



Notification

5

Medical Notification: The Basic Principles for preterm, noticed as developmental impairment; for protection, them, to be disabilities for leading to handicap *

Medical Team of Acibadem Hospital and Eskişehir Osmangazi University Medical Faculty and the contributors*

*Prof. MD. M. Arif Akşit, Neonatology and Pediatric Genetics
Associated Prof. MD. Tülin Fidan, Child Psychiatry
Associated Prof. MD. Coşkun Yarar, Pediatric Neurology
Assistant Prof. MD. Meltem Dinleyici, Social Pediatrics
Prof. PhD. Ömür Şaylıgil, Medical Ethics*

Prematurity is a developmental impairment; we have precautions for safety measures from protection to be disabilities and leading to handicap.

Prematurity is a condition, before the developmental status is unconventional and be organized for alive. The fetus and also mother's health and living conditions are in danger, so, prematurity inevitably occurred and as medically performed.

This impairment is a reasoning of several disabilities and may be grounding to handicaps. Thus, the basic principles have to be considered before the disabilities confirmed. Early detection for special considerations and precious follow up applications is required.

The basic principles are indicated below, for the preterm as an impairment state not to have disabilities leading to handicap.

Outline

AIM: The prematurity as a developmental impairment, is a reasoning for some disabilities, causing handicaps. Therefore, the principles of medical approach to the preterm and the disabilities for protection to handicap is indicated as concepts.

Grounding Aspects: The Human Rights and Disability Acts, National and Universal articles are also taken as grounding of this notions.

Each person as a member of Homo sapiens, sapiens are same, no discrimination in any matter is accepted, all are illegal. Individually everyone is unique and free, by sole characteristics, From the cellular point of view, have potential to be a human being, therefore, respect have to be considered. After the viability phase, the protection and caring of the right to life is obligatory. Live birth means to gin all the legal right of citizenship, earn the heir.

Medical considerations are not only for physical health, to be other aspects are to be included, thus, human is a whole, confirming the social and cultural standpoint.

Life is process until passing out. Physicians and all the medical staff have to be concerned the human for respect and honor, not giving guaranties to be health they have done. Act by the scientific evidences, for ethical conducts and make empathy approach, by their mind and take all the responsibilities, what by they have done. unhuman applications are all illegal.

For healthy, precautions and early checkup procedures are needed, especially for preterm and impaired and disabilities for protection of handicap. Economy aspects and quality of life considerations are not indicated for the medical appliances.

For medical procedures, especially for preterm, impaired and disabilities infants are: a) Realistic and exact configuration of the problem, b) Assessment of the treatment of medical applications, c) improvement, the result of the approaches, d) day to day consideration, by growth and development of the infants.

Key Words: Prematurity, impairment, disability and handicap, the medical principles for the approach

Özet

AMAÇ: Prematürelilik temelinde, kusur, sakatlık ve özürlü olmanın önlenbilmesi açısından tıbbi yaklaşımların ilkeleri sunulmaktadır. Konu başlıca temel haklar ve tıbbi prensipler ile yaklaşım boyutu ile irdelenmektedir.

Dayanaklar/Kaynaklar (Materyal ve Metot): Tüm İnsan Hakları, Özürlü Kanunları temelinde yaklaşım yapılmıştır.

Her insan Homo sapiens, sapiens olarak aynıdır, aynı türün elemanıdır. Herhangi bir ayırım kabul edilemez. Her birey tek ve özel, özgüdür. Hücre düzeyinden itibaren tüm oluşumlar bir insan olarak saygı ve gereken onura sahiptir ve bir insanlık değeridir. Yaşam sınırından itibaren, yaşam hakkı öne çıkmaktadır. Canlı doğum ile tüm birey olarak tüm vatandaşlık haklarından yararlanabilmekte, miras hakkı da oluşmaktadır. Prematürelilik, kusurlu, özürsüz ve engelli olması bir ayrımcılık olarak İnsan Hakları temelinde Kabul edilemez yaklaşımdır ve tüm sağlık hizmetlerinden yararlanma hakkı bulunmaktadır.

Sağlık yaklaşımları sadece fiziksel olarak irdelenemez, sağlıklı olma boyutu, çok farklı temeller ile irdelenmelidir ki, sosyal, kültürel ve ruhsal boyut bunlardandır. Yaşam sadece bir dönem değil, bir süreç olarak oluşmaktadır Hekim tıbbi bilimsel veriler temelinde, insan hakları ve etik esaslar içinde, vicdanı temelinde, empati yaparak yaklaşım yapmalıdır. İnsanlık dışı hiçbir yaklaşım kabul edilebilir değil, bir suç niteliğindedir.

Sağlıklı olmak için olasılıklar, dikkate alınması, ön yaklaşımlar, erken tanısal boyutlar öne çıkmaktadır. Komplikasyon istenmeyen ama olası durumlardır ve tedbiri gerekli kılar. Prematürelilik, kusurlu olmak, sakatlık insan olarak her canlının olabileceği, oluşabileceği durumlar kapsamındadır. Her bireye durumuna göre tıbbi yaklaşım yapılması hakkıdır. Ekonomi ve kalite gibi kavramlar tıbbi yaklaşımlarda Hekimlikte hastalık yok, hasta var prensibi geçerlidir

Tıbbi yaklaşımlarda: a) Geçerli bir tıbbi boyut, b) Aktif yaşamı sağlama durumu, c) Tıbbi yaklaşımlardan yararlanma boyutu, d) Eğitim ve eğitilebilir olma durumu ile yaşamdaki uzun süreli süreç dikkate alınmalıdır.

Bu özellikle prematüre ve bozuklukları, sekelleri ve özürleri olanlar için önemlidir. Bir seferlik bir tıbbi yaklaşım değil, yaşam boyu süreğen yaklaşım gerektirir.

Anahtar Kelimeler: Prematürelilik, kusur, sakatlık ve özürsüz olma, tıbbi yaklaşımların temelleri

Ethical Concepts as Human Rights

Fundamental Basic Rights

- ✓ All human is same, a member of Homo sapiens, sapiens. The baby, as born preterm, and have impairment, disabilities and handicap are also the same Human species.
- ✓ Not to be any discrimination, even gender, race and any other aspects, like nationality, and even due to their disabilities. The person as an individual, born preterm, and have impairment, disabilities and handicap are as a Human Being, no discrimination and grouping is prohibited.
- ✓ Each person is unique, therefore normal is meaning of comparison with others, so not any an acceptable philosophy, what is normal is interrogating perception. Differences confirms the individuals. The natural concept of human being, even preterm born,

very small, tiny infant, even impairment, disability and handicap are also a physical, mental and other differences, that have to be an esteem/honor of the individual.

- ✓ At the cellular stage the ethical and legal considerations must be full of life. In some believes and by legal concept, the cellular stage has the right to be a human, so basically the ethical considerations are required by this phase.
- ✓ Potential to live and born alive is confirm it as member of Human. After 20 gestational weeks, fetus is enough potential to live. Even over 22 gestational weeks in clinical practice is considering the vital aspect, thus, at the embryological stand point it is 20 gestational weeks. After the viability, no consideration of termination, except the mother and infant lifesaving. To be a preterm, and have impairment, disabilities and handicap are not in thought of early delivery.
- ✓ Live birth is the legalization of individual rights. All the person born alive, legally is a member of the community and be the right to have all the individual rights, even have right to have heir. Born free and right to live and to be in secure, for protection and care, for health, security of human contemplations. The preterm, and impairment, disabilities and handicap are also the same Human Legal Rights.
- ✓ By the honor of the humanity act. Humanity considerations require to act by the honor of humanity. All the individual rights are under protection, even by governmental or institutional focuses. The person as an individual, born preterm, and have impairment, disabilities and handicap are also the respect of the Human honor.
- ✓ Clear and comprehensive prohibition of discrimination based on impairment, disability and handicap. As indicated at “**Americans with Disabilities Act of 1990**”, “*An Act to establish a clear and comprehensive prohibition of discrimination based on disability*”. This is included for preterm, impairment, disabilities and handicap ones also.
- ✓ Medical or education perspectives and approaches may be early reduced and functional be active person. The discrimination and the evidence of the impairments are not taken as similar. To be with regular school is the aim to be. Not to be educated and put in a different group as handicap is not an acceptable habit, perspective. It is a kind of discrimination perception. Preterm mostly required extra special care for education to be active member of the community.

Medical Concepts

The basic Medical responsibility of obligations

- 1) Right to live. Each person has right to live. They have the capacity and capability to be a human, even at the cellular phase as ovum and sperm. Respect must be considered as mentioned at the ethical principles. The preterm, and have impairment, disabilities and handicap person are also right to live.
- 2) The meaning of life is not only for physical health. A human is not alone, have a value first for individual aspect and then value in a community and prospects for the human mankind. This value is out of considerations as economy, and others ideas or philosophical evaluations. To be is the first and only reasoning to be a Human and

nothing, even no court has right to even make an argument on it. Physiological and cultural considerations are widening including to physician, nurse and other medical staffs, especially in consideration of Neonatal; Handicap for physiatrist, psychologists.

- 3) Each one, born alive have the right to be medically be in good physical shape conditions. The malformations or the impairments have to be corrected, if rather not to be treated but, have to be medically evaluation and to be a balanced functional status. The handling of the medical conduct or the considerations must be performed before passing, during the life period. Special care must be in consideration for preterm infants
- 4) Life not in a glance, not a first-time consideration, it is continuous action. The growth and development have to be taken care. Follow up procedures are essential for health care. Especially preterm infants and some impariments and disability or handicap infants have to be care by expert medical professions.
- 5) Each physician is as an advocate of humanity, must consider the medical methods and concepts, as a principle of humanity by ethical principles, more than care, for cure and approach, but not taken responsibility the result of to be healthy. Preterm, impairment and disabilities are the primary focused for these aspects.
- 6) Physicians act by ethical considerations; inferior, empathically concise scientific judgement, under consideration of expert personal responsibilities. Due to the medical approach, not to be considered other perspectives other than humanity, for not influenced or taken consideration of the condition, must be by mind and by humanity by soul, for empathy and humanistic principles. Everyone, especially for medical staff, consider themselves, make the empathy, for the preterm, disability, handicap people as themselves. So, they have to act for bearing in mind of them.
- 7) Not any unhuman approach must have any reasoning, be grounding or taking notice for medicine, at personal perspective. The most valuable one is, to be, the life, the esteem is to be human as an individual. Physician must take care and protect and serve the honor of human as humanity principles. Be aware of the preterm, impairment, disabilities and handicap individuals, for special and extra care.
- 8) Protection and caring of babies, from the families are also be in consideration. Caring, supporting and serving to children form the fetal stage to newborn and infant period, especially by family considerations. The educational facilities to family, especially mother, care and health situations condition and facilities must be considered. If any improper findings and if not receptacle or not fitted or cured or taken to proper condition, must be done at the separate place under condition. Babies are not tolerable and not allow to be in toleration, to bad conditions.
- 9) Advisory and teach and trained facilities as an educator must have been gained to the family, Medical staff, especially physicians must be role model and to be on ethical conducts. The preterm, and have impairment, disabilities and handicap individuals needs extra respect, to comprehend and appreciate their condition.
- 10) Education is the meaning to chance to positive way in manner, in behavior and even at the attitudes. It is such a differentiation by cultural concepts. To be a healthy is the meaning of globalization of the perspective of looking from the individual aspect. The meaning of education is not to discriminate the preterm and other disabilities.

- 11) Threads needs/required to take precautions. In case of any threads, not to be caring, not to be education or not to be changing the facilities, not to be in human act, or behavior, the child, the fetus and babies and infant have to be taken in precautions, even by governmental institutions by the medical staffs, social workers and all concepts for helping the infants. Complications are not wanted condition but they are in mind and expected ones. As a social responsibility, we have taken special care for the preterm, and have impairment, disabilities and handicap ones
- 12) Any suspicious aspect has to be needed for evidence to be confirmed. The suspiciousness still not satisfied, the precautions must be also considered. Emergency procedures is applied if the suspiciousness is satisfactory confirmation even no evidence. Evidence can only be confirmed by the investigation, so emergency procedures can be applied before the investigation.
- 13) In case of evidence the legal application must be confirmed. Legal application is required by law, especially to medical staff. In case to consider as personal secret, confident aspect, the physician be punished, not even for fine.

Grounding notification

- 1) Natural Conditional State of the Impairments is to be a human: The nature of to be living organism, as Human Being, problems and impairments are common encountered natural conditional state. Medicine as a scientific notion, are considered the health of Human, for healthy life, considering correspondingly the impairments too. Physician is an advocate of individual, considering the health and under the ethical values and attentions, not knowing the future and became, so not giving treatment guaranties, as a role of God. Preterm infants as inevitable condition and special expert care is required.
- 2) Humanity is obligatory required consideration to each impairment. Humanity impairments are encountered at the human nature concept, so physician as an advocate of the human by humanity perspective, aiming to heal the impairments, compensate, to be a tolerable, to be a member of the community and care and serve himself/herself, if not palliative approaches.
- 3) Disabilities are basis to an impairment, so medical approach required form the first stage of impairment noticed, even at the fetal period. Every person, even at fetal stages and even after birth, whatever the condition and whatever, the finding, the position, have the right to be considered their impairments, and their malformations for medical approach, not to be left apart, not to be considered.
- 4) Follow up and Precautions must be considered for each Human.
 - a. Healthy condition and healthy state must be balanced by the personal considerations. Life goes on, even you have handicaps, so healthy conditions of a human have to be considered and checkup approaches are obligatory for each human. Preterm infants must be continuously evaluated for healthy.
 - b. Physician consider the individual, not the results. Results must be evaluating from the perspective of the condition, the subjective influences as meaning of person.

- c. Physician stand point is to keep the position, save, protect and serve. Informative consent has to be taken, for babies from the families. For right to life conditions, only information have to be given, if refused the legal approach is obligatory performed.
 - d. Each probability of the adverse ones; required considerations, like checkup and continuous admission and examination, even though not evidence is confirmed.
 - e. Evaluation of the human advances, especially children; growth, development.
 - f. Most disabilities are noticeable during the improvement, development. Therefore, continuous considerations are needed for the early diagnosis or confirmed the condition. The early estimation of impairments and educational even medical multi centered application have reduced or even treated or completely cured the aspects, and be a functional ordinary person.
- 5) Suspiciousness required to follow up consideration. First at the balanced and between the standard error or deviation, but later be intolerable condition. Physician conclusion as to continue the follow up, not mentioned as normal.
- 6) Functionality is the meaning of human. A person without any leg, can be movable with armchair, so the function is at least satisfactory.

Stages of Medical Approach (RAID)

Fourth dimensions of the impairment, thus before developing disabilities, before considering the handicaps:

1-R. Rapid evaluation the Reality: Evaluation of the impairments and disabilities and handicaps. For everyone from the fetal stage to early Neonatology perspective must be in considerations.

2-A. Assessment by a medical team. Advancing status, Application aspects due to the Educational condition: Restriction of the functioning for daily life and by evaluation to restore to functionally. At the team, a part of the impairment consideration, like orthopedics etc., the basic branches might be; a) Perinatolog, b) Neonatolog, c) Developmental Pediatrics, c) Child Psychiatrist and physiotherapist, d) Pediatric Neurology and e) Pediatric Genetics.

3-I. Improving: Functional refining, inducing the training of daily acts as human necessities: Personification to be active living Word, but for an individual rights and as equal rights at the Human Rights, with humanity aspects. The consideration of the medical applications and procedures and the educational aspects to the mother, family and another concerning person.

4-D. Duration for growth and development. Daily assessment to Disease, problems; Time concept, improving or steady state, or declination condition. Cerebral Palsy and Autistic Spectrum is not diagnosed before developing is encountered. But some foresight can be done from the happenings of the babies.