates towers of six or more blocks
Is busy with door handles and twist bottle tops

2.1.3 SPEECH AND LANGUAGE DEVELOPMENT

0-3 MONTHS

Murmurs to reply to playful interactions
Notices and responds to sounds

5-6 MONTHS

Vocalizes in response to playful interactions
Turns head in the direction of sounds

7 MONTHS

To express happiness, sadness and anger the infant uses different kind of sounds.
The infant responds to other people's expressions of emotion and appears cheerful generally.

10-12 MONTHS

Most babies at this age respond to simple oral requests. The baby may become skilled at numerous gestures, for instance shaking his or her head.

The baby's chitchatting takes on a new tone of voice and evolves to words such as "dada" and "mama." Possibly certain exclamations, such as "uh-oh!", may be heard.

12 MONTHS

Uses tone of voice and pauses to make sounds that sound like he or she is talking.
At this age, they use very simple and easy words.
Reacts to her/his name.
To get the attention, they use gestures or sounds.

13-18 MONTHS

At this age, they can say 8 to 20 words that can be understood.

18-24 MONTHS

At this age, they can say 50-100 words till 24 months and even put 2 words together to make their first sentences.

2 YEARS OLD

Children at this age mimic what other kids and adults do and say, including how they say or do it

3 YEARS OLD

Can say her/his name and age
Talks with 250 to 500 words and answers simple questions
Talks in sentences of five to six words, and expresses her/himself in complete sentences by age of 4

2.1.4 SOCIAL AND EMOTIONAL, COGNITIVE DEVELOPMENT

NEWBORN

Social and Emotional Milestones

Learns to be comforted by the person caring for her/him
Starts getting attached to the caregiver

1-3 MONTHS

Social and Emotional Milestones

Starts to develop a social smile
Enjoys fun-loving and face-to-face interactions with people
Loves to play with other people and also might cry when playing stops
Coos and babbles
Responds to emotions like love and affection
Can show happiness and sadness at this age
Can mimic facial expressions

3-5 MONTHS

Social and Emotional Milestones

Begins to identify and react to strangers
Tries to get the person who i scaring for child to play (sticks out tongue, pats toys, etc.)
Loves and enjoys playful communication with others (such as peek a boo)

5-6 MONTHS

Play and Social Skills

Keeps eye contact with familiar people during cheerful interaction
Loves to play with toys of varied textures
Loves musical toys
Enjoys different types of movement, for instance being gently swung

7 MONTHS

Social and Emotional Milestones

Is keen on looking into the mirror
Loves social play
Reacts to other's expressions of emotion and often appears cheerful

7-9 MONTHS

Play and Social Skills

Is keen on interacting with others (peek a boo as an example)
Loves playing with objects of varied textures

At this age, they're interested in playing with colourful toys
Raises hands in the direction of an adult to be picked up
Maintains eye contact with people with a cheerful interaction
Moves to explore the environment when they're placed on the floor and it is enjoyable for them
Looks for hidden things, but only if (s)he sees you when you hide it
Loves to play peek a boo and patty-cake

9 MONTHS

Social and Emotional Milestones

Starts having stranger anxiety
May be upset when separated from the person who is caring for the child
They have their favourite objects or toys

10-12 MONTHS

Play and Social Skills

They are keen on interacting with others (e.g. peek a boo)
Keep s eye contact with people during cheerful interactions
At this age, they raise their hands to be picked up
When they're being called, they turn their heads in response to their name
Loves playing and banging musical toys and objects
Enjoys different types of movement, for instance being gently swung in the air by parents
Generally explores the environment when placed on the floor
Loves moving to get desirable toys
Loves to play their favourite toys with people
New things are a bit fearful for them

12 MONTHS

Grins and chuckles in response to another person or when playing
Feels comfortable exploring the room when the person who is caring is nearby
Shows affection and love to familiar people
At this age, they have mild temper tantrums when they are frustrated
Cries when parents leave
Loves to mimic people in play
Shows particular preferences for certain people, toys and objects
Tests parental reactions to her/his activities during feeding (what do you do when (s)he refuses a food?)
Tests parental reactions to her/his conduct (what do you do if (s)he cries after you leave the room?)
They choose their mothers and/or regular caregiver over all others
Extends arm or leg to help when being dressed by parents / caregiver

13-18 MONTHS

Play and Social Skills

They are keen on interacting with people (plays patty cake)
Raises hands to be picked up
Maintains eye contact with people during cheerful communications
Is interested in mimicking others
When they're being called, they turn their heads in response to their name
May be able to locate objects or toys you are pointing to
Applauds hands together in light of social play
Loves playing with different kinds of toys and textures
Loves to bang on and play with musical toys
Willingly explores the environment when placed on the floor
Enjoys being swung and gently thrown in the air by their parents or familiar people
Loves exploring and playing at the play field
Loves swinging on playground swings

18-24 MONTHS

Play and Social Skills

When they're being called, they turn their heads in response to their name
They can take part in little groups with other children
They are curious, knowledgeable, and able to maintain eye contact with others
They are able to play in social situations after a transition time
Points to toys and objects of interest
Can find objects you are pointing to
Explores varied places such as a new play field
Loves swinging on play field swings
Loves being swung and gently thrown in the air
Loves to play with new toys in different ways
Usually plays with toys without mouthing them
Loves to play with musical toys and objects
Loves sitting to look at or listen to a book

2 YEARS OLD

Social and Emotional Milestones

Imitates what other children and adults do and say, as well as how they say or do it
Is happy to play near, if not with, other children
Begins to realize (s)he can do things without their parents' help
Breaks rules more than before, doing things their mother has told not to do, just to test what happens
Shows expanding separation nervousness by year and a half, which typically eases considerably by two years; becomes progressively independent and aware of her/himself as an own person between 24 and 36 months
Mimics to other's behaviour, especially adults and older kids
Progressively is aware of her/himself as separate from others
Increasingly excited about company of other kids
Displays increasing independence

Starts to show aggressive behaviour
Turns his or her head in response to her/his name being called by others
Loves sitting to listen or look at a book
They have tantrums when frustrated

3 YEARS OLD

Social and Emotional Milestones

Is curious, knowledgeable, and able to maintain eye contact with others
Is interested—although uncertain—about going around in new environments and trying new things
Begins to play with kids (as opposed to only playing side-by-side)
Starts being able to comfort and show concern for an unhappy or worried friend without prompting
Takes turns while playing (regardless of whether they don't like to)
Plays "real life" with toys such as toy kitchens and kitchenware
Begins discovering simple ways to solve arguments and disagreements
Shows (but maybe not name) a different kind of emotions beyond happy, sad and mad
When they're being called, they turn their heads in response to their name
Loves to sit and listen or look at book
Generally plays with toys and objects without mouthing them
Can take part in little groups with other children

Play and Social Skills

Explores different places such as a new play field
Loves swinging on play field swings
Can play in social circumstances after a progress time
Loves swinging, being thrown in the air and gentle "roughhousing"
Loves playing with a variety of toys and textures
Can find objects of interest
Can find objects the parent is pointing to
Is able to cooperate in messy activities that result in dirty hands

The following tables show the development of motor, fine motor, language, social emotional and cognitive areas, month by month.

TABLE 1: 0-3 MONTHS DEVELOPMENT

Gross Motor	Fine Motor	Language	Social and emotional, cognitive
• Pushes up on arms and lifts-holds head up while lying on stomach • Capable of moving fists from closed to open • Capable of bringing hands to mouth • Moves extremities away from the surface when excited • Follows a thing with eyes from one side to the middle, but not all the way around	• Keeps objects in turns in tight clench hands • Handles and shakes hand toys	• Murmurs to reply to playful interactions • Notices and responds to sounds	• Starts to develop a social smile • Enjoys fun-loving and face-to-face interactions with people • Loves to play with other people and also might cry when the playing stops • Coos and babbles • Responds to emotions like love and affection • Can show happiness and sadness at this age • Can mimic facial expressions

TABLE 2: 4-6 MONTHS DEVELOPMENT

Gross Motor	Fine Motor	Language	Social and emotional, cognitive
• Uses her/his hands to support her/him while sitting down • Rolls from back to stomach and stomach to back • While standing up with support, lifts the entire weight with legs • Attains for nearby toys while on the stomach • While lying on dorsal, reaches both hands to play with her/his feet	• While lying on back, moves a toy from one hand to the other hand • Can raise their hands to be picked up by their parents • Reaches out and gets objects	• Vocalizes in response to playful interactions • Turns head in the direction of sounds	• Keeps eye contact with familiar people during cheerful interactions • Loves to play with toys of varied textures • Loves musical toys • Enjoys different types of movement, for instance being gently swung • Begins to identify and react to strangers • Tries to get the person caring for her/him to play (sticks out tongue, pats toys, etc.) • Loves and enjoys playful communication with others (such as peek a boo)

TABLE 3: 7-9 MONTHS DEVELOPMENT

Gross Motor	Fine Motor	Language	Social and emotional, cognitive
• Rolls either way (front to dorsal, dorsal to front) • Sits with no support or support from hands • Does push-up position and starts to try to move forward • Supports her/his whole weight on her/his lower extremities • Starting to move with other extremities e.g. creeping • Raises her/his head up and pushes through elbows during Tummy Time • Goes in and out of sitting position • Starts scooting, creeping or crawling • Could stand with support • Sits without support • Sits and reaches for objects without falling down • Starts to move with other leg and arm movement e.g. crawling • Demonstrates more control while rolling and sitting	• Grips small objects, using thumb and fingers (pincer grasp) • Gets little items with thumbs and fingers • Picks up little things with thumbs and fingers • Gets things with one hand • Moves things from hand to hand • Uses raking grasp to hold objects (not pincer)	• To express happiness, sadness and anger they use different kind of sounds • Responds to other people’s expressions of emotion and appears cheerful generally	• Is keen on looking in the mirror • Loves social play • Reacts to other’s expressions of emotion and often appears cheerful • Is keen on interacting with others, e.g. peek a boo as an example • Loves playing with objects of varied textures • At this age, they’re interested in playing with colourful toys • Raises hands in the direction of an adult to be picked up • Maintains eye contact with people while cheerful interaction takes place • Moves to explore the environment when they’re placed on the floor and it is enjoyable for them • Looks for hidden things, but only if (s)he sees you when you hide it • Loves to play peek a boo and patty-cake

TABLE 4: 10-12 MONTHS DEVELOPMENT

Gross Motor	Fine Motor	Language	Social and emotional, cognitive
• Creeps on the hands and knees while the hands and knees support the trunk • Stands and walks around furniture • Goes in and out of various positions to explore the atmosphere and reach the desired toys	• Drops objects into a container with a large opening • Uses thumb and pointer finger to pick up little objects	• Most babies at this age respond to simple oral requests. • The baby may become skilled at numerous gestures, for instance shaking her/his head. • The baby's chitchatting takes on a new tone of voice and evolves to words such as "dada" and "mama." • The baby may make certain exclamations, such as "uh-oh!"	• They're keen on interacting with others, peek a boo as an example • Keeps up eye contact with people during cheerful interactions • At this age, they raise their hands to be picked up • When they're being called, they turn their heads in response to their name • Loves playing and banging musical toys and objects • Enjoys different types of movement, for instance being gently swung in the air by parents • Generally explores the environment when placed on the floor • Loves moving to get desirable toys • Loves to play the favourite toys with people • New things are a bit fearful for them

TABLE 5: 12 MONTHS DEVELOPMENT			
Gross Motor	**Fine Motor**	**Language**	**Social and emotional, cognitive**
• Stands alone and takes a few independent steps • Could take a few steps alone • Can walk two or three steps without support • Gets into sitting position without any assistance • Gets from sitting to crawling or prone (lying on tummy) position • Pulls her/himself up to stand • Keeps balance in sitting when throwing objects	• Uses pincer grasp • Starts to bang two cubes together • Puts things into a container • Removes objects from a container • Releases objects intentionally • Pokes (objects) with forefinger • Tries to imitate scribbling • Claps hands • Points at the objects which they are interested in	• Uses tone of voice and pauses to make sounds that sound like he or she talks • At this age, they use very simple and easy words • Reacts to her/his name • To get the attention, they use gestures or sounds	• Grins and chuckles in response to another person or when playing • Feels comfortable exploring the room when the person who is caring the baby is nearby • Shows affection and love to familiar people • At this age, they have mild temper tantrums when they are frustrated • Cries when parents leave • Loves mimicking people in play • Shows particular preferences for certain people, toys and objects • Tests parental reactions to her/his activities during feeding (What does the parent do when baby refuses a food?) • Tests parental reactions to her/his conduct (What does the parent do if the baby cries after the parents leaves the room?) • They entirely prefer their mothers and/or regular caregiver • Extends arm or leg to help when being dressed by parents/caregiver

TABLE 6: 13-18 MONTHS DEVELOPMENT			
Gross Motor	**Fine Motor**	**Language**	**Social and emotional, cognitive**
• Walks independently and rarely falls • Squats to pick up an object	• Stacks two objects or blocks on top of each other	• At this age, they can say 8 to 20 words that can be understood.	• Is interested in interacting with people (plays patty cake) • Raises hands to be picked up • Maintains eye contact with people during playful interactions • Is interested in imitating others • Turns head in response to name being called • Is able to locate objects the parent is pointing to • Claps hand together in response to social play • Enjoys playing with a variety of toys and textures • Enjoys banging and playing with musical toys • Eagerly explores the environment when placed on the floor • Enjoys being swung and gently thrown in air • Enjoys exploring and playing in the playground • Enjoys swinging in the playground

TABLE 7: 18-24 MONTHS DEVELOPMENT

Gross Motor	Fine Motor	Language	Social and emotional, cognitive
• Stands alone and walks, holding on to the parent's hand • Sticks out the upper and lower extremities to help get dressed and undressed • Walks without any help • Starts to go up the stairs • Can squat to get a toy and stand again	• Drinks from a sippy cup (or standard cup with assistance) • Uses a spoon clumsily and tries to eat something • Gets objects like raisins with thumb and one finger ("pincer handle") • Points, pokes and maybe even pinches someone or something • Puts things into a can or a bucket and takes them out once more • Scrawls with a thick coloured pencil or marker	• At this age, they can say 50-100 words till 24 months and even put 2 words together to make their first sentences.	• When they're being called, they turn their heads in response to their name • Can take part in little groups with other children • Is curious, knowledgeable, and able to maintain eye contact with others • Is able to play in social situations after a transition time • Points to toys and objects of interest • Can find objects the parents are pointing to • Explores varied places such as a new play field • Loves swinging on play field swings • Loves being swung and gently thrown in air • Loves to play with new toys in different ways • Usually plays with toys without mouthing them • Loves to play with musical toys and objects • Loves to sitting to look at or listen to a book

TABLE 8: 2-YEAR-OLD DEVELOPMENT			
Gross Motor	**Fine Motor**	**Language**	**Social and emotional, cognitive**
• Walks, runs and starts to learn how to jump with both feet • Pulls or carries objects while walking • Can throw a ball and kick it • Stands on tiptoes and maintains balance on one lower extremity • Climbs onto and down from furniture without support • Walks up stairs, holding on to the railing; may alternate feet	• Starts to brush own teeth and hair • Can pull pants up and down • May be able to turn on the faucet alone and wash hands • Builds a block tower with at least four blocks / or more • Starts practicing snapping and zipping • Holds utensils and coloured pencils with fingers rather than a clenched hand • At this age, toddlers enjoy turning over containers to pour out their contents	• Children at this age mimic what other kids and adults do and say, including how they say or do it	• Imitates what other children and adults do and say, as well as how they say or do it • Is happy to play near, if not with, other children • Begins to realize (s)he can do things without their parents' help • Breaks rules more than before, doing things their mother told not to do, just to test what happens • Shows expanding separation nervousness by year and a half, which typically eases considerably by two years; becomes progressively independent and aware of her/himself as her/his own person between 24 and 36 months • Mimics other's behaviour, especially that of adults and older kids • Progressively is aware of her/himself as separate from others • Is increasingly excited about the company of other kids • Displays increasing independence • Starts to show aggressive behaviour • Turns his or her head in response to name being called by others • Loves to sit listening or look at a book • They have tantrums when frustrated

TABLE 9: 3-YEAR-OLD DEVELOPMENT

Gross Motor	Fine Motor	Language	Social and emotional, cognitive
• Walks backwards and climbs stairs in a row • Shoots a smaller ball; often catches a bigger ball • Starts tricycle or bicycle pedalling	• Draws a circle with a coloured pencil, leads pencil or marker • Plays with toys with little moving parts and buttons • Turns the pages of a book, one after the other • Builds something with blocks and creates towers of six or more blocks • Is busy with door handles and twist bottle tops	• Can say their name and age • Can talk with 250 to 500 words and answers simple questions • Talks in sentences of five to six words, and expresses her/himself in complete sentences by age 4	• Is curious, knowledgeable, and able to maintain eye contact with others • Is interested—although uncertain—about going to new environments and trying new things • Begins to play with kids (as opposed to only playing side-by-side) • Starts being able to comfort and show concern for an unhappy or worried friend without prompting • Takes turns while playing (regardless of whether they don’t like to) • Plays “real life” with toys like play with a toy kitchen and kitchenware • Begins discovering simple ways to solve arguments and disagreements • Shows (but maybe not names) a different kind of emotions beyond happy, sad and mad • When they’re being called, they turn their heads in response to their name • Loves to sit and listen or look at book • Generally plays with toys and objects without mouthing them • Can take part in little groups with other children • Loves playing with a variety of toys and textures • Can find objects of interest • Can find objects the parent is pointing to • Is able to cooperate in messy activities that result in dirty hands • Explores different places such as a new play field • Loves swinging on play field swings • Can play in social circumstances after a progress time • Loves swinging, being thrown in the air and gentle roughhousing

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2.3.1 DEVELOPMENTAL DELAY

Babies grow and develop at different rates.
The baby can do some of these developmental steps a little early and some a little late. But if (s) he can't do most of it, then a doctor should be consulted.
It may be useful to make an assessment to look at the skills.

2.3.1.1 MOTOR DEVELOPMENT

0-3 Months
Seldom moves on both extremities; seems rigid
Looks excessively loose or droopy in the limbs
Feeding goes slowly or the baby is not sucking the mother normally
The baby can't support her/his head well at month three
The baby doesn't reach for and grasp objects by three to four months
The baby doesn't grasp and hold things at month three

4-6 Months
The baby doesn't bring objects in the mouth for up to four months
There is still tonic neck reflex in four to five months
The baby doesn't push the legs down when the feet are placed on a solid surface up to four months
The baby has trouble moving a single eye or both eyes in all directions
It is normal for the eyes to be cut occasionally in the first months but if the baby crosses the eyes often, there will be a problem

SIGNS OF DEVELOPMENTAL DELAY

7 Months
Looks very rigid and strict muscles and very droopy
The head will lag back if the body is pulled into a sitting position
Approaches with only one hand
Has difficulty getting things into his mouth
Can't sit with help up to six months
Doesn't actually approach objects between six-seven months
Doesn't carry some weight on lower extremities up to seven months

8-12 Months
Cannot stand when supported
Hauls one body side while crawling
Doesn't crawl

2 Years Old
Cannot walk up to 18 months
After walking for a few months, the baby can't accomplish a heel-toe walking pattern
A toy with wheels cannot be pu(s)hed up to the age of two

2.3.1.2 SPEECH AND LANGUAGE DEVELOPMENT

SIGNS OF DEVELOPMENTAL DELAY

0-3 Months
Doesn't prattle up to three to four months

4-6 Months
(s)he starts babbling but doesn't try to mimic your voices up to four months

7 Months
Doesn't smile or creak for up to six months
Doesn't prattle up to eight months

8-12 Months
Doesn't say a single word

2 Years Old
Doesn't speak a minimum of 15-20 words up to 18 months
Doesn't make two-word sentences up to two years old
Doesn't mimic actions or words

0-3 MONTH WARNING SIGNS

Communication
Doesn't cry when being hungry or uneasy
Doesn't realise or reply to violent sounds
Doesn't make eye contact or smile at parents

4-6 MONTH WARNING SIGNS

Communication
Doesn't reply to sounds
Doesn't make any vowel sounds
Abstains eye contact
Doesn't smile or laugh

7-9 MONTH WARNING SIGNS

Communication
Has no interest in interacting with others
Doesn't pursue eye contact along playful interaction
Doesn't respond to sounds or voices
Doesn't babble
Has no respondse to the own name

10-12 MONTH WARNING SIGNS

Communication
Doesn’t look back when someone calls her/him by name
Shows no recognition of familiar simple words

13-18 MONTH WARNING SIGNS

Communication
Doesn’t babble
Doesn’t maintain eye contact
Doesn’t reply when her/his name is called
Makes no attempt to contact

2.3.1.3 SOCIAL AND EMOTIONAL, COGNITIVE DEVELOPMENT

0-3 Months
Has no reply to loud sounds
Won’t blink when a bright light is shown
Doesn’t concentrate and pursue a nearby collateral moving object
The lower jaw constantly vibrates even when he is not crying or thrilled

4-6 Months
Doesn’t interested in new faces or looks very afraid of new faces

SIGNS OF DEVELOPMENTAL DELAY

7 Months
Rejects to cuddle
Shows no connection to the caregiver
Looks like the baby doesn’t like being around people
One eye or both of them constantly turn in or out
Insistent crying or susceptibility to light
Has no response to sounds around her
Doesn’t turning the head to spot voices up to four months
Doesn’t roll in both directions up to five months
Seems that (s)he cannot be comforted at night after five months
Isn’t smiling by her/himself up to five months
Doesn’t pursue objects with both eyes at close and distant ranges up to seven months
Does not try to attract attention through actions up to seven months
Shows no attention in games up to eight months

8-12 Months
Doesn’t search for hidden objects
Doesn’t learn how to use gestures
Doesn’t indicate objects

2 Years Old
Doesn’t know the use of everyday items by fifteen months
Doens’t follw easy rules up to age of two

2.3.1.4 SENSORY INTEGRATION

Opposes to cuddling
When somebody tries to hold the baby, (s)he weeps
Troubled by diaper changes
Troubled by baths and/or water splashing on her/him
Doesn't have a proper sleep pattern
Weeps extremely all day
Doesn't laugh frequently, most of the time feels upset and disturbed
Abstains from eye contact, hardly concentrates on objects or pursuing with eyes
Feels troubled when suddenly being transferred
Feels troubled by swinging motions
Feels troubled when thrown up in the air
Looks like (s)he doesn't respond to her name or familiar voice
Whatever the parent tries, the parent can't calm her/him
Challenging breastfeeding and such actions like sucking, chewing, or swallowing
Doesn't endure new eatables nicely
Consumes a limited number of nutrients, heaves or vomits in different foods.
Often an infection develops in the ear
Is sensitive to outside sounds
Does not play games mutually with acquaintances
Can't feel whether the diaper is wet or dirty
Cries inevitably when changing the diaper
Doesn't want to wear clothes
Strong separation anxiety
Being very angry several times in a day
Feels troubled by bright lights
Feels troubled in public places
Has no fun while playing regular interactive games
Doesn't realize new toys
He cannot change activities or participate in daily routines without any problems when switching from one to the other.
Baby is incomprehensible and often irritated
The baby often hits with the head, bites, squeezes or harms her/himself or others
Shatters toys often
Doesn't act gently to animals
Doesn't seem coordinated, and often hits things
Can't concentrate on a game, parents or toy for long enough to play
Extravagates purposeless or interacts in non-excessive activities
Only uses one hand to manipulate and explore toys and/or can't switch from hand to hand

Uses only one hand to move and explore toys and can't change it between two hands
Can't pair up toys
Makes the hands fist and often keeps them closed
Gets disturbed when the hands or face are unclean
Tenses up and cries when staying with less familiar people
Has trouble starting to eat solid foods

0-3 MONTHS WARNING SIGNS

Sensory
Makes a fist and hands remain like this often
Doesn't concentrate on an object with the eyes
Doesn't like varied movements
Often reluctates being carried

4-6 MONTHS WARNING SIGNS

Sensory
Doesn't give it a shot to reach out and take toys
Doesn't take the own hand or a toy into the mouth
Baby often gets angry for no obvious reason
Baby doesn't monitor moving things

7-9 MONTHS WARNING SIGNS

Sensory
Doesn't like playing with toys with different tissue
Is displeased by playing with musical toys
Doesn't interested in playing with objects of different colours
Doesn't move to explore the surrounding area while on the ground
Doesn't interested in different types of movement like swinging
Seems to be afraid of daily sounds

10-12 MONTHS WARNING SIGNS

Sensory
Feels disconcerted in reaction to movements
Excessive reaction when touching a surface or touching new tissues

13-18 MONTHS WARNING SIGNS

Sensory
Feels disconcerted in reaction to movement
Is sensitive to excessive noise and different surfaces or does not react at all
Cuddling or holding by someone is not a joyful activity
Doesn't like to touch different tissues
Is very afraid when the feet are lifted from the ground and embraced

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2.4 REFLEXES

A reflex action is the result of the coordination of the spinal cord and the peripheral nervous system. This action does not involve the brain. The pathway in which impulses travel during the reflex action is called a reflex arc.

The central nervous system contains the brain, brainstem, and spinal cord. The peripheral nervous system contains the nerves, which leave the brain and the spinal cord and travel to certain areas of the body.

Primitive reflex: Primitive reflexes are innate and central nervous system-induced involuntary reflex attitudes displayed by normal kids in response to specific stimuli.

Righting/Equilibrium Reactions: Correcting responses promote the positioning of the head vertically in space, alignment of the head and body, and alignment of the body and extremities. Equilibrium responses ensure equity when the centre of gravity is disturbed.

Postural reaction: Postural responses are maturational motor skills that develop during the first year of life and form the basis for the achievement of functional motor skills.

2.4.1 PRIMITIVE REFLEXES

Palmar grasp (age of disappearance: 6 months) - https://www.youtube.com/watch?v=VAk68yXSy7E

While baby is in supine position (lying horizontally with the face and torso facing up), placing the forefinger in the palm of the kid

↓ ↓ ↓

Flexion of fingers, fist making

Plantar grasp (age of disappearance: 15 months) - https://www.youtube.com/watch?v=Vy18c5oGLSk
In supine position, squeezing a thumb against the bottom just behind the toes in the foot

↓ ↓ ↓

Flexion of toes

Galant (age of disappearance: 4 months) – see https://www.youtube.com/watch?v=-vBZesEaYYs
In prone position (face and torso facing down), scratching the skin of the newborn child from the shoulder downwards, 2-3 cm lateral to the spinous processes

↓ ↓ ↓

Incurvation of the trunk, with the concavity on the stimulated side

Asymmetric tonic neck reflex (age of disappearance: 3 months) - https://www.youtube.com/watch?v=0oI_yGQViXY
In supine position, rotation of the newborn child’s head to one side for 15 s

↓ ↓ ↓

Extension of the limits on the chin side and flexion of those on the occipital side

Suprapubic extensor (age of disappearance: 4 weeks)
In supine position, squeezing the skin over the pubic bone with the fingers

↓ ↓ ↓

Reflex extension of both lower extremities, with adduction and internal rotation into talipes equinus

Crossed extensor (age of disappearance: 6 weeks) - https://www.youtube.com/watch?v=KvLCm_J0fsM
In supine position, passive total flexion of one lower furthest point

↓ ↓ ↓

Expansion of the other lower appendage with adduction and interior revolution into talipes equinus

Rossolimo (age of disappearance: 4 weeks)
In supine position, light tapping of the 2nd -4th toes at their plantar surface

↓ ↓ ↓

Tonic flexion of the toes at the first metacarpophalangeal joint

Heel (age of disappearance: 3 weeks)
In supine position, tapping on the heel with a clobber, with the hip and knee joint tightened, and the ankle joint in neutral position

↓ ↓ ↓

Rapid reflex extension of the lower extremity in question

Moro (age of disappearance: 6 months) - https://youtu.be/PTz-iVI2mf4
In supine position, unexpected head expansion delivered by a light drop of the head

↓ ↓ ↓

Abduction followed by adduction and flexion of upper extremities

2.4.2 RIGHTING/EQUILIBRIUM REACTIONS

POSTURAL REFLEXES

Labyrinthine righting reflex - https://www.youtube.com/watch?v=0nT8jBEeBsE

Labyrinthine righting reflex keeps up the face in a vertical position and the mouth flat. It tends to be inspired on the off chance that one holds the infant in an upstanding position, at that point tilts the newborn child forward, in reverse, or to the side.

It is so named as it is thought to occur for the reason that it stimulates the labyrinths or vestibular system, and contributes to the shortening or enlargement of the neck muscles that maintain the head in the appropriate orientation.

Neck righting reflex - https://www.youtube.com/watch?v=r1pZWHJPKg0

The neck correction reflex orients the body in relation to the head. Extension of the head through dorsiflexion results in enlargement of the vertebral column, considering that ventroflexion of the head causes stretching or rounding of the vertebral column.

In the event that the head is slanted along the side toward one of the shoulders, this produces parallel ebb and flow of the spine with the concavity coordinated toward a similar shoulder.

Neck rotation brings about the thorax, being carried into evenness with the head.

Body righting reflex

In relation to the ground, the body correction reflex orients the head.

This emerges at around a half year of age and is significant for voluntary rolling.

This reflex can be evoked in newborns up to 18 months of age.

Pull-up reflex

The pull-up reflex shows up around three to four months and happens when the newborn child is in an upright sitting position.

When held by either one or both arms, the newborn child will effort to remain upright using a reflexive reaction of the arms.

Equilibrium reactions

Equilibrium reactions need a response by the entire body and are needed to restore equity after division of the center of gravity.

They are commonly present in all postures (other than standing) by a year old, and require rotation and activation of both extensor and flexor muscles.

LOCOMOTOR REFLEXES

Crawling reflex - https://www.youtube.com/watch?v=_zTP2VI_WaQ

Crawling reflex is frequently present during birth and vanishes around the 3 or 4 month.

It tends to be evoked in the lying down position through application of pressure to the sole of the foot, which results in a crawling response from all four limbs.

Swimming reflex - https://www.youtube.com/watch?v=2dPK5QKTsZA

The swimming reflex is elicited when a newborn kid is placed in or over water in the lying down (prone) position.

This is an efficient reaction of flexion and augmentation of the arms and legs.

It is commonly present in the initial two weeks of life and vanishes around the fourth to fifth month.

Stepping reflex - https://www.youtube.com/watch?v=cn7XPS21avE

Stepping reflex is ordinarily present in the first six weeks and disappears by five months of age.

It is evoked when one places the baby’s feet on the flat surface with its body weight forward. The baby will «walk» forward.

POSTURAL REACTIONS

Postural responses are maturational engine abilities that occur during the first year of life and form the basis for attainment of functional motor skills.

There are seven postural responses:
- Traction
- Horizontal suspension
- Vertical suspension
- Vojta response
- Collis horizontal suspension
- Collis vertical suspension
- Peiper-Isbert vertical suspension

Traction - https://www.youtube.com/watch?v=j-Ev0IASCGI
In supine position, placing the analyst's index finger in the newborn child's hand and pulling the baby at a 45° angle with the assessment bed

Horizontal suspension - https://www.youtube.com/watch?v=BasXYtKOjSs
In prone position, underpinning the newborn child by placing the hands around the baby's thorax without providing support for the head or legs.

Vertical suspension - https://www.youtube.com/watch?v=veyA3DPdx5Y
In vertical position, placing right and left hand in the axillae (armpit), without grasping the thorax and lifting the baby straight up facing the examiner

Vojta response
Underpinning from the vertical to the horizontal position facing the examiner by placing both hands around the baby's thorax in vertical position

Collis horizontal suspension
In prone position, locating one hand around the upper extend and the other around the upper leg and suspending the newborn child in the horizontal position parallel to the examination bed

Collis vertical suspension
In prone position, placing one hand around the upper leg and suspending the newborn child in the upright position with head directed downwards

Peiper-Isbert vertical suspension
Placing the examiner's hands around each upper leg of the baby and suspending the newborn child in the vertical position with head directed downwards in prone position.

2.5 SENSORY INTEGRATION

2.5.1 DEFINITION

Sensory integration refers to people’s qualification to use their senses such as sight, touch, taste, sound, proprioceptive and vestibular to interpret sensory input received from the environment and internal cues, and then react in a way to have significant and purposeful communication with the world around them. The development of sensory completion skills starts at birth and continues throughout a lifetime.

2.5.2 SENSORY INTEGRATION ISSUES

WHAT COULD BE A SENSORY ISSUE?

Excessively touchy or under responsive to contact, development, sights, or sounds
Unusually high or low activity level
Effortlessly occupied; poor regard for errands
Delays in speech, motor skills, or academic achievement
Coordination problems; appears gawky or awkward
Poor body awareness
Trouble learning new tasks or making sense of how to play with new toys
Trouble with tasks that require using two hands simultaneously
Appears to be messed up most of the time
Trouble with transitions between activities or places
Undergrowth social skills
Impulsivity or lack of self-control
Trouble quieting self once “twisted up”

2.6 STANDARDISED ASSESSMENTS FOR CHILD DEVELOPMENT

The information in this section is dedicated to comprehension and disclosing the tests used to decide whether an infant’s improvement is suitable for their age.

Institutionalized evaluation tests are utilized to comprehend the dangers of this gathering of kids and to recognize common advancement from atypical if a youngster doesn’t produce for her/his age, can’t play out the abilities/developments that (s)he needs to achieve, and is in danger of neuromotor formative impediment because of specific dangers during and after conveyance.

The reason for the tests that assess improvement is to identify formative deferrals and atypical advancement in kids.

These tests can be used to decide if an infant has created as per the sequential month (whenever rectified for an untimely age)

For instance, if the baby is born 1 month prematurely and is now 3 months, these tests are expected to be in line with the developmental stages of the 2nd month.

2.6.1 TESTS

- Bayley Scale of Infant Development-III (BSID-III)
- General Movements (GM’s) Analysis, Heinz Prechtl
- Denver Development Screening Test II (include motor and fine motor item)
- The Movement Assesment of Infant (MAI)
- Harris Infant Neuromotor Test (HINT)
- Alberta Infant Motor Test (AIMS)
- The test of Infant Motor Performance (TIMP)
- Peabody Developmental Motor Scales 2 (PDMS-2)
- The Gross Motor Function Measure (GMFM)

BAYLEY SCALE OF INFANT DEVELOPMENT-III (BSID-III)

BSID-III: https://www.youtube.com/watch?v=j7ysEWc0-p8

The Bayley Scales of Infant Development (BSID-3) is an established, standardized test with determined normal values of a newborn child‘s cognitive and motor functioning with well-defined psychometric test properties. The BSID was improved to assess current progressional functioning, assist in the diagnosis of progressional delay, and identify the need for progressional intervention.

The ambition is to measure progressional delays in the very young and non-verbal children.

Target Population and Ages:

- Down syndrome, common developmental disorder, CP, particular or suspected language impairment, asphyxiation at birth, prenatal alcohol exposure, small for gestational age, premature or low birth weight, or other children at risk for developmental delays.
- For ages 1-42 months.

Administration

- 2 questionnaires for social-emotional and adaptive behaviour (using ABAS-II) and 3 sections scored by examiner (cognitive, language, and motor).

Scoring:

- 0 or 1 depending on if the kids are capable of performing the activity for cognitive, motor, fine and gross sub-scales, and language, expressive and receptive sub-scales, scored by the investigator.
- Social, emotional and adaptive questionnaires filled out by parent/caregiver with same scale 0 or 1.

Time requirements

- Administration and scoring is about 30 to 90 minutes.

Proof of validity:

- Article states great legitimacy of the BSID-III at 2-4 years in preterm kids.
- Predictive validity at 81 who stayed in same developmental grouping such as; normal, mild, moderate, severe delayed.

Strengths:

- Ideal for use when you doubtful delays or problems in early development
- Decide the requirement for additional top to bottom thought, indicate strengths, weaknesses, and competencies so that parents and professionals can properly plan for the child,
- Excellent for use in cross-disciplinary teams, and allows for more caregiver involvement in test items.

GENERAL MOVEMENTS (GM'S) ANALYSIS, HEINZ PRECHTL

GMAHP: https://www.youtube.com/watch?v=I-aNAMRtvF8

It is a procedure that is used to understand the future neuromotor problems of premature-babies, high-risk newborn-child in/after the incubator.

The consideration can be completed from birth up to 1 month and 2 weeks of age (corrected age).

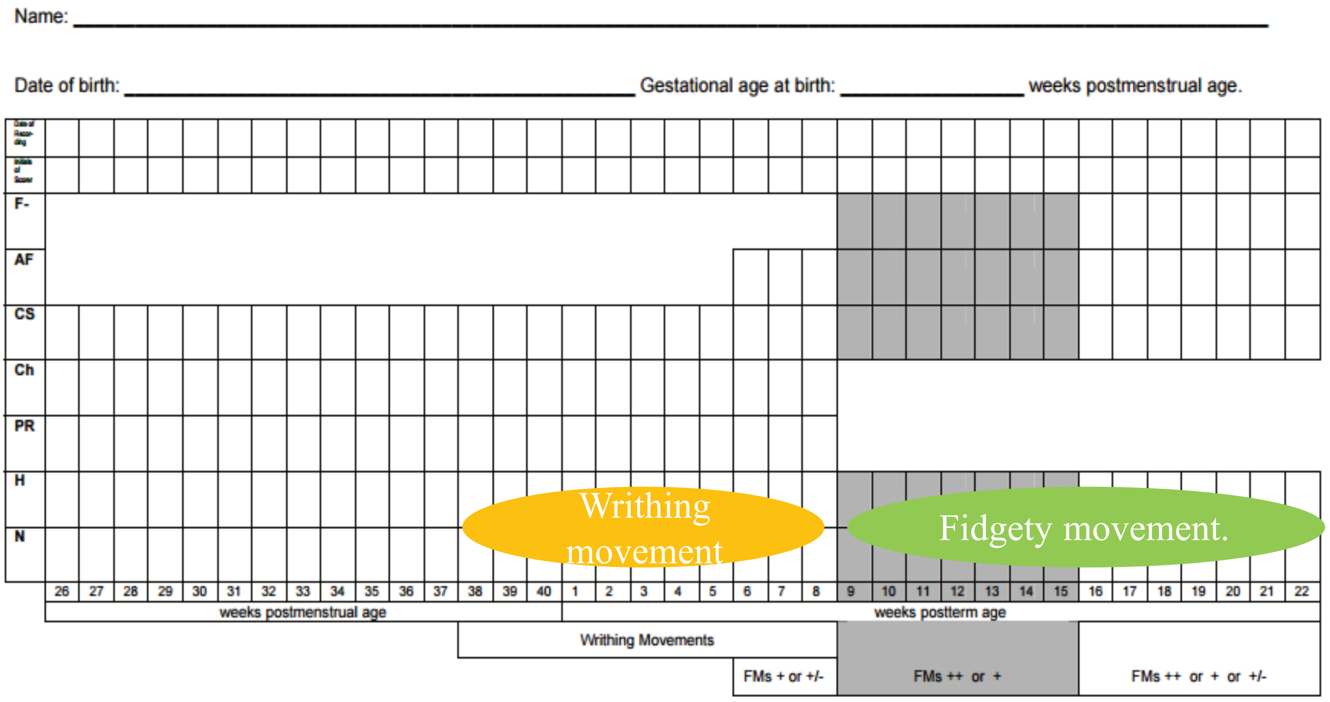
It is non-invasive and non-disruptive. Infants are videotaped in their natural environment (atmosphere) with as few clothes as possible.

The video can be taken by the mother and father or clinicians with proper consent.

The video might be recorded by medicals whilst the infant is an inpatient, an outpatient, or by you in your home.

This technique is favorably predictive of future cerebral palsy.

THERE ARE TWO TERMS:



Name: ______________________________

Date of birth: ______________________ Gestational age at birth: ____________ weeks postmenstrual age.

N, normal age-specific GMs; **FMs**, fidgety movements; **H**, hypokinesis (no GMs during the recording); **PR**, poor repertoire of GMs; **Ch**, chaotic GMs; **CS**, cramped-synchronised GMs; **AF**, abnormal fidgety movements; **F-**, absence of fidgety movements.

BAYLEY SCALE OF INFANT DEVELOPMENT-III (BSID-III)

BSID-III: https://www.youtube.com/watch?v=j7ysEWc0-p8&t=400s
Scoring varies between 0 and 1 depending on whether cognitive, motor and language activities can be performed and made by a specialist. Parents can fill the social-emotional part using the same way. The evaluation and scoring process takes between 30 to 90 minutes.

BSID-III has a good validity (0.81) for 2-4 years old children who were born prematurely.

It is perfect for a more detailed examination when you suspect a developmental delay or various problems in early development. As it determines the strengths and weaknesses and skills, it enables the healthcare professionals and the family to plan together about the child.

THE MOVEMENT ASSESSMENT OF INFANT (MAI)

MAI: https://www.youtube.com/watch?v=y0yI_gnAs6g
The purpose of the test is to test the motor development, including the muscle tone, primitive reflexes and voluntary movements.

MAI is a 65-item benchmark-based assessment developed to assess the condition of four-month-old infants who were initially at risk of long-term neuromuscular problems such as cerebral palsy and who were discharged from the neonatal intensive care unit (NICU).

This test's target population consists of 0-6 months old infants who had a low birth weight. It takes a total of 1.5 hours including talking to the family, performing the test and scoring.

Primitive reflex, muscle tone, volitional movement and automatic reactions are measured in this test. Over 13 points high and 0 to 7 points demonstrates no risk. The health professional must suspect a value between 7-13.

Standard scores develop as normal, minimal problems, or specific problems at 4 and 8 months. Raw scores and risk scores are used in the test. All items are scored from 1 to 5, and 1 point indicates a better function than 5 points. Scores over 8 are considered high risk.

MAI's strengths include predicting mental and motor problems in infants at 12 months, based on 4 and 8 months scores and a high validity.

HARRIS INFANT NEUROMOTOR TEST (HINT)

HINT is an evaluative test and it is used for early detection of cognitive and neuromotor delays in babies between 3-12 months with known risk factors.

The application of the test starts with recording the demographic information of the child and the caregiver and newborn risk factors.

Then, the parent is evaluated with 5 items and the newborn is evaluated with 22 items.

After the 21 evaluation criteria have been collected, the tester makes two summary decisions about the general neuromotor performance of the newborn,:

- one about the developmental level of the baby,
- and the other about the motor performance.

The scoring of the test is done in this way.

HINT has a sensitivity (80%) and specificity (90.9%). It has reliability and validity, it is also easy to use.

PEABODY DEVELOPMENTAL MOTOR SCALES 2 (PDMS-2)

PDMS-2: https://www.youtube.com/watch?v=YknVE0gUztg

Purpose of this test is to evaluate and compare the motor skills of children up to 5 years old, including gross motor, fine motor and total motor.

PDMS-2 is an evaluative test and scores motor parameters, but the sensitivity of the test is valid only for the last 6 months.

THE TEST OF INFANT MOTOR PERFORMANCE (TIMP)

TIMP: https://www.youtube.com/watch?v=ufrAnRGxNnM

TIMP evaluates the movement abilities of infants which is needed for daily life activities.

Purpose of this test is to identify high-risk babies for low motor performance. It can also show motor performance changes over time. It can be performed between preterm (34 weeks) to post term (4 months).

It is a 42-item test with 13 items for spontaneous activities and 5 items for head control in a supported sitting position. The rest of the items address righting reactions and postural control.

ALBERTA INFANT MOTOR TEST (AIMS)

AIMS: https://www.youtube.com/watch?v=c5VwBJcyX8w

AIMS is an evaluative and discriminative test for 0-18-month-old babies, which is identifying “at risk” populations based on various diagnoses, and evaluates the development of motor milestones, as well as steps that are required to achieve them.

AIMS considers 4 different functional positions to assess infant motor skills and contains 58 items. AIMS has good inter-rater reliability between practitioners (values from 0.86 to 0.99). The practitioner should be able to complete the AIMS test in 20-25 minutes.

DENVER DEVELOPMENTAL SCREENING TEST, 2ND EDITION DDST-II

DDST-II: https://www.youtube.com/watch?v=J0fkUwVtpwE

DDST-II is used worldwide as a screening tool to screen children at risk of developmental delay from birth to age 6. The application of the test is based on scoring observation and parental reporting and is applied within 20 minutes.

Filled with parental feedback, the test has a total of 125 items in four areas and includes fine motor adaptive, gross motor, personal-social and language skills.

2.6.2 OBSERVATION CHECKLIST

THE DEVELOPMENTAL MILESTONES CHECKLIST (DMC)

The Developmental Milestones Checklist (DMC) was developed in Kenya to provide motor, language and personal-social scores for children aged from 3 to 24 months.

THE KILIFI DEVELOPMENTAL INVENTORY (KDI)

The Kilifi Development Checklist (KDC) is designed to create a suitable psychomotor development criterion for 6-35 months old children. The inventory consists of 69 items managed by an evaluator who explains and shows each new task before trying child activity. An outlined score is calculated for locomotor skills and eye-hand coordination.

DEVELOPMENTAL OBSERVATION CHECKLIST SYSTEM (DOCS)

DOCS evaluates kids in terms of a three-part inventory / checklist system for:

- overall development (DC),
- compliance behavior (ABC),
- and parental stress and support (PSSC).

The test is suitable from birth to 6 years old.

Infant & Toddler developmental checklists (Children's Learning Institute)

These milestone checklists can be used by parents and teachers of children from birth to 48 months of age.

They are divided into age ranges and areas of development:

- Language
- Social emotional
- Cognitive
- Early literacy
- Physical health
- Motor development.

You can also use pathways.org for observation checklists. All their milestones are supported by the American Academy of Paediatrics findings.

Use these checklists to track your child's development.

If you notice your child isn't meeting any of their milestones, bring this checklist to your healthcare provider to discuss your observations and concerns.

- Milestone Checklist
- Ability Checklist
- Communication Checklist

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MODULE 3

DISABILITY AND THE SPECIFIC NEEDS

CONTENTS

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3.1 INTRODUCTION

Who is this module aiming at?
What kind of information does it provide?
Which type of disabilities and disabling conditions does it present?
How much time should you consider for learning it?
Why should you spend time on it?

We hope this module will reverse your way of thinking of the disability – from *an image of illness and ill health to a distinct way of being in the world.*

3.2 RISK FACTORS THAT MAY LEAD TO DISABILITY OF THE NEWBORN

3.2.1 BIOLOGICAL RISKS

3.2.2 PREMATURITY

Very low birth weight (VLBW)

- 13-90 per 1,000 have cerebral palsy

Extremely low birth weight (ELBW)

- Between 2 and 8 percent are blind
- 1 in 2 have a neurodevelopmental disability
- All have mean IQ and achievement scores that are 9 to 13 points below the normative mean
- Nearly half require special educational assistance and/or repeat a grade.

3.2.3 INFECTIONS

Agents causing congenital infections:

- Toxoplasmosis
- Rubella
- Cytomegalovirus
- Herpes simplex virus (types 1, 2)
- Syphilis
- Hepatitis B virus Hepatitis B virus
- Hepatitis C virus Hepatitis C virus
- HIV
- Varicella zoster virus (VZV)
- Parvovirus B19
- Enterovirus

Disability consequences of Cytomegalovirus

- Neurodevelopmental delay and cognitive impairment
- Microcephaly
- Chorioretinitis
- Intracranial calcifications
- Sensorineural hearing loss

Disability consequences of Toxoplasmosis

- Hydrocephalus
- Microcephaly
- Seizures
- Chorioretinitis
- Blindness (also in adolescent)
- Diffuse cerebral disorders
- Calcifications
- Jaundice
- Hepatosplenomegaly
- Cognitive delay
- Learning disabilities

Disability consequences of Congenital Rubella Syndrome (CRS)

- Cataracts
- Glaucoma
- Retinopathy
- Microphthalmia
- Sensorineural hearing Impairment
- Meningoencephalitis
- Mental retardation;
- Bone lesions (osteitis)
- Thrombocytopenia– “blueberry muffin rash blueberry muffin rash ”, purpura
- Hepatosplenomegaly

Disability consequences of Congenital syphilis

- Hydrocephalus, frontal bossing
- Saddle shape nose, high arched palate
- Short maxilla, Hutchinson’s teeth
- Hearing loss (8th cranial nerve)
- Keratitis
- Perioral fissures

Disability consequences of Neonatal and Congenital Herpes Zoster Virus (HSV) infection:

- Intellectual disabilities
- Paralysis (tetra-, hemiplegia)
- Hydrocephalus/ Microcephaly
- Delayed speech development
- Limb atrophy
- Autonomic nervous system
- Ventriculomegaly
- Cortical atrophy
- Cataracts
- Chorioretinitis
- Learning disabilities

Disability consequences of Herpes Simplex Virus

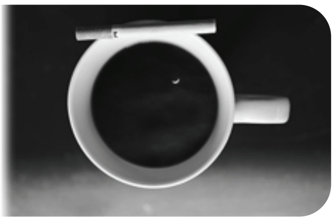
- Developmental delay
- Epilepsy
- Blindness
- Cognitive disabilities

Disability consequences of Group B Beta Hemolytic Streptococcal Infection

Group B Streptococcus (GBS) is a leading cause of infant sepsis and meningitis. On another side almost one-fifth of GBS infant meningitis survivors experience moderate or severe NDI (Nephrogenic Diabetes Insipidus) as:

- Learning disabilities
- Intellectual disabilities
- Speech delay
- Motor, vision, or hearing impairment

3.2.4 INTOXICANTS



Over the past several decades, the use of legal and illegal substances by pregnant women drags the attention of the academic community. The researches in the field prove that almost all known drugs cross the placenta and exercise some effects on the foetus. The nicotine effects on the human foetus have been identified and studied since the 1960s, while the alcohol and opiates effects have been studied since the 1970s. The effects of a variety of other illicit drugs have been studied since the 1980s.

- **Nicotine & Caffeine & Ethanol**

3.2.5 FOETAL ALCOHOL SYNDROME

What could it cause to a newborn?

1.5 DRUG ADDICTIONS

Drug abuse during pregnancy: effects on the mother and the foetus…

- Marijuana
- Opiates
- Methamphetamine

How to identify the drug users among the pregnant women?

3.3 ESTABLISHED RISKS

3.3.1 CHROMOSOMAL ABNORMALITIES

- Numerical abnormalities

- Structural abnormalities

3.4 GIVING THE DIAGNOSIS

To learn that your baby would be stillborn or is expected to have a serious medical condition is always a traumatising experience, not only for the pregnant woman, but the other parent as well. Of course such news has a severe impact mainly on the women, but similar immediate reactions such as shock, disbelief, and intense grief and pain, as well as dissociative phenomena and emotional numbness could be registered with the other partner as well.

Some advices for giving the diagnosis:
Usually there is little time parents have to take the decision to terminate the pregnancy, to opt for therapeutic intervention after prenatal diagnosis, or to accept the diagnosis and decide on continuing the pregnancy.

However, in all cases parents need to be supported and "accompanied" in the process of news sinking in. Although the medical actions may require urgency, further details about the diagnosis and consequences of decisions made should be discussed with parents only after the initial shock has passed.

For further reading: ***Kersting, A., Nagl , M.*** "Grief after Perinatal Loss", in: Milunsky, Aubrey and Milunsky, Jeff M. "Genetic disorders and the foetus: diagnosis, prevention, and treatment" (2016)

3.5 ENVIRONMENTAL RISKS

"Disability" is a relational concept reflecting the level of interaction between the person with impairment/functional limitations and the social and physical environments. Described so, disability stops being a personal, inherent in the individual problem, but a problem determined by the services and support provided to the people with disabling conditions and the extent to which the environment is accommodating to them.

Cultural differences

Poverty

Lifestyle choices and attitudes

3.6 DEFINITIONS AND FUNCTIONAL CLASSIFICATION OF DISABILITIES

The WHO's International Classification of Functioning, Disability, and Health (ICF - https://www.who.int/classifications/icf/en/) defines disability as following:

***Disability** covers problems in organ structures and functioning, activity limitations, and restriction in participation. Improvement in any of these three components reduces disability and improves functioning.*

ICF is the WHO framework for measuring health and disability at both individual and population levels.

A user friendly ICF browser is also available: https://apps.who.int/classifications/icfbrowser/.

3.6.1 INTERNATIONAL CLASSIFICATION OF, DISABILITY, AND HEALTH FUNCTIONING (ICF)

Part I: Functioning and Disability

- **Body Functions and Structures** – describes actual anatomy and physiology/psychology of the human body.
- **Activity and Participation** – describes the person's functional status, including communication, mobility, interpersonal interactions, self-care, learning, applying knowledge, etc.

Part II: Contextual Factors

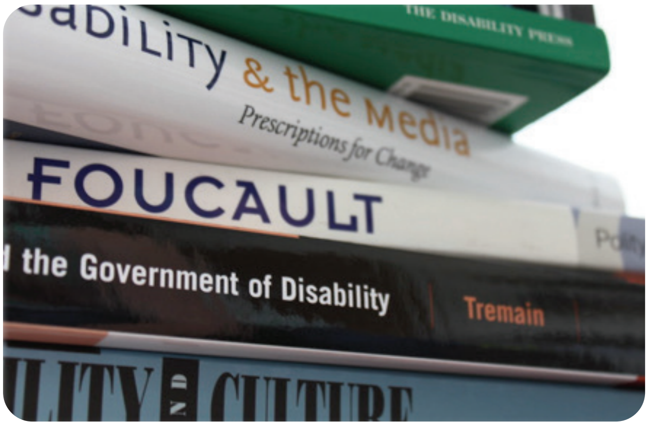
- **Environmental Factors** – factors that are not within the person's control, such as family, work, government agencies, laws, and cultural beliefs.
- **Personal Factors** – include race, gender, age, educational level, coping styles, etc. Personal factors are not specifically coded in the ICF because of the wide variability among cultures. They are included in the framework, however, because although they are independent of the health condition they may have an influence on how a person is functioning.

3.6.2 DISABILITY CATEGORIES

- Mobility and Physical Impairments
- Spinal Cord Disability
- Head Injuries (TBI) - Brain Disability
- Vision Disability
- Hearing Disability
- Cognitive or Learning Disabilities
- Psychological Disorders
- Disabilities

3.7 THE CONCEPT

3.7.1 DISABILITY MODELS



Predecessor models:

- Social model vs. Medical model
- Biopsychosocial model

Postmodern models:

- Identity model
- Human rights model
- Cultural model
- Charity model
- Economic model
- Limits model
- ICF model

3.7.2 IDENTITY MODEL

- Disability as a ***certain type of experience in the world*** which is not designed with disabled people in mind.
- Disability is nothing more than a ***marker, indicating a membership in a minority group,*** exactly like people from a same ethnical group are sharing collective identity.

3.7.3 HUMAN RIGHTS MODEL

- The human rights model moves beyond the explanation of the social factors that are underlying in a disability by ***offering a theoretical framework for disability policy*** based on the principle for the human dignity of people with disabilities.
- The Human Rights model incorporates both the ***first and second generation human rights:*** civil and political as well as economic, social and cultural rights.

3.7.4 CULTURAL MODEL

The ***cultural approach*** does not seek to define disability in any specific way but rather focuses on how different notions of disability and non-disability ***operate in the context of a specific culture.***

3.7.5 CHARITY MODEL

- The charity model seeks to act to the benefit of people with disabilities, encouraging ***"humane treatment of persons with disabilities"***.
- It is interesting that many people from the disability community regard the charity model in a very ***negative light,*** because they think the model is depicting them as helpless, depressed and dependent on other people for care and protection, contributing to the preservation of harmful stereotypes and misconceptions about people with disabilities.

3.7.6 ECONOMIC MODEL

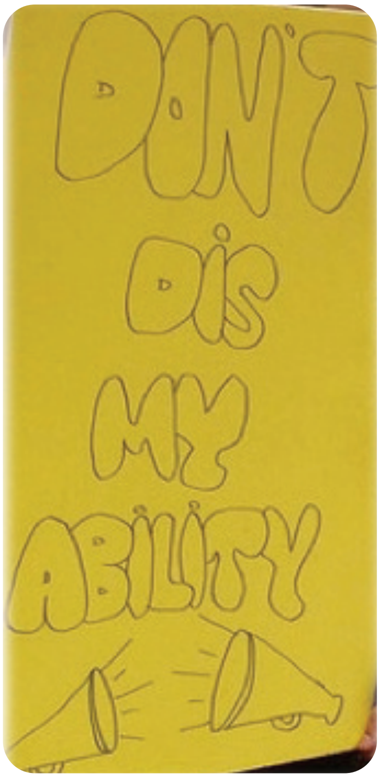
- The economic model of disability approaches disability from the ***viewpoint of an economic analysis,*** focusing particular on labour and employment capabilities of people with disabilities,.
- It is also criticised for framing disability almost exclusively in terms of a cost–benefit analysis, neglecting to take other important factors into account.

3.7.7 THE LIMITS MODEL

- All human beings experience some level of limitation in their everyday lives. Moreover, such limits are experienced to varying degrees during all the phases of our life.
- Rather than being something foreign to the human experience, ***limits are*** as a matter of fact ***a common, indeed quite unsurprising, aspect of being human.***

3.7.8 ICF MODEL

- ICF ***combines*** both the medical and the social disability models. Due to the consideration that the disability is a complex phenomena that is both a problem at the level of a *person's body,* and complex and primarily *social phenomena,* the ICF methodology finds the two cited models partially valid to explain the overall experience of the persons with disabilities.
- The disability and functioning are viewed in the ICF as outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors. Among the contextual factors are: **external environmental factors** (social attitudes, architectural characteristics, legal and social structures, climate, etc.); and **internal personal factors** (gender, age, coping styles, social background, education, profession, overall behaviour pattern, etc.).



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MODULE 4

PHYSICAL AND MENTAL DIMENSION OF THE DISABILITY

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4.1INTRODUCTION

- **Who** is this module aiming at?
- **What** kind of information does it provide?
- **Which** type of disabilities and disabling conditions does it present?
- **How** much time should you consider for learning it?
- **Why** should you spend time on it?

We hope this module will reverse your way of thinking of the disability – from *an image of illness and ill health to a distinct way of being in the world.*

4.2 THE NEWBORN WITH DISABILITY AS A NEW FAMILY MEMBER

- **Stage 1:** The initial "shock" of the news
- **Stage 2:** The grief
- **Stage 3:** The decision making
- **Stage 4:** The first meeting with the baby
- **Stage 5:** Supporting the parent-child relationship during the hospital stay

4.2.1 FAMILY FUNCTIONING AND ADJUSTMENTS

When the child with disability is born, everything makes special and unique sense, but even in the case of a normal birth of a healthy newborn, there is always some differences between the expectations and the reality.

4.2.2 SUPPORTING THE PARENT-CHILD RELATIONSHIP DURING HOSPITALIZATION

It is not possible to take care of the newborn in the best possible way unless we also ***take care for those adults who are the most important for him.***

4.2.3 THE MATTER OF THE PRECISE RECIPES AND PRESCRIPTIONS GIVEN TO PARENTS

It is always tempting for parents to be provided with clear, precise and specific guidance that sounds almost like a recipe for a perfect healthy and happy life. However, each life situation, each family, each single person is unique and has ***unique*** features, attributes and needs

4.3 BIRTH TRAUMA

Within this chapter we are going to observe those disabling conditions related to congenital anomalies or congenital malformations (birth trauma) that could be either diagnosed during the prenatal phase or could be recognized at birth and are significant enough to be considered as a problem.
The aim of the chapter is to help professionals who are going to convey to parents the news that they are expecting/ having a newborn with a disability or disabling condition, and doing it in a way that spares their dreams and hopes.

4.3.1 ANGELMAN SYNDROME

- **General information**
- **Functional limitations**
- **Prognosis**

The parents should know that their AS child will have a ***happy, excitable personality,*** *expressed by hand flapping and arms uplifted while walking, and will smile and laugh a lot.*

4.3.2 DOWN SYNDROME

- **General information**
- **Functional limitations**
- **Prognosis**

The parents should know that their AS child will have a ***happy, excitable personality,*** *expressed by hand flapping and arms uplifted while walking, and will smile and laugh a lot.*

4.3.3 FRAGILE X SYNDROME

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should know that their child with FXS will have various ***strengths****, like in vocabulary, verbal working memory and long-term memory for meaningful and learned information.*

4.3.4 KLINEFELTER (XXY)

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should know that their boy with KS will be friendly, kind, and helpful.

4.3.5 XXY SYNDROME

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should know that none of the XYY syndrome clinical features affect the quality of life of their boy.

4.3.6 PRADER–WILLI SYNDROME

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should remember that their child with Prader-Willi syndrome is an individual and will have own ***strengths*** *and needs.*

4.3.7 TURNER SYNDROME

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should be reminded that despite the physical differences and other problems, with the right medical care, early intervention, and ongoing support, their baby girl with Turner syndrome can lead a ***normal, healthy, and productive*** *life.*

4.3.8 WILLIAMS–BEUREN SYNDROME

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should be reminded that persons with Williams–Beuren syndrome are highly variable, and there are cases of WS people who ***manage to live independently*** *and to* ***have full-time*** *employment in competitive working environments.*

4.4. MULTIFACTORIAL DISORDERS

4.4.1 CONGENITAL HEART DEFECTS

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should be reminded that the functional consequences of congenital heart disease can change as children grow into adolescence and adulthood and that the majority of the effects of these conditions are nowadays reversible.

4.4.2 SPINA BIFIDA

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should be reminded that the individual, family, and parenting characteristics are important variables that predict successful achievement of an adolescent with SB.

4.5 NEUROMUSCULAR DISEASES

4.5.1 CONGENITAL MUSCULAR DYSTROPHY

- **General information**
- **Functional limitations**
- **Prognosis**

It would be good for the parents to be reminded that the degree of cognitive impairment in persons with neuromuscular diseases is greatly variable, and significant cognitive impairment is observed only in some patients.

4.5.2 SPINAL MUSCULAR ATROPHY

- **General information**
- **Functional limitations**
- **Prognosis**

Parents should be reminded that the SMA, as any other disabling condition, will shape the personality of their child, but it will not be who he is going to become. There will be many small and bigger things that their child will not be able to do, however the child will still have a chance to find things that make her/him happy and joyful in life, like travelling, having time with the loving family, watching movies, laughing and many others.

4.6 NEURODEVELOPMENT DISABILITIES

4.6.1 CEREBRAL PALSY

- **General information**
- **Functional limitations**
- **Prognosis**

It would be helpful for parents to know that a significant number of children with cerebral palsy enjoy a good general health and experience challenges limited to motor functions.

4.7 SENSORY IMPAIRMENTS-PHYSICAL AND MENTAL DIMENSIONS

4.7.1 VISUAL IMPAIRMENT

- **General information**
- **Functional limitations**
- **Prognosis**

*Parents should be reminded that while we usually assign a lot of functional limitations to the persons with visual impairments, it seems that there is **only one thing** they **are not able to do**, which is to drive a car. Having in mind the latest innovations in the car industry –autonomous driving cars-, it is just a matter of time for this last limitation to be overcome.*

4.7.2 HEARING IMPAIRMENT

- **General information**
- **Functional limitations**
- **Prognosis**

*Parents should be reminded that their child with hearing impairment **will not feel as a person who is lacking** something because his value system will reveal a different foundation – not a value of what (s)he will hear, but instead a value of what (s)he will see.*

4.7.3 MULTISENSORY IMPAIRMENT

- **General information**
- **Functional limitations**
- **Prognosis**

*Parents should consider that the **environment is essential** in defining later outcomes in MSI children. If their deaf-blind child is provided with an accessible language and an accessible environment in which the child is stimulated and encouraged to investigate the surroundings, (s)he will learn at a similar rate as the hearing and sighted peers.*

*Just tell them more about **Helen Keller** and her real life story of being an author who published 12 books!*

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MODULE 5

ADVISING AND SUPPORT OF PARENTS DURING THE PRE-PREGNANCY AND PREGNANCY PERIOD

CONTENTS

5.1 Definition of Birth Defects
5.2 Classification of Birth Defects
5.3 Genetic Counselling
5.4 Carrier Detection and Predictive Testing
5.5 Informal Two-Way Communication Process
5.6 Coordinate a Transdisciplinary Support Team for Parents of Children with Birth Defects
5.7 Ensuring Effective Implementation
5.8 Long-Term Source of Information and Support

5.1 DEFINITION OF BIRTH DEFECTS

- The formation of a human being, a process sometimes known as morphogenesis, involves an extremely complicated and as yet incompletely understood interaction of genetic and environmental factors.
- 2- 3% of all newborns have at least one major abnormality apparent at birth. The true incidence, taking into account abnormalities that present later in life, such as brain malformations, is probably close to 5%. Minor abnormalities are found in approximately 10% of all newborn babies.
- If two or more minor abnormalities are present in a newborn infant there is a 10-20% risk that the baby will also have a major malformation.
- The long-term outlook for a baby with a major abnormality obviously depends on the nature of the specific birth defect and whether it can be treated successfully.
- The overall prognosis for this group of newborns is as following:
    - o 25% die in early infancy
    - o 25% have subsequently a mental or physical disability
    - o the remaining 50% have a fair to good outlook after treatment

5.2 CLASSIFICATION OF BIRTH DEFECTS

1. Single abnormalities - may have a genetic or non-genetic basis.

- Malformation- a primary structural defect of an organ, or part of an organ, that results from an inherent abnormality in development. Most malformations involving only a single organ show multifactorial inheritance, implying an interaction of gene(s) with other factors.
- Disruption - an abnormal structure of an organ or tissue as a result of external factors disturbing the normal developmental process. This used to be known as a secondary or extrinsic malformation, and includes ischemia, infection, and trauma.
- Deformation - a defect resulting from an abnormal mechanical force that distorts an otherwise normal structure.
- Dysplasia - an abnormal organization of cells into tissue. The effects are usually seen wherever that particular tissue is present. Most dysplasias are caused by single-gene defects and are associated with high recurrence risks for siblings and/or offspring.

2. Multiple Abnormalities

- Sequence - findings that occur as a consequence of a cascade of events initiated by a single primary factor and may result in a single organ malformation.
- Syndrome - consistent and recognizable patterns of abnormalities for which there will often be a known underlying cause. These underlying causes can include

chromosome abnormalities, as in Down syndrome, or single gene defects, as in the Van der Woude syndrome, in which a cleft lip and/or palate occurs in association with pits in the lower lip.

- Association - certain malformations tend to occur together more often than would be expected by chance, yet this non-random occurrence of abnormalities cannot be easily explained on the basis of a sequence or a syndrome.

5.3 GENETIC COUNSELLING

The goal of genetic counselling is to provide accurate information that enables counselees to make their own fully informed decisions. Genetic counselling should therefore be non-directive and the genetic counsellor should be non-judgmental.

- Establishing the diagnosis

Reaching a diagnosis in clinical genetics usually involves the three fundamental steps of any medical consultation: taking a history, carrying out an examination, and undertaking appropriate investigations.

- Family and medical history

Detailed information about the family history will have been obtained by a skilled genetic nurse counsellor. A full and accurate family history is a cornerstone in the whole genetic assessment and counselling process. Further information about the family and personal medical history often emerges at the clinic, when a full examination can be undertaken and appropriate investigations initiated.

- Examination and appropriate investigation

These can include chromosome and molecular studies, as well as referral to specialists in other fields, such as neurology and ophthalmology.

The quality of genetic counselling is dependent upon the availability of facilities that ensure that an accurate diagnosis can be made.

- Calculating and presenting the risk - inheritance, reduced penetration, delayed age of onset

One of the most important aspects of genetic counselling is the provision of a risk figure. This is often referred to as a recurrence risk. Estimation of the recurrence risk requires careful consideration and takes into account the diagnosis and its mode of inheritance and analysis of the family pedigree. Sometimes the provision of a risk figure can be quite easy, but in a large number of situations, complicating factors arise that make the calculation very difficult.

- Calculating and presenting the risk

The factor that most influences parents when deciding whether or not to have a child is the nature of the long-term burden, or severity, associated with a risk rather than its precise numerical value. Therefore a 'high' risk of 1 in 2 for a trivial problem such as an extra digit (polydactyly) will deter very few parents.

In contrast a 'low' risk of 1 in 25 for a disabling condition such as a neural tube defect can have a very significant deterrent effect.

A woman who grew up watching her brother develop Duchenne muscular dystrophy and subsequently die from the condition aged 21 years, may not risk having children even if there is only a 1% chance that she is a carrier.

Other factors, such as whether a condition can be treated successfully, whether it is associated with pain and suffering, and whether prenatal diagnosis is available, will all be relevant to the decision-making process.

5.4 CARRIER DETECTION AND PREDICTIVE TESTING

- Genetic disease affects individuals and their families dramatically but every person, and every couple having children, is at some risk of seeing a disorder with a genetic component suddenly appear.
- There is screening of individuals and couples known to be at significant or high risk because of a positive family history sometimes referred to as targeted, or family screening because it focuses on those most likely to benefit. This includes the carrier, or heterozygote, screening, as well as presymptomatic testing.
- Secondly, there is the screening offered to the general population, who are at low risk - sometimes referred to as community genetic.
- Until recently, couples at high risk of having a child with a genetic disorder had to choose between taking the risk or considering other reproductive options (genetic testing plus IVF to sidestep a genetic disease whereby each embryo is screened for the gene in question, and only those embryos without the disease are implanted).
- Over the past three decades, prenatal diagnosis—the ability to detect abnormalities in an unborn child—has been widely used. Although it may be very difficult for a couple to decide to pursue prenatal diagnosis because of the possibility that this will lead to termination of a pregnancy, prenatal diagnosis is an option that is chosen by many couples at high risk of having a child with a serious genetic disorder or birth defect.

Tests that could be offered to couples:

Ultrasound tests and **magnetic resonance imaging (MRI)**

Cell-free DNA screening, which involves taking a blood sample from the mother and testing it for the genetic makeup of the baby. This test helps doctors identify any abnormal chromosomes in the baby, which can cause problems (e.g. Down syndrome, Turner syndrome).

Amniocentesis and chorionic villi sampling. Amniocentesis involves removing a small amount of amniotic fluid from around the developing foetus. This fluid can be tested to check for genetic problems. Chorionic villi sampling involves removing a small piece of the placenta to check for genetic problems.

Preconception counselling can help couples understand any risks for having a baby with a birth defect before they try to become pregnant.

5.5 INFORMAL TWO-WAY COMMUNICATION PROCESS

Between the family and the genetic unit

The ability to communicate is essential in genetic counselling. Communication is a two-way process. Not only does the counsellor provide information, he or she also has to be receptive to the fears and aspirations, expressed or unexpressed, of the parents.

A readiness to listen is a key attribute for anyone involved in genetic counselling, as it is an ability to present information in a clear, sympathetic and appropriate manner.

Having established the diagnosis and discussed the risk of occurrence/recurrence, the counsellor is then obliged to ensure that the parents are provided with all of the information necessary for them to make their own informed decisions. This should include details of all the choices open to them. These are issues that should be addressed with great care and sensitivity.

For some couples the prospect of prenatal diagnosis followed by selective termination of pregnancy is unacceptable, whereas others view this as their only means of ensuring that any children they do have will be healthy.

Between the family and the genetic unit

- Often an individual or couple will be extremely upset when they are made aware of a genetic diagnosis. It is very common for guilt feelings to set in. The individual or couple may look back and scrutinize every event and happening, for example during a pregnancy.
- The delivery of potentially distressing information cannot be carried out in isolation.
- Genetic counsellors need to take into account the complex psychological and emotional factors that can influence the counselling dialog.

- The setting should be agreeable, private and quiet, with ample time for discussion and questions.
- When possible, technical terms should be avoided or, if used, fully explained.
- Questions should be answered openly, and honestly, and if information is lacking it is certainly not a fault or sign of weakness to admit that this is so.
- Most couples respect and recognize the truth, and some parents of children whose condition cannot be diagnosed derive a curious pleasure from knowing that their child appears to be unique and has astonished the medical profession.

5.6 COORDINATE A TRANSDISCIPLINARY SUPPORT TEAM

For parents of children with birth defects

- The involvement of different members of staff in the provision of genetic counselling depends upon their role within the multidisciplinary team, and the skills, knowledge, experience and qualifications held and used by individual members of the team.
- Centre teams vary in terms of their membership of professionals from social and psychological services.
- Information on genetic testing and interpretation of results is primarily imparted to patients by doctors. However, specialist nurses and psychosocial professionals know patients and families well and therefore have an important role in identifying and reaching individuals who should be offered genetic testing.
- The health care provider could be the neonatologist as primary care physician, a genetic counsellor, neurologist, neurosurgeon, orthopaedist, developmental paediatrician, or a physical or occupational therapist.

Children with medical complexity, who may also be known as “complex chronic” or “medically complex”, have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care needs, and often the need for or use of medical technology.

An example:
A child with medical complexity is one with a genetic syndrome with an associated congenital heart defect, difficulty with swallowing, cerebral palsy, and a urologic condition.

This child would typically require the care of :
- the neonatologist as primary care physician
- multiple paediatric medical subspecialists or paediatric surgical specialists
- home nurses
- rehabilitative and habilitative therapists
- community-based services
- extensive pharmaceutical therapies
- special attention to her/his nutritional needs and growth
- durable medical equipment to maintain health, maximize development, and promote function.

5.7 ENSURING EFFECTIVE IMPLEMENTATION

Of new technologies and treatments

Many genetic disorders are characterized by progressive disability or chronic ill-health for which there is, at present, no effective treatment. Consequently one of the most exciting aspects of the developments in biotechnology is the prospect of new treatments mediated through gene transfer, RNA (ribonucleic acid) modification or stem cell therapy.

It is important to keep a perspective on the limitations of these approaches for the immediate future and to consider, in the first instance, conventional approaches to the treatment of a genetic disease.

Most genetic disorders cannot be cured or even ameliorated using conventional methods of treatment. Sometimes this is because the underlying gene and gene product have not been identified so that there is little, if any, understanding of the basic metabolic or molecular defect.

Of new technologies and treatments

- Dietary restriction, as in phenylketonuria, or hormone replacement, as in congenital adrenal hyperplasia, can be used very successfully in the treatment of these disorders. In a few disorders, such as homocystinuria and some of the organic acidurias, supplementation with a vitamin or co-enzyme can increase the activity of the defective enzyme with beneficial effect.
- Early surgery is an option in the treatment of certain birth defects — and sometimes can take place even before a baby is born. Surgeons now can operate on foetuses to repair structural defects, such as hernias of the diaphragm, spina bifida, and lung problems. These procedures can be controversial, though, because they sometimes cause premature labour. And it’s still not clear whether they always can improve a child’s outcome.

5.8 LONG-TERM SOURCE

Of information and support

The doctors or a social worker at the hospital where the mother gives birth are able to connect parents with the early intervention program, support/ advocacy groups and patients groups.

Early intervention means bringing a team of experts together to assess a child's needs and create a treatment program.

Early intervention services can include:

- feeding support
- assistive technology (tools, devices, and aids that make everyday
- tasks easier for people with disabilities)
- occupational therapy
- physical therapy
- speech therapy
- nutrition services
- social work services

Of information and support

- Support groups are almost always started by families who have dealt with the same condition, and become an invaluable resource to parents throughout the course of their child's life.
- These groups provide a central location to find information, a place to trade stories and offer a sense of community amid isolation.
- Siblings and other family members can find comfort in these communities as well, since their needs are often sidelined but their perspectives provide important contributions.
- Parents are able to ask questions and compare experiences, and "veteran" parents can ease the worries for them a little bit.
- This bonding process can greatly help medical practitioners as the stress level of their patients and the parents is reduced, and the information given to them is reiterated by their peers.
- Support groups hold potential for mutually beneficial relationships with academia as families are often eager to provide insight to studies which may help epidemiologists find answers for their children.
- Support groups are an excellent source of empowerment for all family members and can help families dealing with the biopsychosocial ramifications of birth defects.

MODULE 6

EARLY INTERVENTION SUPPORT AND PREVENTION OF CHILD ABANDONMENT

CONTENTS

6.1. What is Early Intervention?
    6.1.1 Screening, Identification and Assessment in Early Intervention
    6.1.2 Early Intervention Support Services
    6.1.3 Social Support
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6.2 Who Needs Early Intervention Support?
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6. 3. Stress of Family
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EARLY INTERVENTION SUPPORT

Introduction

Module 1 has 2 parts. The first one is about the early intervention support. The second part is the prevention of child abandonment.

Early intervention support

In the first part, learners will be able to find the answers to these questions:
- What is early intervention support
- What does it consist of
- Who needs early intervention support
- How to assess and follow up the babies/toddlers who are directed to early intervention support
- What are the services of early intervention support

Early intervention support is for babies/toddlers from birth to age 3. The 0-3 years period is characterized by the most rapid development of the brain.

Supports and therapies made during this period are essential for the development of the child's potential. This module also gives information about the neurological and physiological changes in the brain during this period.

Learners of this module will acquire the necessary knowledge to provide early intervention support, which will generate social and economic benefits for the parents and community as a whole.

Prevention of child abandonment

The second part is the prevention of child abandonment. There is information provided about the risk factors and the strategies to prevent child abandonment among parents of children with disabilities.

6.1 WHAT IS EARLY INTERVENTION?

- Early Intervention (EI) is the term used to describe the services and supports that are available to babies and young children with developmental delays and disabilities and their families.
- EI includes; screening, identification, assessment and intervention support services.
- Every infant/toddler and her/his family in need of early intervention has the right to receive EI support services as soon as possible.
- It is very important for the babies to reach their developmental potential in the first years.
- A human's brain develops faster than ever before in the first 3 years of life.

- Communication, environment, play, nutrition, etc. all affect brain development.
- During this period the development of the baby should be positively supported.
- With the early intervention, it is aimed to contribute to the "well-being" in a future life by supporting the babies/toddlers and their families with an integrated approach in the early period.

6.1.1. SCREENING, IDENTIFICATION AND ASSESSMENT IN EARLY INTERVENTION

- The first and most important steps for early intervention are screening and identification.
- Early detection allows to start early intervention as early as possible.
- Developmental screening is routinely performed in countries where early intervention is a system.
- Development is the ability of the child to gain skills in all fields throughout her/his life from birth to adulthood.

Child development is generally assessed in 5 areas:
- Physical / motor: vision, hearing, gross motor (rolling, crawling, walking, etc.), fine motor (button buttoning, writing, using fork and spoon, etc.)
- Cognitive: understanding, learning, thinking, memory, etc.
- Social-emotional: communication with others, adaptation to social life, regulation, etc.
- Speech and Language: understanding and using language, reading and communicating
- Sensory processing: effective registration of the senses in the environment and turning them into appropriate motor and behavioural responses

Developmental delay is defined as a delay in two or more developmental domains of gross/fine motor, speech/language, cognition, social/personal and activities of daily life living, affecting children under the age of 5 years (Mithyantha R. 2017).

Developmental screening is very important to identify developmental delays.

The American Academy of Paediatrics recommends developmental and behavioural screening for all children during regular visits at these ages:
- 9 months
- 18 months
- 24 or 30 months

Assessment of the baby/toddler involved in early intervention support is important to determine both the needs and follow-up the development.

Assessment tools are used for:
- early screening for developmental delay
- determining the current state of the baby/toddler and service eligibility
- planning the program
- program evaluation

All tools used must be standardized, evidence-based and fit for purpose.
- Please read module 2 for detailed information

Parents should be actively involved during the assessment of the baby/child.

Expert should listen carefully to the parents' observations, concerns and needs about their baby/child.

Family-centred interventions offer these the opportunities.

Family-centred practices and family-centred care are terms that have been used widely to describe a particular approach to collaborate with parents of young children where parents are the primary persons who make informed decisions on behalf of their children.

https://canchild.ca/en/research-in-practice/family-centred-service

6.1.2. EARLY INTERVENTION SUPPORT SERVICES

Early intervention support is a program for babies and toddlers at 0-3 age and their families.

The scope of the early intervention support services is the babies/toddlers who have one of the following:
- Risk for developmental delay
- Developmental delay
- Disability

The situation of every baby/toddler who needs EI support is completely unique.

Even if they have the same diagnosis, each baby/toddler and their family are different.

Experts in the EI support unit focus on providing basic and new skills by identifying developmental needs but at the same time EI support services should be holistic.

The most important focus of the EI support services should be towards empowering the family.

Babies and children learn best from everyday experiences with familiar people, places, plays, and routines.

It is also the best way for the baby/child to have the EI support in a familiar environment (home, school).

If it is not possible it can be done also at a rehabilitation service, hospital, therapy clinic, etc.

The intensity of the intervention program is performed on an individual level. This situation may change over time.

For instance: for some babies/toddlers, EI support should done one-to-one with frequent sessions at the beginning. However, as they make progress the sessions may decrease.

Only babies who are followed as infants at risk and who are not diagnosed with a disability or developmental delay should be followed up at developmental intervals.

EI support programs have very different models and vary according to countries.

The following are the basic support services:

- Physiotherapy
- Occupational therapy/ergotherapy
- Education
- Language and speech
- Social support
- Medical support

Physiotherapy: Physiotherapists in the early intervention support team are concerned with the evaluation, follow-up, and therapy of babies and toddlers with limited mobility or atypical development during the period from birth to 3 years of age.

Occupational therapy/ergotherapy: Occupation therapists / ergotherapists focus on the independence of the child in daily life skills at home, at school, and in the community.

Education: focuses on the child's developmental skills and learning. It is aimed to gain all skills, so as to be ready for the school period.

Speech-language therapy: can help with speech, language, eating and drinking skills.

6.1.3. SOCIAL SUPPORT

Social Support:

Shumaker and Brownell (1984) defined social support as "an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient."

Social support acts as a protective factor in coping with stressful situations, reducing the impact of stress on both mental and physical health.

Social support is critical for any family at risk of having a disabled baby or that already has a disabled baby/child.

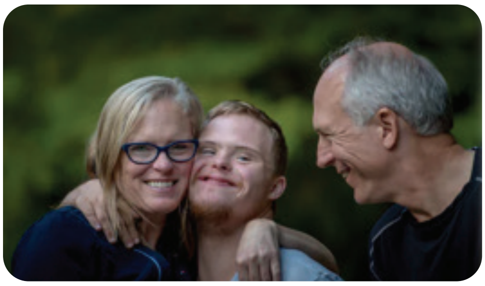
Please read the module 1 for detailed information about social support.

A baby/child with congenital disabilities or an infants at risk affects the whole family.

Parents try to meet all the needs of their babies, but on the other hand, their needs such as belonging to the community, respect, and value are also continuing.

Parents may feel socially isolated because of this particular situation.

The well-being of the family is essential for the development of the child and to reach her/his full potential.



Parental-baby relationships have a major effect on all areas of development of the baby.

The absence of social support adversely affects family relations.

The stresses of the families that are in special situations decrease with social support and makes it easier for them to cope with the situation.

All kinds of social support will have a positive impact on the family and indirectly on the development of the baby.

Health professionals should guide families about taking social support and encourage them.

Sources of social support can be formal and informal:

- Formal: government agencies, non-governmental organizations, voluntary organizations
- Informal: family members, relatives, friends, neighbours, peers,

In Turkey, the standardization of support and care services for people with disabilities is conducted by the Ministry of Family, Labour and Social Services

The Ministry also carries out projects related to these issues. 'Turkey's Unified Social Assistance System' Project determines financial need of the citizens.

'Support Disability Program' carried out between 2011-2019 is a program that supports psychosocial and medical rehabilitation of people with disabilities.

'El Bebek Gül Bebek Derneği' is a non-governmental organization (NGO) located in Turkey. They have 2 good projects for supporting families:

So, Mom, how are you?

Within the scope of the project, parents of the premature babies come together and talk about how to protect the psychology of being a premature parent from discharge and diseases. These meetings are held in hospitals.

My mother is with me

The NGO is building a mother's room so that mothers can stay in their newborn intensive care unit and stay with their babies in some hospitals.

Down Turkey is an NGO in Turkey. They have projects for the families:

Family Information and Support Education

It is an online multimedia e-learning application developed to meet the information and support needs of families with children with intellectual disabilities.

The European Down Syndrome Association (EDSA) is a non-profit organisation supporting and representing people with Down syndrome across Europe. They have a platform; http://www.edsafamily.com/

The aim of that platform is to create a network between families who have child with Down Syndrome around the world. Families can host each other in their homeland.
Down Turkey supports families during the registration process.

6.1.4. MEDICAL SUPPORT

Medical Support:
The Convention on the Rights of the Child (CRC) and especially The Convention on the Rights of Persons with Disabilities (CRPD) Article 25 address early intervention very clearly:

…"provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children…."

Basic medical services (investigation, medication, small interventions) during hospitalisation and after may be free, according to the Social Insurance and Health System of every country, but the situation is different from country to country for the disabled new-borns, during their stay in the hospital and afterwards.

The "European Standards of Care for Newborn Health" is an interdisciplinary European project collaboration to develop standards of care for key topics in newborn health.

The project brings together around 220 healthcare professionals of different professions, parent representatives and selected industry specialists, from more than 30 countries. The focus of the project is on the treatment and care of preterm and ill newborn babies in the hospital and as they grow up.

The aim of the project is the development of standards for 11 broad areas of neonatal health. The development and publication of standards was an important step towards harmonising treatment and care for preterm and ill newborn babies across Europe.

Initiated by the European Foundation for the Care of Newborn Infants (EFCNI), the European Standards of Care for Newborn Health project serves as a reference for the development and implementation of binding standards and guidelines on a national level.

If you want to learn more about this Project please visit: https://newborn-health-standards.org/

Bulgaria
In Bulgaria there are a series of health and social services (0-7 years), recovery centres and care centres for disabled children, 0-3 years old and above, and day-care centres for disabled children.

Romania
In Romania there are centres , but they cover few areas of child development. There is no multidisciplinary centre that could cover all the needs of a disabled child, neither state nor private.

Turkey
In Turkey, children up to the age of 18, even without parents, benefit from health services without any conditions.

Belgium (Flanders)

Kind en Gezin (Child and Family) is an agency that works actively in 'Public Health, Welfare and Family' policy area in Belgium. Kind and Gezin provides free advice and support to pregnant women and families with children under three years old.

Developmental Disorder (COS) centres assist with early diagnosis in babies and young children. A multidisciplinary team (specialized doctors, psychologists or remedial educators, speech therapists, physiotherapists and social assistants) carries out the various specialized studies. Babies, toddlers, preschoolers and young children with (the suspicion of) a developmental disorder or developmental delay can go there. Also at risk babies: seriously premature babies or babies with an extremely low birth weight, full-term babies with perinatal problems (problems around birth).

Children and adults with disabilities are entitled to support to arrange their care. Different types of tools and support are available to help.

The VAPH is the Flemish Agency for Persons with a Disability. People with disabilities are entitled to a budget with which they can finance customized care and support.

6.2. WHO NEEDS EARLY INTERVENTION SUPPORT?

Early intervention support services apply to babies/toddlers who have any of these:

- Risk for developmental delay
- Developmental delay
- Disability

Risk factors for developmental delay are:

- **Biological risk factors** (i.e. genetics; parental health and behaviours during pregnancy; complications during birth; infections the mother might have during pregnancy or the baby might have very early in life; and exposure of the mother or child to high levels of environmental toxins, etc.)
- **Socioeconomic risk factors** (i.e. low-level paternal education, Low-level maternal education, low-level household income, ⩾ 3 children in the family, etc.)

In this unit you will get information about socioeconomic risk factors. Please read module 3 for biological risk factors.

6.2.1. COUNTRY SPECIFIC MECHANISMS

Available evidence indicates that nearly a quarter of young children in developing countries are at risk for or have established developmental delays or disabilities (Walker et al., 2011).

The United Nations adopted two international human rights treaties that, when taken together, articulate a human right to early intervention for infants and young children with disabilities

- The Convention on the Rights of the Child (CRC)
- The Convention on the Rights of Persons with Disabilities (CRPD)

They describe the standards by which all States Parties can guide the development of programs, services, and laws necessary to comply with the Conventions (Sharan E. Brown,2012).

The Convention on the Rights of the Child (CRC) Article 21 calls for a broad commitment from States stakeholders to "enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life."

Included in this duty is the requirement in Article 21(1)b that these services begin "at the earliest possible stage, and are based on the multidisciplinary assessment of individuals needs and strengths."

Although the effectiveness and benefit of early intervention is known, it is not possible to be applied under equal conditions all over the World for a variety of reasons.

In some countries, early intervention is applied systematically, while in others there is no systematic practice under the name of early intervention.

Bulgaria

In Bulgaria there is a series of health and social services (0-7 years), recovery centres and care centres for disabled children, 0-3 years old and above, as well as day-care centres for disabled children.

There are also Early Intervention Teams. These include a paediatrician and other necessary specialists, midwife or nurse, physical rehabilitation therapist, psychologist, special teacher, speech therapists, lactation consultant, social worker who provide the needed medical and social care at home. This care consists of necessary treatments, rehabilitation, parent trainings, psychological support, consultation, etc.

Romania

In Romania, only children with a disability certificate/certain diagnosis can benefit from care facilities, as well as the children who come from defective social centres (day-care centres).

Turkey

In Turkey, any infant / child under 18 years old, with a developmental delay or a disability can get a Special Needs Report for Children (ÇÖZGER).

With this report the needs of children with special needs are documented in a different way from that of adults. This report aims to provide access to health, education, rehabilitation, social and economic rights and services.

The validity period of this report is at least 1 year.

This report can be obtained from public hospitals.

With this ÇÖZGER report, parents have recourse to Guidance Research Centres affiliated to the Ministry of National Education and get a Special Education and Evaluation Board Report. The report enables individuals to receive services from the Special Education and Rehabilitation Centres affiliated to the Ministry of National Education. Within these centres, they have access to physiotherapy, special education, speech and language therapy and psychological support services.

The report enables each individual to receive 8 sessions per month, freely, at the Special Education and Rehabilitation Centre.

Belgium (Flanders)

Kind en Gezin (Child and Family) is an agency that works actively in 'Public Health, Welfare and Family' policy area in Belgium. Kind and Gezin provides free advice and support to pregnant women and families with children under three years old.

Developmental Disorder (COS) centres assist with early diagnosis in babies and young children.

A multidisciplinary team (specialized doctors, psychologists or remedial educators, speech therapists, physiotherapists and social assistants) carries out the various specialized studies. Babies, toddlers, preschoolers and young children with (the suspicion of) a developmental disorder or developmental delay can go there. Also at risk babies: seriously premature babies or babies with an extremely low birth weight, full-term babies with perinatal problems (problems around birth).

Children and adults with disabilities are entitled to support to arrange their care. Different types of tools and support are available to help.

The VAPH is the Flemish Agency for Persons with a Disability. People with disabilities are entitled to a budget with which they can finance customized care and support.

Please read Module 4 for more information.

6.2.2. FAMILY/ECONOMIC/HEALTH RISK FACTORS

Family

- Poverty
- Homelessness
- Substantiated child abuse or neglect
- Low level of education of parents
- Parental mental illness
- Lack of adequate environmental factors
- Single parent

Economic

- The state does not support early intervention fees

Health

- Lack of prenatal care
- Lack of postnatal care (baby and mother)
- Malnutrition of baby
- Inadequate detection and monitoring risky pregnancies
- Adverse birth conditions
- Lack of screening and early diagnosis (lack of information and system)

6.2.3. SOCIO-ECONOMIC GAINS OF EARLY INTERVENTION SUPPORT

As early intervention supports both the child and the family, it also affects the society as a whole:

- Early Intervention provides beneficial outcomes to children, their family and the community
- It maximizes the children’s and families’ chances for success
- It provides lasting benefits in the children’s life
- It prevents persistent social problems, social exclusion and damaging parenting
- It is cost-effective with long term public savings

(Allen, 2011, Pithouse 2007, Barnes and Freude-Lagevardi 2002)

Early intervention gives the opportunity to the children with special needs to soften and even lower the negative effects of their situation, while allowing them to reach their full potential so they need less private and social support in the future.

Parents of more independent children can return to their jobs earlier as well.

The contribution of early intervention to the economy is supported by scientific studies:

- Longitudinal studies find that the personal benefits (cognitive development, behaviour and social competence, educational attainment, earnings), social benefits (reduced delinquency and crime) and government savings (higher tax revenues, reduced social welfare spending), associated with intervening early in a child's life clearly outweigh the costs (Karoly et al.,2005).
- Early investment raises the productivity of later investment. This return is generated from returns to the individual in terms of increased earnings, higher education, improved physical and mental well-being, and also through the positive externalities to society in terms of reduced crime and delinquency, public expenditure savings and increased tax revenues (Heckman, 2001).

6.3. STRESS OF FAMILY

6.3.1 FAMILY STRESS CAUSED BY SPECIAL CONDITION OF THE BABY/CHILD

Parenting stress is defined as a specific kind of stress perceived by parents when performing parental roles.

Having a child is a condition that is considered crucial by the society and causes positive emotions in families.

On the other hand, the negative feeling that parents experience because of having a baby/child with a special condition creates a dilemma for them. This dilemma also increases the level of stress in parents (Uğuz, Toros & Yazgan Inanc, 2004).

Please read module 1 for detailed information.

For a special condition, there are internal and external stressors for families. Examples of internal stress factors include the child's illness, chronic needs, social interactions, child behaviours, sibling relationships, and family activities (Kisler & McConachie, 2010).

Families may feel inadequate due to the child's repetitive behaviours and lack of social skills and their social lives are negatively affected. The fact that individuals in the social environment misunderstand or misinterpret the problematic behaviour of the child also leads to the social withdrawal of the families (Higgings, Bailey & Pearce, 2005).

Parents invest huge amounts of energy in childrearing, but at the same time enjoy their parenting role.

When faced with caring for a child with a developmental disability, families confront a number of emotional, physical, and financial challenges.

Parents can experience physiological stress and disappointment when their child fails to fulfil their hopes of having a healthy offspring, or a "perfect child".

Mothers take more responsibility in the care of children with a special condition. This situation makes it difficult for mothers to cope with stress. The accumulation and increase of stress leads to emotional problems such as helplessness, anxiety and depression (Şentürk & Saraçoğlu, 2013).

As the stressors brought on by increased childcare demands become more extensive, parents can feel increasingly depressed, helpless, or worthless.

All the stresses, challenges that parents face can lead to breakdown of relationships. According to the studies, the divorce rate among parents of kids with special needs is higher than that of couples in the general population (Robbers et al, 2011, Freedman and Kalb 2011)

Taking care of a baby at risk increases the mother's vulnerability to depression and anxiety. This is true for especially:

- A long hospitalization for extremely premature infants
- Higher incidence of medical complications
- Multiple interventions in neonatal intensive care unit (NICU)
- Long-term chronic diseases such as bronchopulmonary displasia, feeding problems, possibly brain injury
- Serious concern about the well-being and development of the infant

Note: *Please, read* ***Module 1*** *for detailed information about stress of family.*

6.3.2 EFFECTS OF FAMILY STRESS ON DEVELOPMENTAL OUTCOME

It is important to try to understand parenting stress in the context of the child's developmental traits. In addition, each family system has its own unique structure. Therefore, the effect of parenting stress on development may vary in every family.

Toxic stress (such as abuse, neglect, extreme poverty, violence, household dysfunction, and food scarcity) has a significant impact on the proper development of the children's cognitive and language development and social competences and on problem behaviours.

Results suggest that parenting stress is both an antecedent and consequence of child behaviour problems. Simultaneously, child behaviour problems are an antecedent and consequence of parenting stress. These variables appear to have a mutually escalating or deescalating effect on each other over time.

Highly stressed parents may not model good self-regulation for their children, which may lead to more behaviour problems. With regard to the opposite direction of effect (child behaviour to parenting stress), child behaviour problems may create more stress in the broader socioeconomic environment (e.g. school, neighbourhood), leading to augmented parental stress.
(Cameron L. Neece,2012)

The stress experienced by parents having a baby / child with special needs affects different attitudes and behaviours during the child's admission process. In this process, some parents may be overly protective of their children, while others may find it difficult to accept the role of parenting and may be rejecting. Such processes can affect the structure of the child's personality and the different areas of development that interact with each other (Doğan, Bitlis, & Özen, 2005).

Depressed mothers reportedly spend less time playing, providing stimulating objects, and engaging in verbal interaction, and overall exhibit poorer attachment and more disturbed feeding and safety practices.

Parenting stress and depression may disturb the mother infant bond, and mother infant interactions, which may in turn negatively affect the cognitive, neurologic, behavioural, and social development.

Maternal depression and stress may affect the infant's development as early as 1 month.

Infants as young as 3 months can reportedly detect depressive behaviours expressed by their mothers.

Depressed mother have an expressionless face, engage in decreased social interaction with their infants, provide less verbal stimulation, perform less stimulating and encouraging tasks, and have poor attachment.

Social environmental factors play a great role on the language development. More responsive mother-child interactions at 12 months were associated with higher scores on the Receptive Language Subscales. (Joyce Magill-Evans & Margaret J. Harrison, 2010)

Experience of stressful life events during pregnancy increased the odds for the early cessation of prevalent breastfeeding (Jianghong Li,2008).

Breast feeding for ⩾ 1 months was positively associated with improved motor development outcomes at 10, 14 and 17 years of age (Tegan Grace,2017).

According to a longitudinal study (Grace T, 2011)

- Pregnancy stress results in lower motor developmental scores in offspring. This was shown at 10, 14 and 17 years.
- Late pregnancy stress has a greater influence on motor development during late childhood and in adolescence, than early pregnancy stress.
- Stress during pregnancy contributes to a poorer motor development in the long term.

A review study (Giavana Buffa, 2018) indicated that:

48 articles were identified according to Prenatal stress and child development.

Five studies analyzed outcomes later in infancy such as temperament and motor development, all showing significant results; and nine in childhood such as behavioural development, asthma, and physical growth, with eight showing significant results.

An infant temperament fully mediates the relationship between parenting stress and infant attention skills, and partially mediates the relationships between parenting stress and sleeping deregulation, eating deregulation, inhibition and separation problems, negative emotionally and positive emotionally (Anna L. Zonderman 2012).

6.3.3 MANAGING STRESS OF FAMILY

Parenting a baby at risk or with a disability is a more difficult, stressful experience than parenting a typical baby.

It is possible to reduce the effects of depression and stress by supporting the parents' self-efficacy.

It is important for parents to gain and support the competencies to cope with difficult situations and produce solutions to problems in the care of the baby/child with special condition. Providing family education and counselling services regarding the child's inadequacy and problem behaviours may reduce the problems and increase self-efficacy.

Please read Module 7 for detailed information

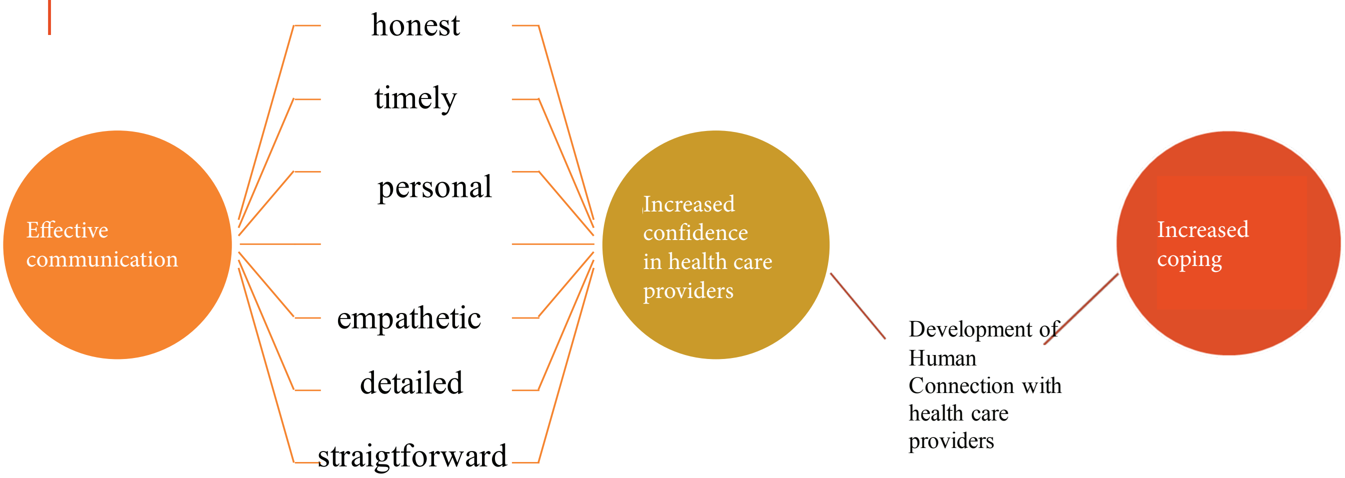
Dream of hearing an infant's first heart beat, revealing the gender, and bonding with a perfect baby are replaced with the technologically advanced medical world of specialists, paediatric subspecialist, nurses, testing, neuroimaging, and the worry that accompanies this new level of the unknown.

Parents' experiences with the health care providers during the medical diagnosis of their child affects their ability to cope with their newfound circumstances and can impact the quality of life of their family unit.

Coping is the "constantly changing cognitive and behavioural efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the resources of the person."

Effective coping is best achieved if parents feel as if they are equipped with sufficient resources.

Health care provider communication.
AL Kravotil and WA Julion.



Picture representing the relationship between health care providers (HCP) communication, parental confidence and coping.

- Provide timely and detailed information:
  - Parents required immediate and detailed information about the suspected foetal anomaly, otherwise they try to find this by themselves.
- To retain the parents' confidence and empower them:
  - Providing written information to take home, including a list of reliable and valid resources.
- To practice a multifaceted family centred care.
  - Communication and a family centred care network engenders trust when it is delivered empathetically in an unbiased and nonjudgmental manner.

It has been scientifically proven that the information and feedback provided by healthcare workers reduces the anxiety scores in both parents. Accordingly, periodic reunification of the children's parents and healthcare professionals, and provision of education and counselling services will serve to raise awareness. This helps to reduce stress and anxiety.

In addition, according to the wishes of the families, specialist psychologists, educators, doctors, nurses, and child development experts can be brought together more frequently. Organizing activities in which families having babies/children with a special condition can come together in group meetings, ensures that they know that they are not alone. This is an important value in stress management (Kaytez, Durualp & Kadan, 2015).

Social support plays an important role for families coping with stress. At the same time, it will be useful to learn about coping strategies that will resist the stressful events and situations. In this way, they will be able to increase their resilience and look at life with more hope.

Life satisfaction is associated with different types of social support. Therefore, when parents have support, it makes their lives easier, they are more saturated and less stressful in life.

A multidisciplinary health-care team can reflect a broad array of expertise, and this can decrease the parental distress while increasing the parental coping.

The synergism between disciplines provides comprehensive and individualized care that minimizes uncertainty and helps parents feel empowered and supported.

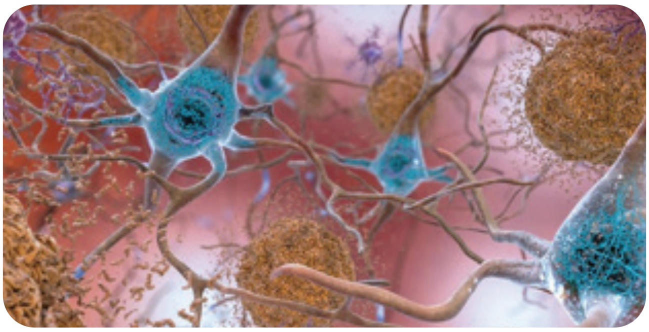
Health care providers first need to develop a better understanding of parents experiences, considering both culture and context.

6.4. IMPORTANCE OF EARLY INTERVENTION SUPPORT

Postnatal brain development is extremely complex since there are lots of events occurring. All these have long-lasting consequences for the brain function, which may impact growth as well as motor, social, emotional and cognitive function in later life.

It is very important to intervene with accurate methods in the early period when the brain develops very fast, thus contributing to a healthy brain development.

6.5 PLASTICITY OF BRAIN



Brain plasticity also called as neuroplasticity is a term that refers to the ability of the brain to change itself by making new connections.

Neuroplasticity enables us to develop from infancy to adulthood, learn new things throughout life, and to recover after brain damage.

6.5.1 IMPORTANCE OF EARLY INTERVENTION SUPPORT

There are 3 type of plasticity

Experience-independent: Experience-independent plasticity results from the fact that the genome generates a rough approximation of connectivity that is modified by both internal and external events. Neurons that are active together increase their connections, whereas those that are not coincidentally active weaken their connections.

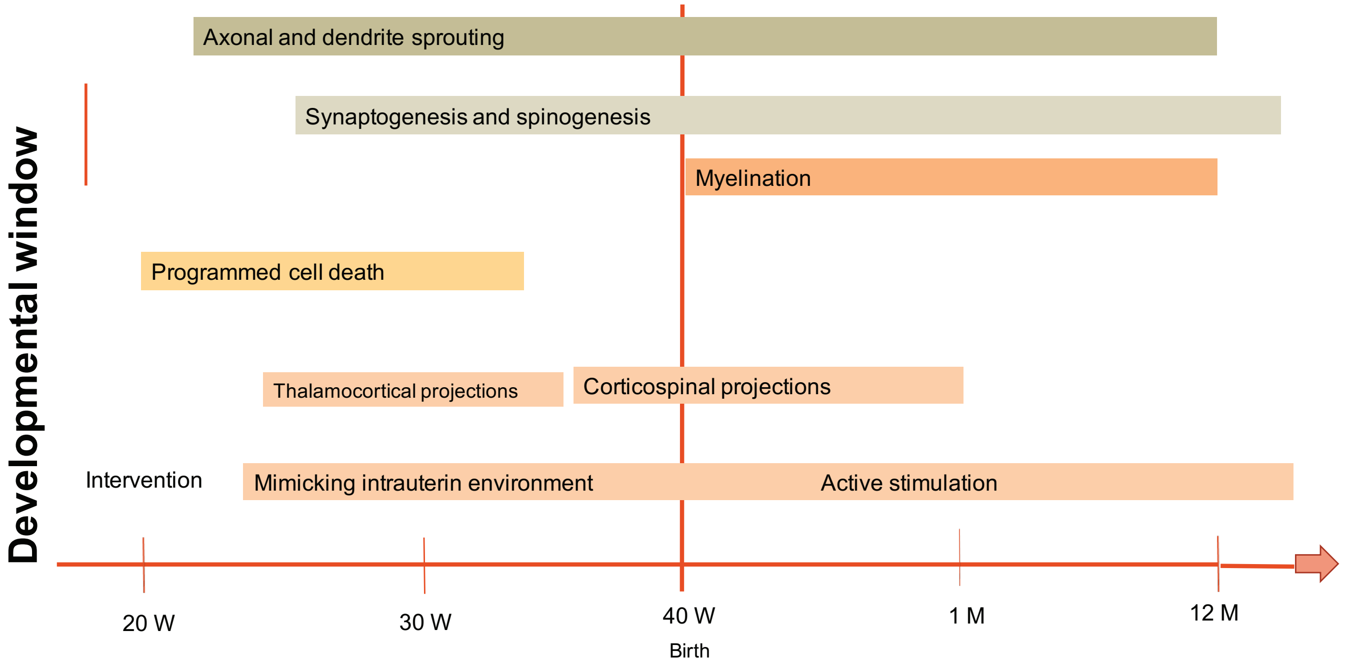
Experience-expectant: Experience-Expectant Plasticity describes the normal, generalized development of neuron connections that occur as a result of common experiences that all humans are exposed to in a normal environment. These early universal experiences are visual stimulation, sound (specifically voices), and bodily movement.

Experience-dependent: Experience-Dependent Plasticity is the continuing process of the creation and organization of neuron connections that occurs as a result of a person's life experiences. Differing life situations and circumstance influence how certain areas of the brain develop and continue to grow.

Biological perspectives:
Neurogenesis, synaptogenesis, and synaptic pruning represents for building the Central Nervous System (CNS). This process is genetically programmed, in time-limited periods, called critical and sensitive periods during which the brain is most amenable to change.

The next slide illustrates the most intensive heterogenetic events during the human pereterm and postnatal period: the developmental 'window' for structural-functional plasticity of neural systems and appropriate types of interventions.

The scheme is modified according to Graaf-Peters and Hadders-Algra, 2001 and Judas et al, 2011.



Timely interventions are very important considering the developmental window events. For instance: In premature babies, when the baby and the brain were developing in the optimal condition in the womb, this situation is interrupted with preterm birth and the baby has to continue to develop outside of the womb.

The neonatal intensive care unit (NICU) is totally different from the womb. In NICU the developing nervous system of the baby is constantly exposed to stress:

- Sensory bombardment
    - Sound
    - Light
    - Tactile stimulation
- Procedures
- Multiple caregivers
- Sleep splitting and deprivation

The brain is fragile and has a high risk of bleeding as its maturation is not completed.

EI supports should be done with the cooperation of the family to reduce the baby's stress and improve the neurodevelopment for the babies in the NICU.

These are:

- Kangaroo care
- Planning nurse care routines
- Positioning strategies
- Light, sound modulation
- Nutrition methods
- Pain management
- Parents' participation and support

One of the most important EI supports for premature babies is the kangaroo care (KC).

The holding of an infant with ventral skin-to-skin contact typically in an upright position with the swaddled infant on the chest of the parent, is commonly referred to as KC

It is recommended that KC, as a feasible, natural, and cost-effective intervention, should be a care standard in the delivery of quality health care for all infants, regardless of the geographic location or economic status.

Numerous benefits of its use have been reported related to mortality, physiological (thermoregulation, cardiorespiratory stability) and behavioural (sleep, breastfeeding duration, and degree of exclusivity) domains. It is considered an effective therapy to relieve procedural pain, and contribute to improved neurodevelopment.

(Marsha L Campbell-Yeo, 2015)

Positioning of the babies in NICU is also very important for neurodevelopment.

In the foetus uterus, the baby is in a closed area with good-limits to support physiological flexion development. It enables the foetus to extend its arms and legs, then it encounters resistance and gently returns to the flexion position.

This physiological flexion is essential for normal posture and motion control development.

With the proper positioning babies usually feel more secure and are more physiologically stable if they have boundaries (nesting) placed around them, as they are used to an enclosed womb.

(Wales Neonatal Network Guideline - Supportive Positioning Guideline)

Early ages are the basis of other periods of human life. In the first three years, babies/children develop faster in all areas of development (movement, mental, language, social, emotional and physical). In these years, the brain is in a process of structuring and learning faster than ever during human life.

In the first years of life, the rapidly developing, sensitive and vulnerable structure of the brain is highly affected by all stimuli, both positive and negative.

Positive early experiences are decisive for the long-term well-being of a child and it is effective throughout life.

In order to give early positive experiences to children in a natural environment, it is very important to recognize opportunities and empower the family.

EI experts should empower the family to do what they should do in their daily routines.

EI experts and families should be in collaboration to enhance the children's participation in family routines with family-selected goals.

EI support should be on:
- the children's functioning in their everyday routines
- supporting families.

Commonly accepted developmental theories are "Dynamic Systems Theory" and "Neuronal Group Selection Theory".
- The Dynamic System Theory is based on the nature of complex systems following non-equilibrium rules. According to this theory, development is not dictated by endogenously determined maturational processes. Development is a self-organizing process with many intrinsic and extrinsic factors. For the optimal development genetically programmed maturation of central nervous system (CNS), interaction with family members, playing toys, environmental, social, cultural factors should be optimal.

- The Neuronal Group Selection Theory is based on the fact that genetic instructions play a substantial role in the primary determination of the brain development. It is the starting point for epigenetic cascades allowing for the interaction with the environment and activity-dependent processes, but it doesn't include variation. Environment and experience improve the variation of primary brain development. It is important to increase the movement, play, communication repertoire of the baby/toddler. In EI approaches, the activities that involve the movements initiated by the baby, and plays involving trials and errors, enrich the baby's experience and repertoire.

As known according to literature, sensory and motor experiences, language and cognitive experiences, prenatal, postnatal stress, parent-child relationships, poverty, playing peers, siblings or parent, feeding, sleeping, chemical elements, gut bacteria, immune system,..., all have an effect on the plasticity.

"The genes are the bricks and mortar to build a brain. The environment is the architect."
Christine Hohmann

PLASTICITY MECHANISMS AFTER BRAIN INJURY

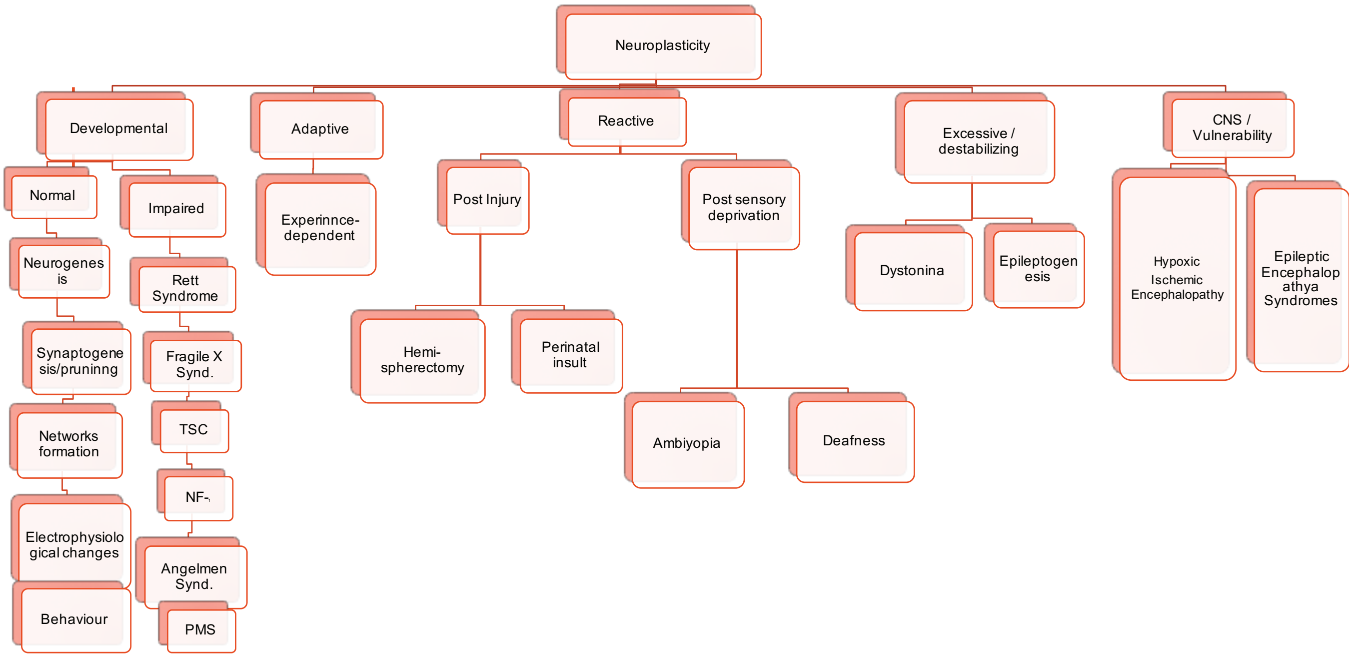
The central nervous system is very vulnerable during the first years of life.

The brain can be easily affected by many factors such as infections, bleeding, hypoxia, adverse environmental conditions, neglect, and malnutrition.

These adverse events have different pathophysiological mechanisms of brain damage and they affect different areas in the brain.

The plasticity mechanism of the brain with an injury is related to time, type, size, and localization of the damage.

The plasticity is higher if the brain damage occurs before maturation of the central nerve system.



Patterns of neuroplasticity in the developing brain. CNS: Central Nervous System. TSC:Tuberus sclerosis synd.NF-1: Neurofibromotisis synd.PMS:Phelan- MC Dermid Synd.

PLASTICITY MECHANISMS AFTER STROKE

Following focal damage to the motor cortex and its descending pathways, the surviving portion of the brain usually undergoes substantial structural and functional reorganization that occurs in perilesional areas, as well as in the ipsilesionals and contralesional cortices (as demonstrated in animal studies and human neuroimaging studies).

These plastic changes reflect the capability of the brain, particularly the cerebral cortex, to alter the structure and function of neurons and their networks in response to damage caused by a stroke.

Motor recovery after stroke peaks approximately four weeks after the damage and then slows down over 1 months.

Perinatal stroke is commonly the cause of hemiplegic cerebral palsy (HP CP) (Anna P Basu, 2014).

Constraint-induced movement therapy (CIMT) and bimanual therapy are the most used and evidence-based methods in HP CP for increasing the upper extremity function.

Also Hybrid therapy (CIMT and bilateral therapy together) are commonly used after stroke.

All these methods must be done under the observation of a physiotherapist or ergoterapist.

PLASTICITY MECHANISMS AFTER HYPOXIC-ISCHAEMIC INJURY (HI)

HI brain injury induces an immediate inflammatory response, which has been shown to last days and even weeks following an initial insult.

HI does not result in a uniform or global brain injury but causes selective damage to different brain structures.

In preterm infants periventricular white matter is a particularly vulnerable HI, resulting in a selective pattern of injury, called periventricular leukomalacia (PVL).

Clinical findings of PVL indicate that motor ability of legs, sensory, cognitive and cortical visual impairment ar emostly affected.

In term infants severe HI causes selective damage to the sensorimotor cortex, basal ganglia, thalamus, and brainstem.

Clinical findings are a severe motor disorder, rigidity, impairment of mostly upper extremities, and speech difficulties.

Although there are motor difficulties after HI, babies are still babies and their need for movement, communication, play, and exploratory continues.

It is important to offer environments that allow babies with motor difficulties to explore the environment, movement, and their own body.

In the early intervention, a special program is planned for each baby's needs and it is implemented in the natural environment of the baby in cooperation with the family.

6.5.2 NEURONAL MATURATION

In the foetal and first years of life, the CNS is so active as it will never be for the rest of the child's life.

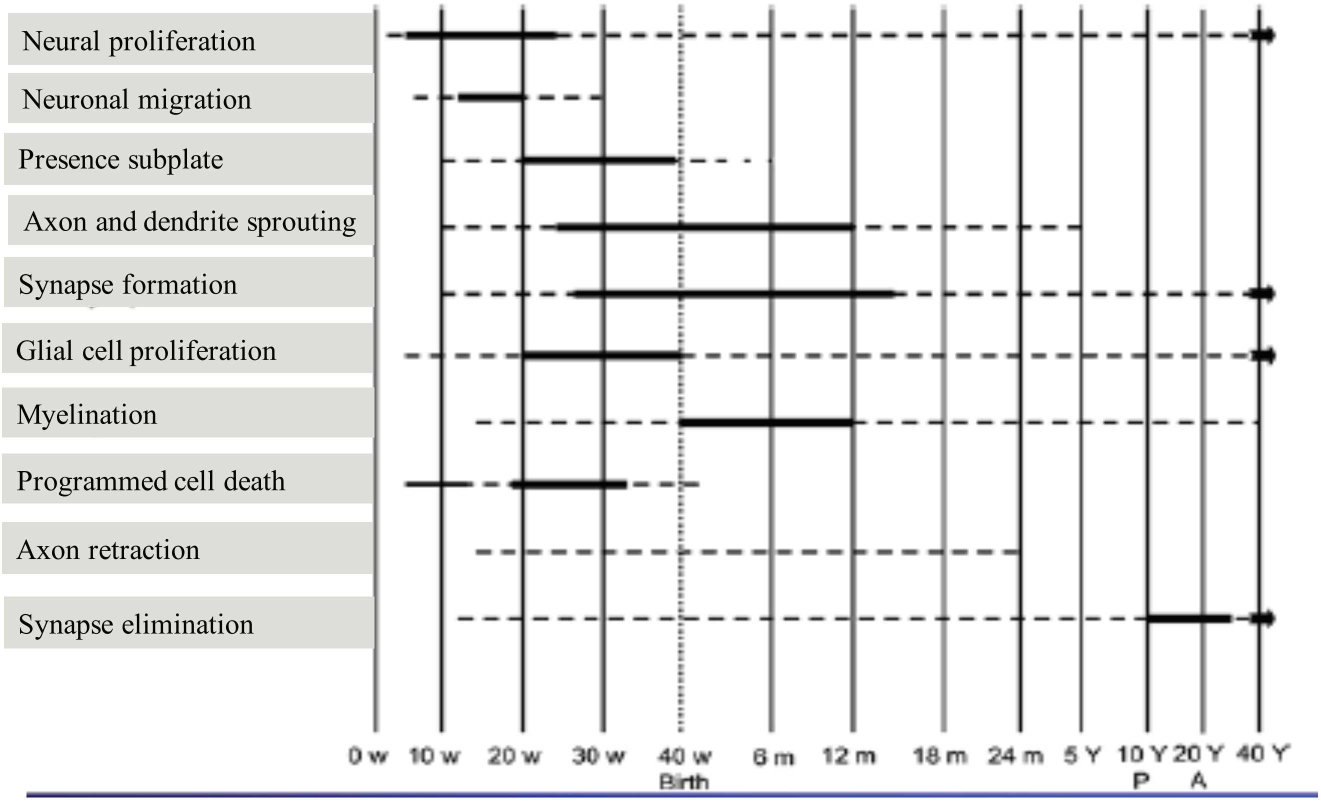
Brain structures develop with successive events such as neuronal and glial cell proliferation, neuronal migration, presence of subplate neurons, etc.

Biological and environmental factors are easily affected by these processes of the CNS, positively or negatively.

Early intervention provides unique opportunities in this period.

Neurodevelopmental processes during human ontogeny

(De Graaf-Peters & Hadders-Algra, Early Hum Dev 2006; 82: 257-66)



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1.5. PREVENTION OF CHILD ABANDONMENT

1.5.1. DEFINITION OF CHILD ABANDONMENT

Two definitions of child abandonment:

- **Open abandonment** is defined as a child being knowingly left behind by her/his parent, who can be identified, and whose intention it is to not return but to willingly relinquish parental responsibility.
- **Secret abandonment** is defined as a child being secretly left behind by her/his parent, who can not be identified, and whose intention it is to not return but to willingly relinquish parental responsibility anonymously.

(The European Commission's Daphne Programme-Child Abandonment and its Prevention in Europe)

1.5.2 RISK FACTORS OF CHILD ABANDONMENT

Child abandonment is a common phenomenon all over the world. Risk factors and incidence vary depending on cultural beliefs and norms.
A list has been compiled by The European Commission's Daphne Programme.
Identified factors were grouped into four:

- child characteristics
- caregiver characteristics
- family characteristics
- societal factors

Child characteristics	Caregiver characteristics	Family characteristics	Societal factors
• Child disability • Child health problems	• Negative childhood experiences • Poor parenting model • Substance misuse/addiction • Parental mental health problems/illness • Young mother (often in the care system herself or lacks family support) • Unwanted pregnancy • Lack of education (general education and sex education)	• Child maltreatment • Domestic violence • Lack of material resources • Poverty • Poor living and social conditions • Large family/large number of children • Lack of social support or social isolation/exclusion • Parental imprisonment • Roma families • Ethnic minority • Single parenting	• Poverty and unemployment • Lack of education • Inaccessibility of contraception • Lack of well-trained, well-resourced professionals • Lack of effective policy and practice • Cultural beliefs and norms regarding abandonment and institutional care

1.5.3. INCIDENCE OF CHILD ABANDONMENT

Special baby hatches are available in 11 European countries where men and women can leave babies anonymously and safely but few children are secretly abandoned in this way (4 to 7 infants each year per country). Baby hatches can be found in Austria, Belgium, Czech Republic, Germany, Hungary, Italy, Latvia, Lithuania, Poland, Portugal, and Slovakia.

Belgium (Flanders)

Child abandonment is illegal in Belgium, but some baby hatches are operational. Very few infants were secretly abandoned since then.

Bulgaria*

More than 1000 children were abandoned in 2018, according to a report from the Social Assistance Agency. This is one of the clear symptoms of a continuing tendency for a large proportion of the country's population living at risk of poverty or social exclusion, two factors that are most often cited as key reason in abandoned infant cases.

Nearly half of the children are abandoned in the maternity home – 441. Their childhood starts in a social institution or they are separated from their parents and they are brought up by strangers.

First in the negative statistics for the most abandoned children among the districts is city of Plovdiv – 115. Following are Stara Zagora and Sofia-city. In 2018, nearly 500 children were returned to their families. By 31 August 2019, their number was 275. In 2019, social services worked on over 3000 cases, trying to prevent the separation of parents and children. 1272 of these cases have been successfully completed.

* https://china-cee.eu/2019/12/02/bulgaria-social-briefing-over-1000-bulgarian-children-are-abandoned-by-their-parents-every-year/

Romania

In 2017, 55302 children were in care of the Romanian state, while 18,197 of them were living in orphanages.*

* http://www.mmuncii.ro/j33/images/buletin_statistic/copil_an2017.pdf

Turkey

In Turkey, the Ministry of Family, Labour and Social Services Children's Services Directorate-General is responsible for the status and protection of abandoned babies.

There were 102 abandoned children in 2011.

More recent data about this issue is not available.

1.5.4 STRATEGIES TO HELP PREVENT DISABLED CHILD ABANDONMENT

Disability Rights International (DRI) is dedicated to promoting the human rights and full participation in society of people with disabilities worldwide.

https://www.driadvocacy.org/

For the last 13 years, DRI has been working on a worldwide campaign to shut down orphanages and institutions that, in far too many cases, neglect or even abuse the rights of the children. DRI believes that an alternative where "development funding is moved to community and family-based care" is the way forward.

This means rather than ploughing money into orphanages and institutions which are often exploitative and damaging to a young person, money should go towards programmes that support families.

It seems obvious that the best place for a child to grow and develop is with her/his family.

The current system of institutionalising individuals, rather than supporting families, still exists in some countries. It is a stain on the charity sector and highlights the failures of the development model triumphed by many.

According to the report of the European Commission's Daphne Programme-Child Abandonment and its Prevention in Europe, following strategies should be applied to prevent child abandonment:

- Day-care facilities
- Mother-baby units
- Family planning services
- Counselling services for the mother and/or the whole family
- Financial support
- Programmes that focus on high risk families and child identity
- Parent training centres
- Help lines to support mothers in need
- Guidance on preventing child abandonment at maternity units
- Social workers in maternity units
- Training of hospital staff to be able to recognise and manage
- Provision of positive counselling in high-risk situations

Home care service and social support to home-bound parents can help reduce the abandonment of children with disabilities.

There should be services to prevent family separation and provide social care networks.

Learning to have a disabled child is a big shock for the family.

It is important that the health professional has enough time for the parents and has been trained in this matter.

Parents should feel that they can access the right information when they need and that they are not alone.

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MODULE 7

COMMUNICATING WITH THE FAMILY

CONTENTS

Introduction

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INTRODUCTION

IN THE COMMUNICATION WITH THE PARENTS

The purpose of this module is to understand the importance of communication between the medical staff and the parents of the newborns with congenital disabilities and/or prematurely born.

It contains the detailed attributes of an efficient communication with the family, the perspective and expectations of the parents in communicating with the medical staff, the challenges the medical staff has to face and also the specifics of communication when it comes to the Neonatal Intensive Care Unit (NICU).

The learners will understand the difference between optimal vs. poor communication in these situations and what strategies they can apply for a better interaction with the parents.

7.1. EFFICIENT COMMUNICATION WITH THE FAMILY

7.1.1 THE ATTRIBUTES OF A GOOD COMMUNICATION

Good health care communication:

- Is a very important skill to effective and safe medical practice / routine healthcare.
- Implies the ability to communicate with compassion, empathy, and sensitivity because issues discussed are intimate and private.
- Can be learned and trained.
- Has a therapeutic effect on the patient and it's the basis for a good relationship.

Good health care communication:

- is vital for accurate diagnosis, for the development of the successful treatment plan, to improve the patient knowledge and treatment adherence, and to improve the general and psychological outcome.
- offers guidance for parents in the context of life-altering conditions of a child.
- enables the family to readjust better to a distressful and challenging situation, including a child's unanticipated impairments.

Lack of proper training could lead to emotional disengagement of the medical personnel from the patients.

Effective health care communication:

- takes care of the needs of the patient and the whole family
- is indispensable
- has three basic elements:
    - **is informative** – the medical personnel provides information regarding the illness or disability.

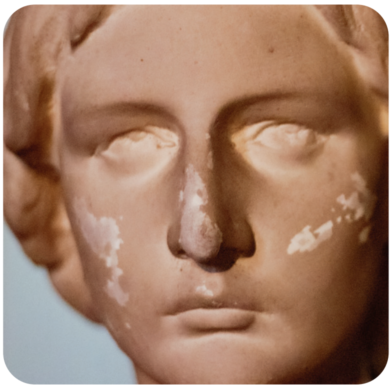
- **expresses / manifests empathy** – attention and interest in parents' and child's story and feelings.
- **creates a partnership,** an alliance, inviting the parents to express their perspectives, concerns, feelings, and suggestions during the consultation.

Predictive factors of effective communication between medical personnel and parents/ patients are:

- the perception of caring and interest
- a warmth attitude by the physician / nurse
- and responsiveness

During this communication, the medical personnel has to take into account **two types of needs:**

- the need to know, to understand the medical condition - cognitive need
- the need to feel understood, known, seen as an individual – affective need



It is important that medical personnel (doctors and nurses) have:

- behaviour related with tasks – conducts related with delivering the news, information and asking questions.
- interpersonal abilities - includes affective behaviours that reflect attention and respect, interest, empathy, caring, warmth, both verbal (reflective response) and nonverbal (posture, gesture, mimics, eye contact).

An example of a reflective response is: "When you tell me that you don't think you can succeed with this, what is the hardest thing about your child illness for you and your family?"

7.1.2 THE PARENTS' PERSPECTIVES

- **The interpersonal skills of the medical staff and the way of communicating influences in great extent parent satisfaction with quality of care.**
- When they are informed for the first time about the child's problems, the child's incurable diagnose, about long-term impairments, or death, parents are more attentive to the affective behaviour of the physician, making a distinction between the way of the communicating and the news itself. The non-verbal-communication and empathy prevailing over verbal information conveys.
- Usually parents want to know about the baby's condition, but sometimes what medical staff think is important or useful for them to know, could be a source of anxiety and stress.
- For this reason, during this initial discussion with the physician and in the following interactions, they need to acknowledge their fear, anxiety, grief, anger, mistrust. They are experiencing and want to be invited to share their feelings, worries and ask questions.
- Parents who feel like they are not treated with respect, whose fears remain unrecognized and unaddressed, feel unhappy about the information provided, even if these are very detailed explanations.

- When the parents become upset, bewildered or feel guilty, it's important for them that their emotions are recognized, accepted and acknowledged. Medical personnel have to wait until their attention turns back to the discussion.
- **The most delicate phase of the communication process is when the parents hear for the first time the bad news. Their emotional state could impede the full and proper understanding of the information, generating misinterpretation and compromise further the trust in the medical team. For this reason it is necessary to have successive communication sessions where you convey the bad information again and parents can ask and express their concerns.**
- **It's better that both parents participate at the initial communication / meeting.** This promotes mutual support between them, facilitates the acquisition of information and allows a common language between the parents and medical team to develop, which makes future communication easier.
- Especially in life altering conditions, chronic illness, incurable diagnoses, unanticipated impairments of the child, or death, studies show that parents:
  - need recognition by the physicians or nurses of the child being an individual with a unique value and second as an ill person.
  - need more and clear information, delivered as soon as they know about their child's health condition, an immediate prognostic, possible treatments and long-term implications.
  - need advice regarding medical and social implications in the child's development and behaviour.
  - **need that someone from the medical staff, preferably someone that knows the child from the beginning, to plan and supervise the long-term care plan.**
  - **want to be treated as partners in their child's care giving, while their concerns and views should be heard and integrated into the care giving plan.**
  - need psychological advice and assistance to preserve the family integrity and emotional support, and encouragement in their efforts.
  - need to know about other families in a similar situation and to be put in social contact with them.
  - **find a source of strength in medical personnel who are well informed, honest, and empathic, especially when the parents struggle to adapt to a difficult situation.**
  - need childcare education, social support and professional services for the child.

7.1.3 CHALLENGES FOR MEDICAL STAFF

The situation of meeting and communicating for the first time the baby's serious condition to the parents is a very difficult task and may challenge the physician's feelings or social competency.

For them this task implies:
- to transmit the diagnosis, sometimes in an emergency situation
- to explain effectively the severity of the problem and possible treatments
- to soothe the fears of the parents
- to acquire / obtain the informed consent for medical procedures
- to offer the parents attention and support in an emphatic manner

A number of factors could make the communication more difficult:

- The unforeseeable of the situation and the lack of ultimate / absolute answers.

This uncertainty requires, particularly in the case of prematurity but also in many other cases, the ability to describe the science-based diagnosis or problem in terms of probabilities and not certainties. At the same time, you have to get the parent's trust and give them hope without encouraging unrealistic expectations.

- The lack of relationship and familiarity with the parents.

It's helpful to know that parents, despite their emotional state, want to know accurate and up-to-date information.

They want the cause explanations of their baby's condition, her/his diagnosis, and the prognosis.

They want to know about possible treatments and future outcomes.

It's important to find what they really want to know, their fears and concerns, and encourage them to ask directly whatever they need to know and express their feelings freely.

- The fear of own emotions and the fear of showing them.

It's a common misconception among medical staff to think they should not become emotionally involved regarding their patients.

This misapprehension prevents empathic communication, especially during a critical situation for the parents when they need a non-judgmental attitude, understanding, encouragement, and support.

The ability to maintain a tight contact without being overwhelmed and handle the own emotions is not an easy task. Fortunately, this can be learned in special training courses and counselling.

- The knowledge that the situation and discussion is a great psychological and emotional burden for parents.

This apprehension can be mitigated through an empathic manner of providing the information and creating a good relationship

This way you support the parents, permitting them to hope for the best and you compensate for the negative impact of the situation and the news.

7.1.4 COMMUNICATION FEATURES IN THE CASE OF NEONATAL INTENSIVE CARE UNITS

In the NICU, there are a series of particular factors that make the communication especially problematic:

- The newborn's medical condition.
- The specific conditions - emotional and working - of the medical and nursing staff.
- The setting of the NICU.
- The parents' emotional state.

Newborn's medical condition:

- At first interaction, intensive care units can seem for parents a threatening unnatural environment, highly technological and full of busy healthcare providers. This creates the impression that life of their child is threatened, generating disorientation and anxiety for parents and making effective communication difficult.
- The premature babies, particularly the extreme preterm ones, sometimes suffer sudden deteriorations or complications of their health condition. **Especially when they emerge after the baby has overcome the critical stage, when the parents are confident that the baby's health will be improving, these news are very hard to accept by parents. This can cause a failure in the medical communication and compromise the trust in the medical team that then has to be rebuilt with patience.**

The specific conditions - emotional and working - of the medical and nursing team:

- The first meeting with parents of a baby with a serious medical condition is a very challenging situation. The medical staff has to:
  - communicate the diagnosis
  - inform about the severity of the problem.
  - calm down parents' fears
  - explain the possible treatments and outcomes
  - obtain their informed consent for medical procedures
- At the same time, they have to be empathic, sensitive and offer support and understanding for parents.

The NICU setting:

- This full of high-tech equipment environment where different members of the medical team (doctors, nurses, support staff, technicians etc.) are permanently present, transform the space in an unnatural place for parents to meet their child. The emotional stress level is high.
- They encounter multiple healthcare providers who give them information about their child in a range of circumstances and manners. This creates a confusing and intimidating effect, especially during the first visit to the unit and even later on as well.
- In this space, there are various sources of information and multiple communication processes in progress simultaneously, between medical personnel and parents, and between various members of the medical team.
- Parents receive information directly and intentionally delivered by the medical team, but absorb, at the same time, also other messages from the surrounding dialogues. This is vital to understand, because every comment, direct or indirect, could be registered and interpreted later by the parents as being significantly important. For this reason, it is essential to maintain

a calm and rational atmosphere, requiring from the medical team not only communication skills, but also self-awareness and sensitivity.
- Obtaining accurate and up-to-date information is important as it helps parents to assume their parenting role, gives them some sense of involvement and control, and helps them to cope with the fear and uncertainty of the situation.

The parents' emotional state:
- The most delicate aspect of communication in NICU is created by the emotional stress level and by the vulnerability of the parents.
- It's a very consuming situation, with intense emotions and the constant uncertainty make negative reactions understandable.
- **The parents usually have no past experience, they feel disoriented and have difficulties to grasp the significance of what the medical team told them.**
- The communication of the diagnosis makes the parents pass from a future of pleasurable expectations to a future full of anguishing moments, leading to an existential break / division / crisis, a before and after.
- The first encounter with the baby's medical condition, at the beginning of the communication process between the parents and the medical team, is the most problematic period for both parties in terms of interaction and communication.
- In this phase of the communication process, the information provided can be easily distorted and misinterpreted and this can undermine the parent's trust in the medical staff.
- In those moments, all the parents are experiencing an initial shock, followed by other phases, which can alternate and vary in duration and intensity. There are a series of emotional reactions, normal in these circumstances, ranging from shock, denial, guilt, fear, anger, depression, and, finally, the acknowledging and acceptance of the baby's condition.
- It is essential for the medical team to understand that a single meeting with parents, no matter how extensive it is, cannot offer a full understanding and acceptance of the baby's condition. The proper conditions to understand and learn are missing. During these moments, asking questions, following the explanations, and making decisions is very difficult for parents. Sometimes merely to think rationally is impossible for them.
- For this reason, it's necessary to propose and arrange other meetings, at short intervals and give the parents the trust of your availability to speak and answer their questions, when they feel necessary.
- In the following meetings it is vital to verify if the information conveyed has been correctly and fully understood, if they are fully aware of the prognosis, and if they hear the most worrying and serious aspects of the baby's condition.

7.1.5 METHODS FOR EXPRESSING EMOTIONS FOR PARENTS

Regular activities than can help parents to express their emotions:
- Psychological support groups, coordinated by a psychologist
- Moral support groups, coordinated by a veteran parent
- Art therapy (handmade workshops)
- A closed group on Facebook or WhatsApp for a mutual support for parents
- A standard electronic/printed document to be distributed to parents, addressing all the commons issues in their situation, the medical checks, the development stages, and the emotional state
- Call Centre

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CONTENTS

7.2. Communication in various situations
  7.2.1. Communication of bad medical news
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    7.2.1.2. Recommended methods /protocols – ABCDE model
    7.2.1.3. Recommended methods /protocols – BREAKS
  7.2.2. Particularities of communication in Neonatal Intensive Care Units
  7.2.3. Particularities of communication, alternative methods
  7.2.4. Defective communication

7.2. COMMUNICATION IN VARIOUS SITUATIONS

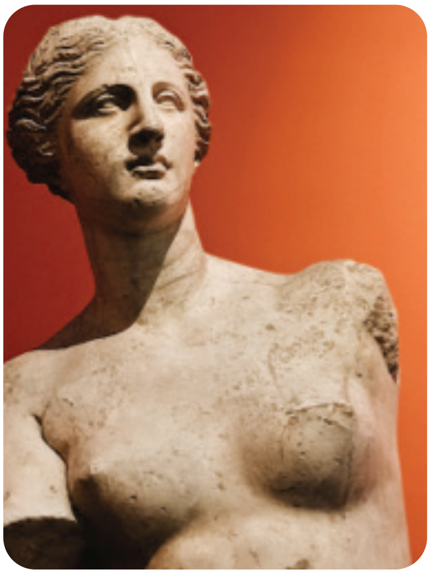
7.2.1. COMMUNICATION OF BAD MEDICAL NEWS

- Bad news can be understood as any information that affects the person at a cognitive, emotional and behavioural level. Their results persist for a period of time and drastically affect an individual's view of her/his future.
- Bad news may include confirming a diagnosis of a life-ending illness or a diagnosis that will affect a patient's life expectancy, disease recurrence, the presence of a chronic diagnosis, a chronic illness that worsened, results of genetic tests, interventions that proved to be ineffective, the change of the course of a treatment when previous attempts failed, the presence of irreversible side effects, comorbidities, resuscitation, etc.
- Conveying bad news is a skilled communication that can be learned, as part of the art of medicine.
- The manner in which medical personnel communicates the bad news can have a profound effect on both the receiver and giver, the patient and the medical personnel, the physician and put an indelible mark on the medical-patient relationship.
- Breaking bad news insensitively can cause patients additional distress alongside the psychological impact of the news itself, and can hinder their well-being, compromise the quality of her/his life and future contacts with other health care professionals.
- **A metasynthesis of breaking bad news in oncology by Bousquet et al (2015) emphasizes the emotional burden for a clinician too: guilt, anger, anxiety, exhaustion.**
- Lack of proper training could lead to an emotional disengagement of the medical personnel towards their patients.
- Good communication, properly structured and well-orchestrated, could have a positive therapeutic effect on patients.
- Researches emphasize that there are **several strategies developed to support best practice in communicating bad news** with empathy, offering guidance and recommendations in tough situations: 6 step SPIKES protocol (Baile et al, 2000), ABCDE, ad BREAKS. All these methods include using formats of structured listening to what the patient knows and wants to know, giving information in understandable amounts, reacting to the news, and checking for understanding.

When possible, before communicating not good medical news, it is preferable to include one or two sentences regarding the child, making some remarks about her/him, not related to the diagnostic and the medical condition.

"Have you seen John today? He seems very peaceful and he gained some weight."
"Did you take Mary yesterday in your arms? I bet she was very happy!"
"I've seen John today, and in spite of the fact that he is tiny and fragile, he fights like a true hero."

7.2.1.1. RECOMMENDED METHODS/PROTOCOLS FROM RELATED LITERATURE - SPIKES



SPIKES a 6-step strategy

- Acronym for: **Setting, Perception, Invitation, Knowledge, Emotion or empathy, Summary or Strategy.**
- It is an approach developed by Walter Baile, Robert Buckman and their colleagues at the University of Texas MD Anderson Cancer Centre in Houston TX.
- It was designed to help healthcare professionals break bad news.

SPIKES a 6-step strategy - Step 1 - Setting up

Establishing an appropriate setting for conversation, preparing what to say prior to the meeting:

- It will make you feel prepared and reduce anxiety.
- It is essential for successful communication.
- You should evaluate the appropriate vocabulary to use, the news that will be shared and the implication to the family.
- You will work in close collaboration with other healthcare professionals to deliver a unified, consistent message.
- The specific care plan is important too.
- You will invite the patient to involve other people important to them.

Prepare the physical space and the manner in which the news will be shared, ensure time and privacy:

- Choose, if it is possible, a quiet and private space.
- To minimize the distraction, ask the patient to switch off their phones prior to the conversation.
- Be prepared to manage time constraints and interruptions.
- Involve significant others.

Communication researchers have indicated that a very small part of meaning in any communication is conveyed by the words themselves and estimates that what is actually said represents 5 %, the tone of voice 35 % and body language and non-verbal communication is 60 %.

There are **few rules** about body language in order to ensure optimal communication, and to reduce or eliminate body signals that illustrate nervousness:

- sit down while speaking.
- look attentive and calm.
- maintain eye contact and an open posture.
- place your feet flat on the floor with your ankles together and putting your hands, palms downward, on your lap, so as to assume a successful neutral position.

Use an **“active listening mode”**: silence, repetition of important words or repetition of the phrase / sentence, nodding, smiling, saying ”hmm”, “I see”, minimize questions, summarize, reflect feelings in a flexible and integrated mode.

- Silence shows respect for what the patient is saying and encourages her/him to continue, lets her/him relate what they want to say, rather than what you want to know, or give her/him time to cope with bad news.
- Repetition of the most important words from the patient’s previous sentence in your sentence and summarizing confirms that you have been listening as well as understanding and encourages further communication. For example if the patient said “I’m afraid that the treatment doesn’t succeed”, you can reply “What aspects makes you doubt?”.
- Repetition of the last sentence/phrase encourages the patient to continue.
- Encourage the patient to talk or ask questions - they can be given non-verbally with a smile, or nodding or by expression like “I see”, “mmm”.
- **Questions are very useful when you check the understanding of what you have said to the patient or checking facts, but less helpful when you want to convey your real interest in the patient’s viewpoint.**
- Reflecting patient’s feelings give legitimacy to their emotions and encourage them to tell more. When the patients have difficulties to express their emotions you can reflect with them by saying: “I see that you found this very distressing“, “It seems as though you found this very disturbing / worrying”, “It sounds as though you find this very sad / confusing”.

SPIKES a 6-step strategy - Step 2 - Perception

- Apply the principle ”ask before you tell” and evaluate what the patient and family know about the medical condition or what (s)he suspects and what they want to know: “What did you think was going on with the child ?”, “What have you been told about this till now / so far?”.
- Understand the patient’s level of comprehension.
- Explore the patient’s perception of the news regarding the child’s illness or test results, because this will determine how the news is conveyed.
- Be aware whether the patient is engaging in any form of denial such as: omission of the essential but unfavourable medical details of the illness, wishful thinking, or unrealistic expectations from the treatment, but accept them. They are coping mechanisms dealing with the overwhelming loss and must not be confronted at this stage.
- The challenge is to respect the level of information desired, as well to be able to communicate enough for further testing and treatment, and to provide informed consent.

SPIKES a 6-step strategy - Step 3 - Invitation from the patient to give information

- Find out how much information of the medical condition and/or treatment the patient would like to know and to what level of detail:
  - “How much information would you like me to give you about your child’s diagnostic and treatment?“.
  - “Would you like me to give you details of what is going on or would you prefer that I just tell you about treatments that I am proposing?”.

  - “ Do you prefer to know all the details about what is going on?”.
- Accept the right of the patient not to know at this moment.
- If the patient expresses the desire to ask questions later, offer to answer them.

SPIKES a 6-step strategy - Step 4 - Knowledge

- communicate the bad news clearly and simply, avoiding a professional jargon and scientific language, respecting the level of the patient’s comprehension and wishes for disclosure.
- take into consideration the education level, socio-cultural background, current situation and emotional state.
- use concrete examples if it’s possible.
- give the information slowly and in small chunks so that the patient and the family can follow you and use pauses to check for understanding.
- If there is a positive aspect, give it first: “highly responsive to treatment”, “treatment available”.
- Otherwise, use a “warning shot” statement to allow the patient and family to prepare emotionally for the bad information that is coming: “Mr./ Mrs. ..., I am sorry that I have to tell you”, ” Things are not going as we had hoped”, “Unfortunately / Sadly / Regrettably I have some bad news to tell you...” , “I deeply regret I’ve got some bad news..”.
- If the news indicates a poor prognosis choose your words carefully because the family and patient will cope with the news in the upcoming days.

SPIKES a 6-step strategy - Step 5 - Emotion, empathy

- As response to the bad news, patients will have a variety of emotional reactions such as sadness, shock, silence, crying, sobbing, mistrust, anger, blame, grief, etc.
- As a doctor / nurse responding to the patients’ emotion is one of the most challenging parts of breaking bad news.
- Acknowledging the patients’ emotions and addressing them as they arise with a kind and appropriate response, demonstrates that you understand the source of their feelings, empathize and respect their difficult situation.
- The medical personnel could offer support and a therapeutic approach by giving an ”empathic response”, which consist of few steps:
- Observe and listen to recognize the patient’s emotion. If you are not sure what emotion the patient is experiencing or the patient remains silent, use open questions to find out what they are thinking and feeling.
- Identify the cause / reason for the emotion which usually is connected with the bad news. If you are not sure, it is better to ask the patient using exploratory questions.
- Give the patient time to express their feelings and make a connection statement, letting them know that you have made the connection between the emotion and its source: “I’m sorry to say that the treatment doesn’t seem to be working (silence)”, “ I realize that the information I give to you puts you in a stressful situation”, “ I know that this piece of information can be very upsetting”.
- Make a statement that reflects your empathic understanding: “I know that this is not what you wanted to hear“ ,“I wish the news where better”.
- It’s not necessary to experience always the same emotions to give an empathic response, or to show your perception of their feelings.
- Empathic responses validate the patient’s feelings, and let them know that you understood why (s)he was upset, normalizing her/his feelings and reducing their embarrassment and isolation.

- As a doctor / nurse you can use the empathic response also to acknowledge your own sadness and emotions: " I also wish that news were better".
- A combination of exploratory questions with empathic and validating responses is one of the most powerful ways of providing support to your patients.

Examples of exploratory questions:
- "Tell me what you're worried about?"
- "Could you tell me more about your concerns?"
- "What aspect do you feel that frightened you?"
- "Could you tell me what you mean?"
- "You said you are worried about … Tell me more!"
- "What do you mean ?"

Examples of empathic responses
- "I see that you are very upset / sad / confused / frightened."
- "I know this is not what you are expecting to hear!"
- "I know that it is very difficult for you to hear this information."
- "I can see how upsetting / painful / distressing this is for you!"
- "I'm sorry to have to tell you this…"
- "I was also hoping for a better result!"

Examples of validating statements:
- "Your reactions are perfectly normal in this situation."
- "Anyone in your situation would have had similar feelings / emotions / reactions."
- "I guess anyone in this situation would have the same reactions."
- "It's normal to think in this way."
- "It's fully understood to have these concerns / questions."
- "It's normal to give you time to understand what's going on."

SPIKES a 6-step strategy - Step 6 - Summary and Strategy

- Summarize the discussion, checking the patient's understanding of the information that has been provided.
- Ask the patient and the family if they want to clarify something else.
- Establish a plan with the patient, family for the future; in this way you mitigate their distress.
- Make it clear to them you are available for another meeting in the future: "We will talk again tomorrow / in few days / etc."

7.2.1.2. RECOMMENDED METHODS/PROTOCOLS FROM RELATED LITERATURE – ABCDE MODEL

ABCDE model

- It's a practical model developed by Rabow and McPhee
- It's an acronym for:
  - Advance preparation
  - Building a therapeutic environment / setting
  - Communicate appropriately
  - Deal with patient and family reactions
  - Encourage and evaluate the news

Advance Preparation:

- What the patient knows and understands at this moment?
- When you talk to the patient, encourage for the presence of a family member or a support person.
- Find a place and a time suitable for transmitting the bad news.
- Prepare yourself emotionally.
- Think or write a script with words and phrases to use.

Build a therapeutic environment:

- Find a quiet place to communicate without interruptions.
- Arrange adequate seating for all.
- Stay close to the patient to touch her/him if appropriate.
- Reassure her/him about pain, suffering.

Communicate Well:

- Use intelligible language, not acronyms, jargon, or euphemisms.
- Use breaks in communication and allow for silence.
- Be direct and use expressions to transmit empathy: ”I’m sorry / regret that I have bad news for you”.

Deal with patient and family reactions:

- Listen attentively and explore actively.
- Be aware of physiological responses of the patient, assess cognitive coping strategies and affective responses.
- Have empathy.

Encourage and validate emotions, Evaluate the News:

- Evaluate what the news means for the patient.
- Assess further needs of the patient: What are her/his near-term plans? What are their needs?
- Make suggestions and give referrals for more support.

7.2.1.3. RECOMMENDED METHODS/PROTOCOLS FROM RELATED LITERATURE – BREAKS

BREAKS strategy for breaking bad news

- It’s an acronym for **Background, Rapport, Exploring, Announce, Kindling, Summarize.**
- It’s a strategy developed by Robert Buckman.

Background:

- Knowing in-depth the patient’s medical problem is the key to effective communication.
- Be prepared to offer answers for common and reasonable questions and doubts that you can anticipate from the patient and the family.
- Before breaking the bad news, it is necessary to take into account the patient’s cultural and ethnic background, educational level, emotional status, coping skills, and the support system available.
- Assure that you have enough time to complete the task.
- Maintain eye contact.
- Expect any kind of emotional breakdown and be prepared to offer consolation.

Rapport :

- Establishing a good rapport with the patient is fundamental for the continuous and therapeutic conversation and relationship.
- Stay away from a patronizing attitude.
- An unconditional positive regard is necessary for good communication.

Exploring:

- Start with what the patient knows about her/his medical condition, her/his child`s medical condition.
- If the patient allows it, try to involve the significant others in the decision-making process.
- It's necessary to explore the history, the investigations and the difficulties met in the process.
- Assess the potential conflicts between the patient's beliefs about diagnosis and the diagnosis itself.
- Try to explore and understand the possible concerns of the patient before you offer reassurance.

Announce:

- A warning statement is desirable.
- Information should be given in a short, clear and apprehensible language.
- A useful rule of thumb is not to convey more than three bits of information.
- Avoid medical jargon, even euphemisms, if they create confusion.
- Avoid elaborate explanation or monologs.

Kindling:

- Patients may have a variety of reactions: being silent, breaking down in tears, getting up and pace round the room, denial of reality, grim humour.
- Offer space for the free flow of emotions.
- Sometimes the patient will be overwhelmed and will not actively listen to what you say after you pronounced the status; assure that the patient listens to what is being told by asking them questions like "do you listen to me?", "do you hear me? "and put her/him to recount what they have understood.
- Assure that the patient understands the nature of the disease, the gravity of the situation, the realistic course of the disease, the treatment options.

Summarize:

- Summarize the session, care plans, and the patient's concerns.
- Assure the patient of your availability to respond to other questions in the next meeting and establish the date.

7.2.2. PARTICULARITIES OF COMMUNICATION IN NICU

- Communication in the NICU may include bad news, in a strange environment and with many unknown health care professionals.
- The constant uncertainty of the premature baby's situation, the sight of their suffering and the frightened child, the inability of the parent to touch or alleviate the baby's distress and pain, and the lack of communication with him/her... all these elements make the parents' negative reactions more understandable.
- **Understanding how the parents cope with bad news may prevent judgemental conclusions and offer the space for empathic responses.**
- It's necessary to take into account the fulfilment of parental needs offering them empathic responses and family centred care, improving the communication between parents and medical staff.

For a good communication in the NICU (Neonatal Intensive Care Unit) or PICU (Paediatric Intensive Care Unit), there are few basic requirements:

- It's necessary in the first days that members of the team are introduced to the family and their roles are also explained to the family. If the family members are aware beforehand that their newborn will stay in the NICU or PICU the family may be invited to visit the unit preliminary in order to be familiar in advance with the environment and the professionals who will take care of their baby. This will decrease the tension, fear and the uncertainty that usually future parents experience.
- **If possible, at the beginning, speak with the parents in a private room, because reciprocal and effective communication requires a proper environment, and crowded and small spaces in the NICU make it difficult.**
- Listen and understand what the parents know about the baby's condition and what worries them.
- Verify how much they understood, using open-ended questions and reflective explanation and assert your availability for other meetings.
- Maintain a frequent communication with the patient.
- After the first meeting, it's important to talk to parents in the presence of the baby, describing and emphasizing both aspects - positive and critical.
- Use hopeful but honest communication and acknowledge the insecurity.
- Give an indication that the premature baby is seen as and care for as an individual, personalizing information and using the child's name.
- Discuss the likely and hoped-for outcomes and provide timeframes for improvement.
- Provide consistency by choosing the same caregivers or, if it's not possible, by caregivers delivering the same message.
- Inform the parents of any change of location, condition, treatment plan.
- Avoid last-minute surprises when feasible.
- **Encourage parents to touch, talk and cuddle their baby. This way, you help them to bond with their child, overcoming their negative feelings of alienation, guilt, sadness, etc.**
- Prepare the parents during the clinical bedside rounds for when they can stay with their baby during invasive procedures.
- **Written, audiotape and computerized education for families could contribute to a better understanding.**

7.2.3. PARTICULARITIES OF COMMUNICATION AND ALTERNATIVE METHODS IN NICU

- Researches highlight that even in the cases of parents contented with the information received from the medical team about their baby and when communication with neonatologist was good, **the nurses can be seen as:**
- a person who spent the most time explaining the baby's condition.
- a primary source of information.
- **the person who told them about important changes in their baby's condition.**
- the most important person in providing emotional support.
- Although most parents have internet access, the internet should be referred to as a reliable source of information. It is preferred to receive medical information from the medical team.
- **As the lack of regular and informative communication on behalf of health care professionals is a reason for parental complaints, a research has studied whether an individual baby diary could improve the level of communication satisfaction.**

- The diary was distributed at the admission in the NICU and parents received a leaflet with explanations. The diary was easily accessible, attached to a folder of the baby's incubator. Medical staff wrote updates about the baby's progress and well being, and about staff and / or parents' interaction with their baby. Parents wrote memories or notes as well as questions or concerns for staff to address during face to face communication.
- The diary was complemented by face-to-face communication and encouraged parental involvement.
- In conclusion the diary acted as an aid to improve the communication with parents about their baby and to complement the other types of communication.
- Some articles encourage the use of audio recordings to allow parents to listen to the information whenever they want to get a better understanding and possibility to give accurate information to the other members of the family who could not be present.

7.2.4. DEFECTIVE COMMUNICATION

- **The parents most frequently criticize the quality of the relationship with medical personnel. It's important to create a trustful and good relationship, because this relationship has a profound impact on the parental satisfaction, the treatment adherence, or the recall of an instruction.**
- It is important that the communication towards the parent regarding the child is performed as an individuality, **calling the child's name and highlighting the positive aspects,** regardless of how small they might be.

- **We don't talk about him as if he weren't there, even if he is a newborn or a baby, and we don't reduce him to a diagnostic.**

  "How are you, John/Mary? What a cool body you have. Let's see how you're doing today. Yesterday you gave us quite a scare!"

  "You've managed today to make John take your breast? This is extraordinary. You make a really good team!"

Other sources that can impede understanding and interfere with effective healthcare communication are the patient's belonging to a minority and his culture or subculture, or limited understanding of the country's language (a different native language and insufficient knowledge about the country's language).

These situations require special attention and awareness of the existence of different norms and taboos and it's preferable to ask directly family members about their communication etiquette.

Also it's preferable to collaborate with a trained translator who is aware of all these cultural norms.

Other communication barriers experienced by ethnic minorities are:

- perception of inferior quality of offered care
- limited access to heath care
- stereotyping of their cultural groups
- the control over the conversation by doctors through medical jargon or an aggressive approach
- low educational level;
- age
- gender
- excessive waiting times
- style of dressing

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MODULE 8

INTERACTION WITH PROFESSIONALS

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8.1 CLINICAL CASE DISCUSSION: USING A REFLECTING TEAM

Doctors discuss clinical cases every day. The routine way of doing this, whether during ward rounds, team meetings or other conversations, is so familiar that few give it any thought.

Generally speaking, one person presents a case, and then everyone else chips in with questions, information and advice until some kind of decision is reached: perhaps an investigation, diagnosis or treatment.

It combines the features of routine team conversations and collaborative learning groups, and can be used for conversations lasting anything from a few minutes to an hour.

The method is known as "a reflecting team". Reflecting teams originated in the world of mental health care, but have been successfully adapted in order to train doctors and health professionals in the skills needed for supervision and effective case discussions.

8.2 TEAMWORK

Hospitalists (physicians whose primary professional focus is the general medical care of hospitalized patients.) provide a unique history-taking perspective that is useful to social workers in their work.

Foremost, social workers bring a rich understanding of the available resources that patients need after discharge and a view of the patient's nonmedical circumstances.

Together, these professionals' daily interactions generate more effective discharge planning as a part of the multidisciplinary team.

There's a pattern that develops whereby at some time in the morning the hospitalist and social worker will get together and talk.

Perhaps the area where the social worker most teaches the hospitalist regards available resources to solve problems over and above the purely medical.

But nothing can replace the availability of the hospitalist to discuss patient cases, not only with the social worker but also as a team with the patient and family.

Although everyone on a multidisciplinary team can bring something to the discussion that makes the team work better, social workers and hospitalists collaborate well in painting a more comprehensive picture of the patient's lifestyle, living habits, and needs.

8.2.1 WHO IS WORKING IN THE NEONATOLOGY DEPARTMENT?

- Neonatologists (paediatricians specializing in newborns)
- Paediatricians with special attention to newborns
- Nurse specialist: this is a neonatology nurse with a master's degree, she is authorized to work in the nursing and medical field, and works with neonatologists and paediatricians
- Ward doctors (assistants), have graduated as a basic doctor and want to specialize in paediatrics but are not yet in training
- Co-assistants (medical students)
- Neonatology nurses, nurses with training in the care of premature and sick babies
- Paediatric nurses
- Nurses in training for neonatology or paediatric nurses
- Head of department, department assistants and secretaries
- Interns
- Employees of other departments, such as the social worker, physiotherapist, lactation consultant, speech therapist, radiology assistant, specialists, etc. who introduce themselves if they are involved in the treatment.

8.2.2 GENERAL PRACTITIONER

The general practitioner (GP) is a physician who provides both the first contact for a person with an undiagnosed health concern as well as continuing care of varied medical conditions, not limited by cause, organ system, or diagnosis.

8.2.3 GENETIC COUNSELLOR

A genetic counsellor is a professional that advises individuals and families affected by or at risk of genetic disorders to help them understand and adapt to the medical, psychological and familial implications of genetic contributions to disease.

The goals of genetic counseling are to increase the understanding of genetic diseases, discuss disease management options, and explain the risks and benefits of testing.

8.2.4 NEUROLOGIST

A child neurologist, or pediatric neurologist, is a doctor who treats children who have problems with their nervous system.

The neurologist treats disorders that affect the brain, spinal cord, and nerves, such as: cerebrovascular disease such as a stroke, Demyelinating diseases of the central nervous system such as multiple sclerosis, headache disorders, infections of the brain and peripheral nervous system, etc.

Some common neurologic tests used to complete the

evaluation include:

- Computed tomography (CT) or
- computer-assisted tomography (CAT) scans
- Magnetic resonance imaging (MRI)
- Electroencephalography (EEG)
- Nerve conduction studies and electromyography (NCS/EMG)

8.2.5 NEUROSURGEON

A paediatric neurosurgeon devotes his or her practice to the neurosurgical care of children.

Paediatric neurosurgeons concentrate on the special surgical problems of children involving the brain, spine or peripheral nerves.

They care for infants, children, and adolescents, and also help to counsel parents expecting a baby who may have been diagnosed before birth with a neurosurgical problem.

8.2.6 PAEDIATRIC ORTHOPAEDIC SURGEON

This specialty covers the diagnosis and treatment of a wide range of problems of the joints, bones, ligaments, tendons, muscles and nerves affecting babies, and children up to 18 years of age.

Paediatric orthopaedic surgeons work with children, using both surgical and non-surgical techniques.

A multi-disciplinary orthopaedic team incorporates highly experienced consultants and advanced diagnostic equipment such as MRI and CT scans, done by expert technicians.

8.2.7 CONDITIONS THE ORTHOPAEDIC SURGEONS TREAT INCLUDE

- foot and ankle conditions including congenital foot deformities and flat foot
- club foot
- hand deformities
- hip disorders
- dysplasia
- fractures and dislocations
- irritation
- Perthes disease
- infections of the bone and joint
- knock knees (genu valgum)
- bowed legs and slipped upper femoral epiphysis
- spinal deformities including scoliosis

8.2.8 PHYSIOTHERAPISTS

Physiotherapists (PTs) are health care professionals who know a lot about how the body moves and how to improve movement.

During the sessions, the PT teaches the person exercises and special stretches. This therapy can strengthen weak muscles and show the person new ways of getting around.

The PT also teaches the child's parents about using crutches safely on flat surfaces and stairs. It's important for kids to wear good supportive shoes, like sneakers, when using crutches.

8.2.9 OPHTHALMOLOGIST

Ophthalmologists are allowed to use medications to treat eye diseases, implement laser therapy, and perform surgery when needed.

Ophthalmologists may participate in academic research on the diagnosis and treatment for eye disorders.

8.2.10 NEONATOLOGIST

Neonatologist are taking care for the prematurely newborns or those who are critically ill at birth.

Some of the problems that these critically ill babies face could range from premature birth and low birth weight to birth defects, underdevelopment and lack of oxygen at birth.

Neonatologists work with these babies from the time they are born till the time that they leave the neonatal intensive care unit.

The neonatal intensive care unit or NICU as it is more commonly called is the intensive care unit for newborn babies who are born with major health issues.

8.2.11 GYNAECOLOGIST

The gynaecologist is a doctor with specialist qualifications in delivering babies and providing medical care to women during pregnancy (antenatal care) and after the birth (postnatal care).

Obstetricians have the skills to manage complex or high-risk pregnancies and births, and can perform interventions and caesareans.

Many have also trained in women's reproductive health (gynaecology).

8.2.12 AUDIOLOGIST & SPEECH THERAPISTS

The audiologist is a doctor of audiology who is extensively trained in the science of hearing.

Speech therapists can help a child understand how to talk, interact, engage, play and communicate with both children and adults.

8.2.13 DEVELOPMENTAL PAEDIATRICIAN

Developmental paediatricians have a specialty interest, training and experience in the development of children:

- how they grow,
- how they acquire knowledge and skills,
- how they learn to behave and socialise.

They use their training to understand children from a medical point of view, in order to determine the reasons for different problems of development and behaviour.

8.2.14 OCCUPATIONAL THERAPIST

Occupational therapists help babies with sensory processing delays and disorders by first diagnosing the disorder, and then applying various exercise techniques to help the baby or child become more comfortable and adapt easier to daily living.

8.2.15 COMMON EXERCISES AND ACTIVITIES

- Relaxing bath time activities, using soft soaps and gentle massages
- Specialized toys and activities to help babies learn how to deal with sounds, lights, and touch appropriately
- Sand and water therapy
- Joint and brushing compressions
- Proprioceptive input activities
- Vestibular input activities
- Feeding therapy
- Olfactory input activities

8.2.16 PROFESSIONALS FROM SOCIAL SERVICES

The main aim of social care is to enable individuals to live a comfortable and independent live as long as possible, supporting those who need a degree of additional physical and practice support.

Its central role is the provision of care and support to children or adults in time of need, or elderly with needs emerging from illness or disability.

Social care is provided by a range of different types of individuals and organisations.

Informal carers represent the majority of providers of support to (older) people in their own homes.

In addition, local authorities play an important role, primarily in terms of provision and assigning and meanwhile as commissioners of services from a variety of providers.

Third sector and private organisations also have a key role in terms of social care, including both those who are charged by local authorities to provide this care and also those who are financed through self-funding or charity.

8.2.17 LONG-TERM SOURCE

Of information and Support

Siblings and other family members can find comfort in end-user/parents communities as well, since their needs are often sidelined but their perspectives provide important contributions.

Parents are able to ask questions and compare experiences, and “veteran” parents can ease the worries for them a little bit.

This bonding process can greatly help medical practitioners as the stress level of their patients and the parents is reduced, and the information given to them is reiterated by their peers.

Support Groups

Support groups hold potential for mutually beneficial relationships with academia as families are often eager to provide insight to studies which may help epidemiologists find answers for their children.

Support groups are an excellent source of empowerment for all family members and can help families dealing with the bio-psychosocial ramifications of birth defects and find their light in the darkness.

MODULE 9

PSYCHOLOGICAL SUPPORT OF THE MEDICAL PROFESSIONALS AND BURNOUT PREVENTION

CONTENTS

- 9.1 Compassion Fatigue
  - 9.1.1 Definition
  - 9.1.2 Creating Awareness
- 9.2 Precautions
  - 9.2.1 Self-Care Strategies
  - 9.2.2 Care for the Other (Peer Support)
  - 9.2.3 Cases
- 9.3 Support
  - 9.3.1 Coping Strategies
  - 9.3.2 Seeking Professional Help

INTRODUCTION

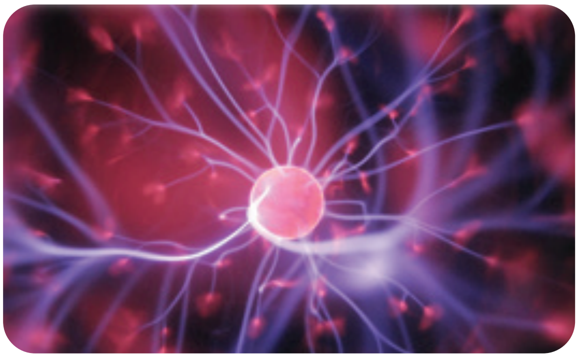
The burnout syndrome was first described in two scientific articles published in 1974, one by Herbert Freudenberger and one by Sigmund Ginsburg.

In his original 1974 article, Freudenberger describes the state of being burned out as 'becoming exhausted by making excessive demands on energy, strength, or resources' in the workplace.

According to Freudenberger, burnout is characterised by physical symptoms such as **exhaustion, fatigue, frequent headaches and gastrointestinal disturbances, sleeplessness, and shortness of breath.**

Behavioural signs are f**rustration, anger, a suspicious attitude, a feeling of omnipotence or overconfidence, alcohol abuse, excessive use of tranquilisers and barbiturates, cynicism, and signs of anxiety, depression.**

Freudenberger not only described the symptoms of burnout but also argued that it is primarily 'the dedicated and the committed' who are most likely to burn out.



Freudenberger didn't just describe the burnout syndrome, he also suggested preventive measures.

As he believed that burnout is particularly linked to specific working environments and organisational contexts, he proposed intervening at the organisational rather than just the individual level.

His recommendations included shorter working hours, regular job rotations, and frequent supervision and staff trainings.

Other important consequences of burnout are: relationship problems, reduced job satisfaction, while it is negatively correlated with organizational functioning, thus potentially generating medical errors, reduced professional efficacy, suboptimal care.

Freudenberger's initial work was followed by a significant number of psychological and medical studies, starting with research by Christina Maslach and her colleagues in the late 1970s and early 1980s.

Maslach focused on the measurement of burnout. He developed the Maslach Burnout Inventory (MBI), which is still the most widely used questionnaire for measuring burnout today.

He identified three dimensions of burnout:

- Exhaustion - sensation of being overwhelmed
- Cynicism - about the meaning of your work
- Professional inefficacy

Exhaustion and cynicism are considered the main core of burnout.

The original form of MBI has another three dimensions

- **emotional exhaustion** (9 items) - reflects the sensation of being emotionally tired due to work and with a lesser capacity of commitment than other workers (reliability of MBI: Cronbach alpha = 0.89)
- **depersonalisation** (5 items) describes callous and insensitive behaviour towards patients (Cronbach alpha = 0.66)

- **personal accomplishmen**t (8 items) expresses feelings of competence and achievement (Cronbach alpha = 0.79)

Other research "The consequences of burnout syndrome among healthcare professionals in Spain and Spanish speaking Latin American countries" stated that "High values in the case of emotional exhaustion and depersonalisation, and low values in the case of personal accomplishment, are indicative of burnout syndrome (Gil-Monte & Peiró, 1999; Maslach& Jackson, 1986)."

BURNOUT VS DEPRESSION

The symptoms of burnout tend to be **job related** and situation specific rather than general and pervasive, as in the case of a depression.

Work-specific burnout symptoms could generalise across all situations and spheres of life, hence leading to a **'real depression'.**

Increased exhaustion
- context-specific → BURNOUT
- context-free → DEPRESSION

There are several differences between burnout and depression about topics such as their concept, etiology dimensions of diagnosis and symptoms, according to Nil et al. As explained in the following slide.

	Burnout	**Depression**
Concept	Socio-psychological reasons	Clinical diagnosis
Etiology	Outcome of chronic stress at work	Psychiatric disorder
Integrative dimensions of the phenomenon/ diagnosis	According to MBI (Maslach Burnout Inventory) : • Emotional exhaustion • Depersonalization	Guiding symptoms according to DSM IV/ICD-10: • Depressive mood • Loss of interest and joy
Adjuvant symptoms	• Exhaustion • Tiredness • Reduced empathy • Frustration • Sleep disturbance • Feelings of worthlessness and failure	• Change in weight/appetite • Sleep disturbance • Psychomotor agitation/retardation • Fatigue/tiredness • Feelings of worthlessness and guilt • Suicidal thoughts

Based on a set of 92 studies on burnout and depression:

- Symptoms of burnout and depression overlap, and most burned-out professionals also exhibit depressive symptoms.
- Burnout and depression levels are moderately to highly correlated, particularly so far as the exhaustion component of burnout is concerned.
- Results regarding the causal link between burnout and depression are heterogeneous.
- Somatic and biological levels of analysis seem to suggest some degree of distinctiveness.
- Burnout and depression are found to differ in regard to their links to both job-specific (burnout),and to generic (depression) factors.

9.1 COMPASSION FATIGUE

9.1.1 DEFINITION

Compassion fatigue is a term that is used to describe a stress response in healthcare professionals. *

Compassion fatigue is considered a key contributor to the loss of compassion in healthcare.

Compassion fatigue appears to lack a conceptual foundation.

Compassion fatigue cannot be empirically validated or measured. There is the "Compassion Fatigue" scale, but due to psychometric properties, Stamm developed another instrument, "The professional Quality of life scale (Pro-QOL)" with three subscales :

- compassion satisfaction
- compassion fatigue composed from burnout
- secondary traumatic stress

9.1.2 CREATING AWARENESS

Development of the Compassion Fatigue and Burnout Process

There are three major models:

Golembiewski and colleagues: In this model, it is suggested that burnout progresses from depersonalization through lack of personal accomplishment to emotional exhaustion. Golembiewski and colleagues permits the generation of eight logically possible combinations, called phases. The model proposes that the succeeding phases are progressively virulent, from depersonalization to emotional exhaustion. Therefore, individuals with low levels of burnout would tend to report low scores in each of the three subdomains.

Leiter and Maslach: This model states that burnout progresses from emotional exhaustion through depersonalization to lack of personal accomplishment. In this model, chronic high job demands are presumed to trigger emotional exhaustion as an individual stress response. In turn, high levels of emotional exhaustion would lead workers in both contactual professions ("contactual" refers to the intense relationship with allegedly "difficult" populations).

Lee and Ashforth: This model states that emotional exhaustion can be positively related to depersonalization, but that personal accomplishment developed independently of depersonalization; rather, they propose that elevated levels of emotional exhaustion directly evoke decreases in personal accomplishment, rather than indirectly through depersonalization.

SIX MAJOR INFLUENCES ON COMPASSION FATIGUE AND BURNOUT:

- Workload and its intensity, time demands, and complexity.
- Lack of control of establishing and following day-to-day priorities.
- Insufficient reward and the accompanying feelings of continually having to do more with less.
- The feeling of community, in which relationships become impersonal and teamwork is undermined.
- The absence of fairness, in which trust, openness, and respect are not present.
- Conflicting values, in which choices that are made by the management often conflict with their mission and core values.

JOB SETTINGS AS RISK FACTORS FOR COMPASSION FATIGUE AND BURNOUT

- High Work overload
- Lack of control
- Insufficient reward
- Breakdown of the community
- Absence of fairness
- Conflicting values
- Job insecurity
- Lack of acknowledgment by the patients
- Helplessness in situations when medicine can`t help
- Lack of the opportunity to learn
- Lack of the autonomy
- Lack of performance feedback
- Emotional demands (an occupational factor)
- Effort-reward imbalance
- Perceived burnout complaints among colleagues and hospital organizational characteristics(as organisational factors)

WORKING CONDITIONS AS RISK FACTORS FOR COMPASSION FATIGUE AND BURNOUT

- Involvement with people
- Daylight
- Shift work
- Extra working hours
- Patients with aggressive behaviour
- Lack of medical equipment and supplies for contemporary medical services
- Ambient noise
- Overcrowding
- Lack of sufficient rest
- Personal attachment – living with patients’ problems
- Time pressure
- Work – family interference and role stress (is considered an occupational factor)

PSYCHOSOCIAL FACTORS FOR COMPASSION FATIGUE AND BURNOUT from research Systematic review of burnout risk factors among European healthcare professionals

Stress: previous stress

Personality characteristics: neuroticism, extraversion, hardiness, optimism…etc . (see next slide)

Personality variables like extraversion, optimism and neuroticism seemed to be significant but weak burnout predictors, especially for the personal accomplishment dimension (Buhler & Land, 2003; Hudek-Knezevic et al., 2011). Hardiness as personality characteristic predicted all burnout dimensions, according to a study among a sample of Spanish nurses (Garrosa et al., 2011).

Coping mechanisms: Studies associated different coping mechanisms with burnout and highlighted that healthcare professionals who experience burnout use more emotion focused coping (e.g. substance abuse, unhealthy eating habits) or defensive coping strategies (e.g. isolating from friends and family, denying the problem or the use of humour) (Demir et al., 2003; Sharma et al., 2007; Sharma et al., 2008).

For example, a study among Italian HIV/AIDS and oncology health care workers revealed that denying the problem predicted a lower personal accomplishment while using humour as a coping strategy explained higher emotional exhaustion (Dorz et al., 2010).

INDIVIDUAL RISK FACTORS FOR COMPASSION FATIGUE AND BURNOUT

- Neuroticism: Emotional instability.
- Agreeableness: Being friendly and kind.
- Conscientiousness: Conscientiousness is the personality trait of being careful, or diligent.
- Hardiness: Hardiness is a personality trait that is associated with a person's ability to manage and respond to stressful life events with coping strategies that turn potentially unfortunate circumstances into learning opportunities.
- Locus of control: An external locus of control supports a belief that one is helpless, without blame, and not in control of one's successes and failures. An internal locus of control will attribute the success and failures to the own efforts.
- Alexithymia ("no words for feelings"): It is a personal trait characterized by the subclinical inability to identify and describe emotions experienced by one's self or others.
- Perfectionism: Wish for everything to be complete and impeccable.
- Dispositional Optimism: Expecting the best possible result from every circumstance.
- Proactive Personality: Proactive personality is defined as a disposition relating to individual differences in people's proclivity to take personal initiative in acting to influence their environments in a broad range of activities and situations (Bateman & Crant, 1993).
- Family / private life issues: Personal problems add stress and make it harder to think and solve the problems of others.

DEMOGRAPHICAL FEATURES AS RISK FACTORS FOR COMPASSION FATIGUE AND BURNOUT

- Gender: women are 1.6 times more likely to report burnout
- Age: burnout is more prevalent in younger age groups
- Marital status: workers who are single experience burnout the most
- Education: a high degree of emotional exhaustion among people with post-graduate education has been identified

RECOGNITION OF BURNOUT SYNDROME

You are at a high risk of Burnout if you are feeling some of the below mentioned conditions:

- Emotional exhaustion: feeling down, without any energy all day long.
- Depersonalization: not seeing patients and their family members as unique human beings but as objects.
- Reduced personal accomplishment: getting worse in the things you do.
- Overwhelming fatigue / headaches: suffer from it regularly 1, 2, 3 times per week or even every day.
- Loss of intrinsic motivation: don't want to do your job anymore or you do it with displeasure
- Cynical view of one's job: think that only the own work matters
- Sense of inefficacy and failure: feeling nothing is right and you cannot change it
- Increased tension / anxiety: feeling tension and fear that something bad will happen
- Lack of lenity towards patients and their family members
- Interpersonal, marital and family conflicts: you don't feel well in your own skin, fighting with your partner, children, etc.
- Social isolation and withdrawal from the usual daily activities: you don't want to go to theatre with friends as usual or you don't want to meet people at all or you don't want to do your usual hobby
- Responding to patients and their family members in a mechanical manner: you don't consider their feelings, thoughts, personal dignity

9.2 PRECAUTIONS

9.2.1 SELF-CARE STRATEGIES

Burnout is the result of stress underlying social relationships in a professional context. The condition is associated with a reduction of physical and mental health and can lead to diminished performance accomplishment, which can affect work activities.

Self care strategies contain several options which a person who is under burnout risk can apply on her/himself. They are very effective if they are used on time and can be divided into two dimensions: physical and mental.

Health professionals should fuel their bodies in both areas.

In self care strategies, the main goal is to improve the **physical and mental health.**

- Manage your workload
- Work with purpose, focus on the task that you feel experienced the most
- Exercise, meditate
- Learn the stress management strategies

TIPS FOR SELF HELP

If you don`t want to receive professional help, you may try another ways to cope with the burn-out.

- Use personal experience: try to talk with other persons who are in the same or similar situation like you (doctors from other units or hospitals). Make efforts to learn from their experience. You may ask them what they do when they are exhausted and what their copying strategies are.
- Try to take break: invite a friend and go together to a social event (cinema, theatre, concert) where you can reduce the psychological pressure.
- Reduce your contact with negative people and spend more time with your loved ones.
- Pay attention to the positive aspects of your work: ask yourself what made you happy and content at the end of the day. Try to find peer support groups where you can join. Peer support groups give space to the person to share her/his issues, professional challenges, and the group together discuss possible solutions to overcome difficult situations. Such group may help you ,and you may help other group members as well. Nowadays, these peer support groups are functioning in the format of online communities where privacy is guaranteed. You don`t need to be physically present or to reveal your identity. You can freely share your thoughts, doubts, fears, worries and everything that embarrasses you in an anonymous manner.

9.2.2 CARE FOR THE OTHER (PEER SUPPORT)

Peer support is crucial to avoid a burnout syndrome, especially for healthcare professionals who have developed compassion fatigue and need support from their colleagues.

It is clear that there is significant distress and a high risk of burnout of the healthcare professionals. It is possible that important regional differences exist, but given the nature of the stressors it is likely that similar findings will be obtained.

In a study conducted among physicians, there are two key issues that were found:

- Rehabilitative intervention for the severely burnout physicians (10% of population) is obligatory
- Teaching/indicating preventive/self-care strategies to others (especially the younger colleagues)

PREVENTION OF BURNOUT

How to rest sufficiently?

- Relaxing from everyday stress is really important for all health care professionals.
- You can try some relaxing techniques like meditation, yoga or breathing techniques.
- The best way to reduce stress and thus to prevent a burnout is to do something you really love to do. This can be:
  - a sport activity
  - a creative hobby– hand making different things, knitting, sewing, gardening or pottery
  - long walks
  - book reading
  - listening to music
  - meeting friends.
- But remember, the most efficient rest is to do something that you really enjoy. Doing nothing sometimes just increases the tension and anxiety of the person, because the brain is reviving again and again all stressing moments and constantly analyses your worries.
- Remember that everybody needs a rest. All of us deserve to take a break from time to time and you must not be ashamed to admit this. First for yourself and then to inform your employer.

How to reduce occupational stress?

- The easiest thing is to create a pleasant atmosphere at the workplace. Put some plants, colourful and happy pictures, remove all old and broken objects (old chairs, tables etc.) if you can.
- Don’t engage yourself with bad talking.
- Learn to say “No!”, this will not compromise you, but make others to respect you more.

9.2.3 CASES (INCL. RESULTING LACK OF SUPPORT TOWARDS PARENTS OF NEWBORNS WITH DISABILITIES)

For further information, please look IO6

9.3. SUPPORT

9.3.1 COPING STRATEGIES

Diagnosis: For the assessment of burnout, several screening tests have been developed. To date, more than 90% of the studies on burnout topics have been performed with the Maslach Burnout Inventory (MBI) test.

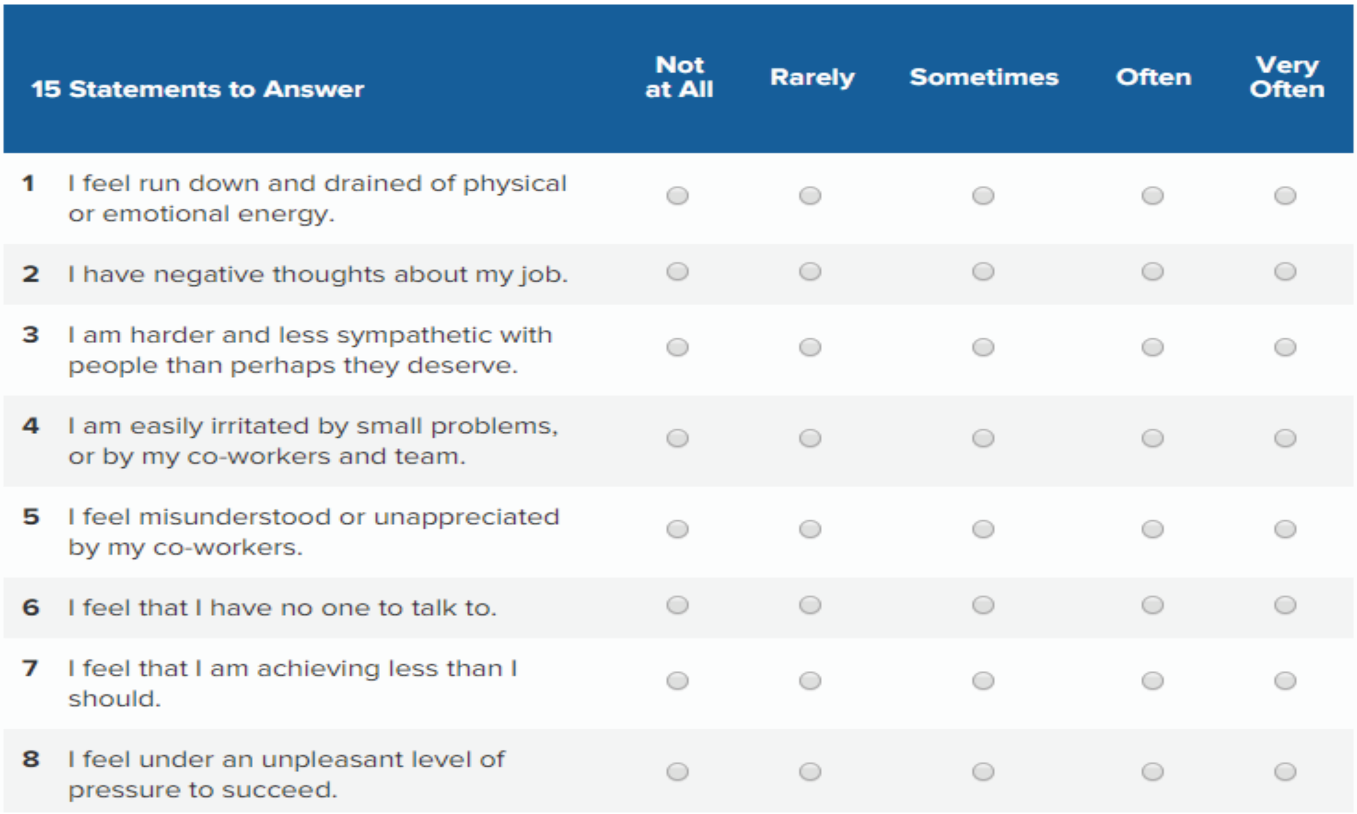
The main difference between psychiatric disorders as described by the ICD-10 and the various definitions of the burnout syndrome, is that burnout, despite numerous overlaps with psychiatric symptoms, is a workplace-related social construct.

9.3.2 SEEKING PROFESSIONAL HELP

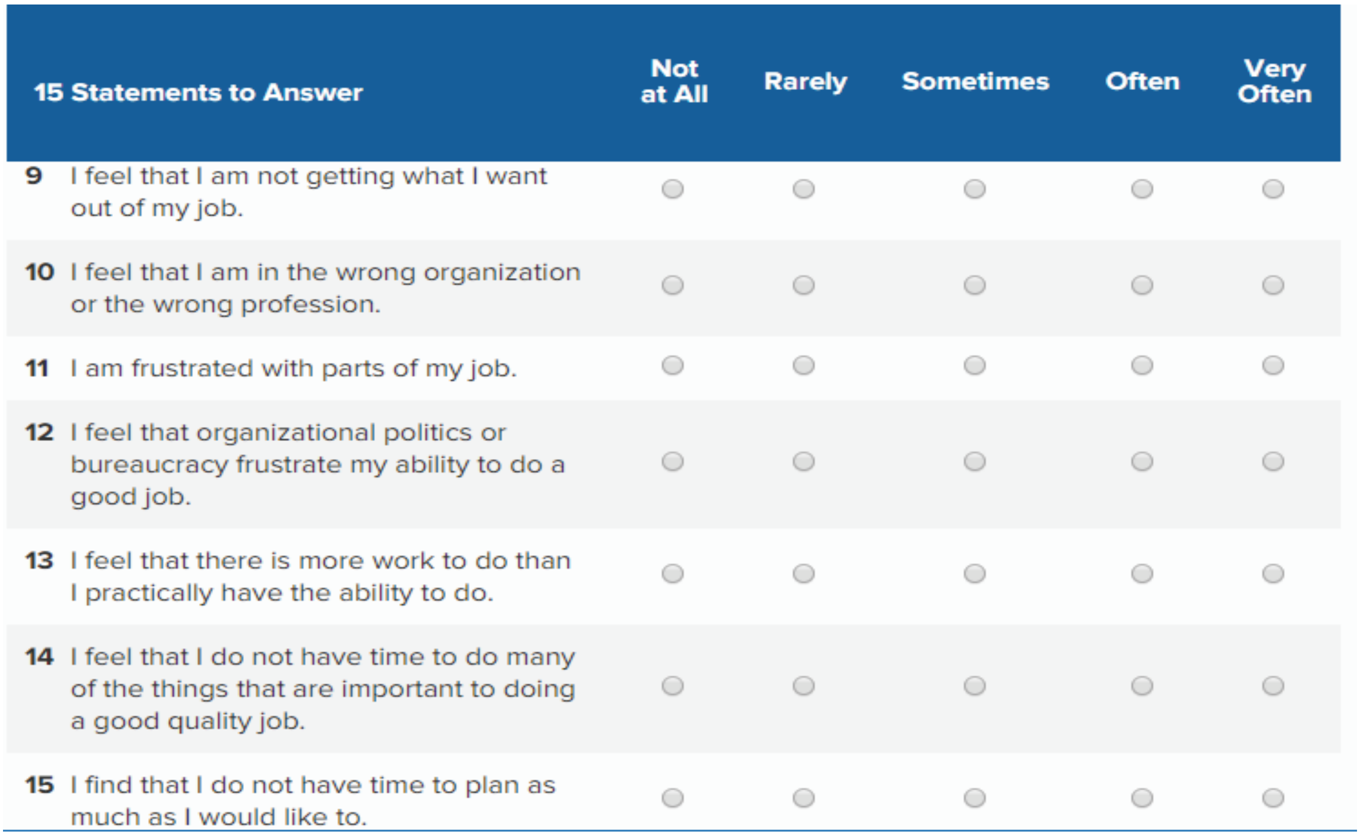
- The common pathway is the common etiology (study of causation or origination) that underlies the burnout process.
- The treatment process can prepare with following psychological disorders, such as depression, anxiety, sleep disturbance, etc.
- If you recognize the signs of compassion fatigue or burnout, you should seek for support from a specialist: psychologists or psychotherapists.
- Make a medical examination: your colleague can find the main exhaustion of the body and give you as a treatment rest, vitamins, etc. to reduce the burnout.

When choosing the professional who will help you, be aware that (s)he should be:

- Interested about your personality, your potential to cope with the situation, rather than your particular problem.
- Working together with you on the symptoms, rather than trying to remove them.
- Thinking together with you about possible solutions, rather than giving ready recipes.

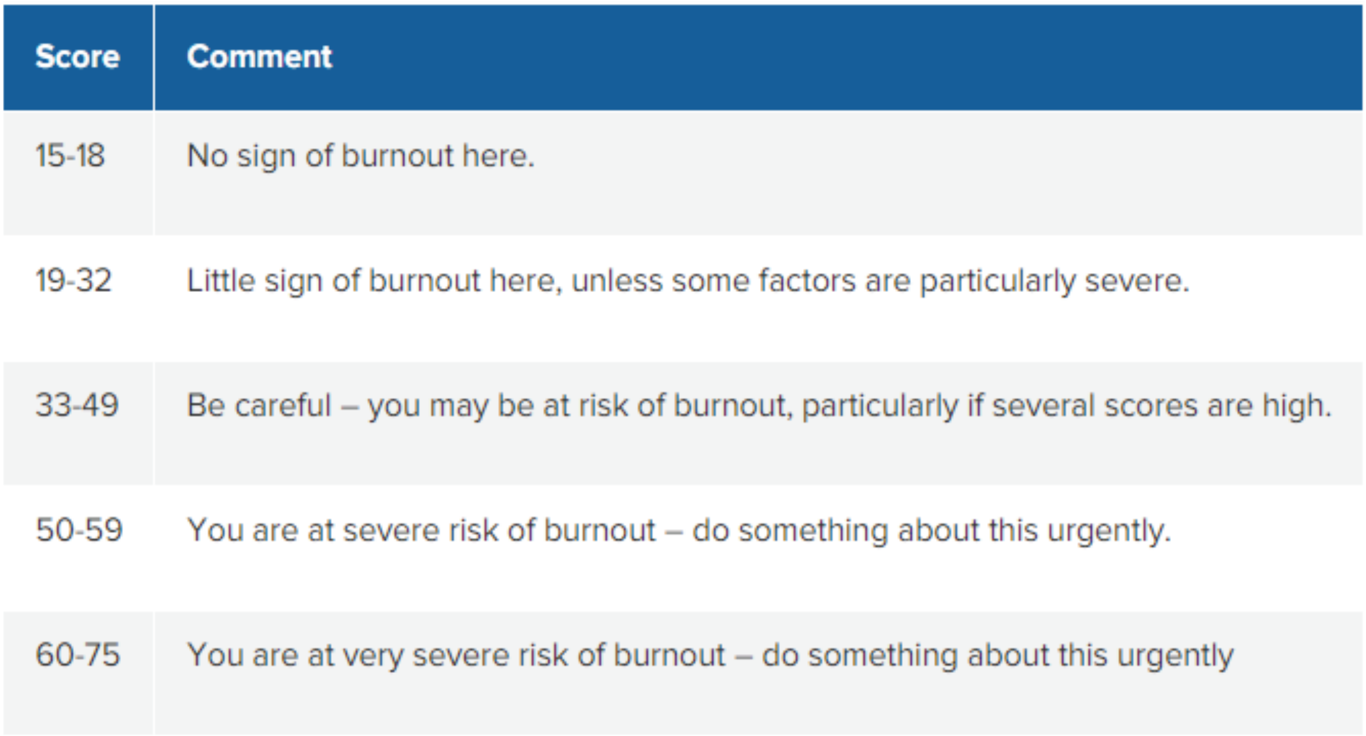


	15 Statements to Answer	Not at All	Rarely	Sometimes	Often	Very Often
1	I feel run down and drained of physical or emotional energy.	○	○	○	○	○
2	I have negative thoughts about my job.	○	○	○	○	○
3	I am harder and less sympathetic with people than perhaps they deserve.	○	○	○	○	○
4	I am easily irritated by small problems, or by my co-workers and team.	○	○	○	○	○
5	I feel misunderstood or unappreciated by my co-workers.	○	○	○	○	○
6	I feel that I have no one to talk to.	○	○	○	○	○
7	I feel that I am achieving less than I should.	○	○	○	○	○
8	I feel under an unpleasant level of pressure to succeed.	○	○	○	○	○



	15 Statements to Answer	Not at All	Rarely	Sometimes	Often	Very Often
9	I feel that I am not getting what I want out of my job.	○	○	○	○	○
10	I feel that I am in the wrong organization or the wrong profession.	○	○	○	○	○
11	I am frustrated with parts of my job.	○	○	○	○	○
12	I feel that organizational politics or bureaucracy frustrate my ability to do a good job.	○	○	○	○	○
13	I feel that there is more work to do than I practically have the ability to do.	○	○	○	○	○
14	I feel that I do not have time to do many of the things that are important to doing a good quality job.	○	○	○	○	○
15	I find that I do not have time to plan as much as I would like to.	○	○	○	○	○

Score Interpretation



Score	Comment
15-18	No sign of burnout here.
19-32	Little sign of burnout here, unless some factors are particularly severe.
33-49	Be careful – you may be at risk of burnout, particularly if several scores are high.
50-59	You are at severe risk of burnout – do something about this urgently.
60-75	You are at very severe risk of burnout – do something about this urgently

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MODULE 10

WORK BASED LEARNING THROUGH WORK BASED PEER MENTORING SUPPORT

CONTENTS

10.1 Definition
10.2 Actors and Their Roles and Responsibilities
10.3 Implementation Stages
10.4 Example Cases

10.1. DEFINITION

Mentoring is a powerful and widely used mechanism for people to learn many and new things related to their personal, social and professional skills, knowledge and competence.

The first recorded modern usage of the term can be traced to a book entitled "Les Aventures de Télémaque", by the French writer François Fenelon. In the book the lead character is the one of the Mentor. this book was published in 1699 and was very popular during the 18th century and the modern application of the term can be traced to this publication.

In contemporary days there are many definitions about mentoring and here the most popular and relevant to the MEDVET project are provided:

- *"support, assistance, advocacy or guidance given by one person to another in order to achieve an objective or several objectives over a period of time"* (Michael J. Marquardt, 2005)
- *"off-line help by one person to another in making significant transitions in knowledge, work or thinking."* (Clutterbuck, 2014)

Mentorship has been described as a complex, inter-mutual process that occurs between two people of different levels of knowledge and expertise. this professional interaction integrates and enhances career, educational, interpersonal, and psychological development. (1)

The mentoring relationship is based on commonly recognised values, such as: clear and open communication, trust, mutual respect towards the personality of the other person and assertive cooperation of both parties. In fact, good mentors do also learn from their mentees.

For instance, an experienced doctor with long term and acknowledged practice and achievements may learn more about the application of the new technologies in the contemporary medicine from a young colleague who just completed her/his specialisation in using medical robots in the robot-assisted surgery.

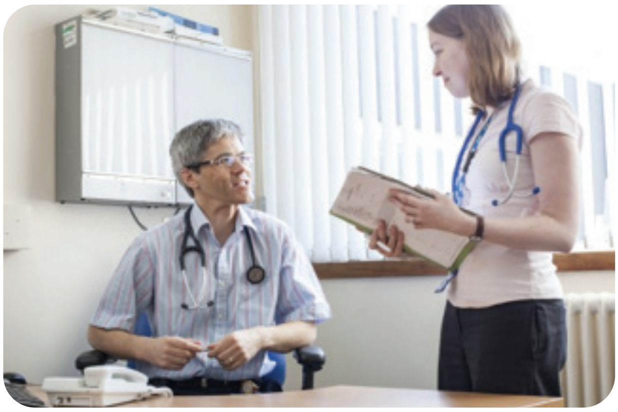
Mentoring is a fruitful and informal collaboration among individuals which:

- is an activity that occurs below the consciousness of individuals;
- is based on voluntarily participation;
- is a structured process based on a common agreement and action plan, embraced both by the mentor and the mentee.

10.2 ACTORS AND THEIR ROLES AND RESPONSIBILITIES

The main participants in the work based mentoring process are the mentor and mentee who want to:

- collaborate on a peer basis in order to solve the problem;
- discuss a case;
- find a better medical approach;
- prepare an article for their recent achievements as a result of joint work.



The **mentor** has a multiple role in the process and normally serves as a role model for the mentee. Among the main responsibilities are these related to the direct planning and implementation of the process as well as keeping privacy, ethics and safety.

The mentor should:
- Share knowledge and experience with the mentee in a way that benefits the mentee in her/his self-confidence, professional career development, identifying adaptive strategies for coping with distress at work;
- Listen and draw out the thoughts and ideas of the mentee;
- Offer the mentee a constructive, meaningful and trustworthy advice and feedback;
- Maintain an intimate and confidential relationship;
- Ensure an environment in which the mentee feels comfortable about voicing her/his concerns, fears and desires;
- Seek support or advice by other specialist when (s)he is feeling not confident enough;
- Recognise and respect the boundaries of the mentor-mentee interaction and understand the need for delicacy and support;
- Commit the necessary time to the mentoring relationship and being available at the mutually agreed upon times.

Main responsibilities of the mentee

The role of the mentee is as equally important for the final success of the mentoring process as the one of the mentor. In the usual case the mentee is motivated and willing to receive guidance and support in order to achieve the mutually set goals of the work based mentoring. The mentee should:
- Commit the necessary time to the mentoring relationship and be available at the mutually agreed upon time;
- Exchange ideas and experiences with the mentor in a friendly manner;
- Take advantage of the experiences and opportunities provided by the mentor;
- Maintain the confidentiality of all shared information;
- Keep the mentor informed about any problems, concerns, or progress made during the mentoring process;
- Follow through on commitments and agreed tasks;
- Recognise and respect the boundaries of the mentee-mentor interaction and understand the need for delicacy;
- Being conscious about the mentor’s time, to arrive to the meetings prepared with a list of topics to be discussed , and being open to receive a positive or negative feedback.

10.3 IMPLEMENTATION STAGES

Like most relationships, the one of the mentoring progress goes through consecutive stages. Your formal mentoring relationship will likely go through four stages:
- **Stage I - Building up the relationship**
- **Stage II - Sharing preferences and setting goals**
- **Stage III - Working towards achieving goals/ deepening the commitment**
- **Stage IV - Ending the formal work base mentoring and planning next steps**

Remember that these stages can overlap as mentoring, especially the one which happens at the work place, is flexible and usually follows the dynamic of the work process.

STAGE I- BUILDING UP THE RELATIONSHIP

Within Stage I, it is expected that you will get to know each other better and start to establish a trustworthy relationship.

It is also important to set up a timetable for regular communication, preferably in person, shortly after the end of your the working time or within the working hours, if this is specifically agreed with the management of the hospital.

The mentor may ask the following questions within this first stage:

- Tell me more about yourself, your concerns, your medical achievements, challenges and the micro environment you are working in.
- What are some of your initial aims related to our work-based mentoring?
- Are there any topics that you don't like to be touched on?

STAGE II- SHARING PREFERENCES AND SETTING GOALS

In Stage II, you will exchange more in-depth information and agree upon attainable goals of the work-based mentoring. As the mentoring relationship evolves, be prepared to practice active listening and regularly express encouragement.

For example: Your mentee may need to enhance her/his skills in a concrete domain i.e. communication with patients, better collaboration with senior experts, facing patients` suffering, passing bad news, handling the fatigue, etc.

In addition the mentee may need your advice on a key decision. An example of such decision can be either to apply more conventional methods in medical treatment or to explore the innovative ones, to spend more time on researches and scientific publications or to be more committed to the family life.

Guide your mentee to refer back to her/his goals on a frequent basis as a strategy for refocusing on goals and measuring progress. Referring to the goals is also a good way for you to figure out whether you are helping your mentee to achieve them.

STAGE III – WORKING TOWARDS ACHIEVING GOALS/ DEEPENING THE COMMITMENT

Stage III is usually the longest one as it covers the actual implementation of the work based mentoring. It is expected that you are going to support your mentee towards achieving the goals of the mentoring through:

- targeted conversations;
- sharing links to the relevant materials/publications/videos/life books;
- introducing the mentee to other medical professionals with experience linked to the topic;
- invitation to observe a particular medical procedure or morning report.

You, in the role of mentor, may also feel confident enough to challenge your mentee to think in non conventional ways, or approach the problem in a more creative way, but always according to the commonly recognised high medical standards and rules.

You may also try to make your mentee see the problem from different perspectives and to ask what will be the best possible or the worst possible outcome. Thus the mentee will explore the problem from different points of view and will find out that even in the worst situation there is a way out.

It is important that the mentoring process is maintained and the active participation is kept, despite the busy schedule of both parties. If the mentor hasn't heard from the mentee for some time, it is recommended to make a call and check.

- The third stage is also normally the highly rewarding phase of the work based mentoring, but some challenges may pop up. Below are some examples of challenges that other mentoring couples have shared and resolved:
- Limited time and energy
  - Promise a realistic available time which you can deliver.
- Not being the "expert" on all your mentee`s questions and needs
  - Inform your mentee in the very first Phase that it is very likely you don`t have all the answers or solutions, and you are open for learning together, as well as seeking for support from other experts who are more experienced and competent on particular issues.
- Not being able to give priority to the mentoring support in case the daily responsibilities can not be postponed
  - Discuss with your mentee that sometimes it may happen that your duties can take priority over the mentoring support. However, both of you are expected to make efforts to catch up.

STAGE IV - ENDING THE FORMAL WORK BASED MENTORING AND PLANNING NEXT STEPS

As the work-based mentoring is time bound, it is expected that in the last stage you discuss future opportunities for collaboration and mutual support.

You may also consider the option whereby the mentee takes the role of mentor for other less experienced colleagues, who want to benefit from your outcomes.

Last but not least you may think together about other types of support. For instance job coaching, peer support and exchange of good practices with colleagues from foreign countries.

If you both believe that the mentoring process was beneficial and useful, you may invite the management of the hospital to seek for opportunities to implement work based mentoring on a regular basis as part of the human resource development policy.

10.4 EXAMPLE CASES

In this chapter we provide some examples of mentoring schemes and their impact on the participants. Literature review reveals that there are many evidences of the positive outcomes of mentoring. In the next slides we present some links and examples to prove this statement.

- A research paper describing the learning experiences of final-year student midwives in labour wards within the Brussels metropolitan region, Belgium - *Vermeulen J, Peersman W, Waegemans M, et al. Learning experiences of final-year student midwives in labor wards: A qualitative exploratory study. European Journal of Midwifery. 2019;3(August). doi:10.18332/ejm/111802* - *http://www.europeanjournalofmidwifery.eu/Learning-experiences*-of-final-year-student-midwives-in-nlabor-wards-A-qualitative,111802,0,2.html#references
- An example by Champlain Maternal Newborn Regional Program on how to develop a formal mentorship program to facilitate novice nurses' transition - *http://www.cmnrp.ca/uploads/documents//Mentorship_Program_CHEO_2019_05.pdf*
- Mentoring in Medical practice: how to do this effectively - *available at https://ubccpd.ca/sites/ubccpd.ca/files/2015-SRPC-Mentoring-in-medical-practice.pdf*

  6 Characteristics of an Effective Hospitalist Mentoring Program – Jennifer L.W. Fink, 2018 - available at https://www.medscape.com/viewarticle/894424

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