

Rīga Stradiņš University
Faculty of Medicine
2nd level higher professional study programme "Medicine"

Distress and Anxiety in Mothers with Newborns in Neonatal Intensive Care Unit

SCIENTIFIC THESIS

Author:
Alisa Bobrova
Student ID No. 015119

/Signature/

12th November 2018

Supervisor:
Arturs Miksons
RSU Department of
Psychosomatic Medicine and
Psychotherapy

/signature/

_____ 2018

Rīga, 2018

Abstract in Latvian

Ievads: Jaundzimušo uzņemšana intensīvās terapijas nodaļā (ITN) ir sarežģīta pieredze mātēm. Termins „sarežģīta“ attiecas uz simptomu un negatīvo emociju pārpilnības klātbūtni. Tādas mātes ir pakļautas ievērojamam distresa un trauksmes līmenim. Šī literārā pārskata mērķis ir izpētīt sarežģīto stāvokli, koncentrējoties uz distresa un trauksmes jēdzieniem, mātes un jaundzimušo attiecībām un hospitalizācijas sekām.

Metodes: Tika apkopotas un pārskatītas publikācijas par pieredzi mātēm, kuriem jaundzimušais atrodas ITN hospitalizācijā. Kopā tika analizēti un apspriesti 15 pētījumi. Analīze un diskusija tika veikta, pamatojoties uz klīnisko literatūru par tēmām, kas saistītas ar distresu, trauksmi un piesaistīšanās, caur psihodinamisko ideju lēci

Diskusija: Intensīvās terapijas nodaļā mātēm piemīt ievērojama trauksme un ciešanas. Satraukuma sajūta ir difūza, milzīga un nemainīga visā slimnīcā atrašanās laikā. Slimnīcas darbiniekiem būtu jāpievērš uzmanību un jā rūpējās par mātēm, nevis izturēties pret viņiem kā pret aculieciniekiem. Stratēģijas, kas saistītas ar emocionālu distresu atzīšanu un iejaukšanos, ir vitāli svarīgi ITN aprūpes aspekti. Mātei jābūt tuvu savam zīdainim, ja to atļauj jaundzimušā stāvoklis.

Secinājums: Mātes un slimnīcu personāla attiecību uzlabošana ir vissvaīgākais. Jāveicina tādi pasākumi kā mācību video, informatīvas lekcijas un fizisks kontakts ITN nodaļās, lai uzlabotu maternitātes hospitalizācijas pieredzi.

Abstract

Introduction: Newborn admissions to the neonatal intensive care unit (NICU) are a difficult experience for the mothers. The term difficult refers to the presence of abundance of symptoms and negative emotions. These mothers are susceptible to experiencing significant levels of distress and anxiety. The purpose of this literature review is to investigate the difficult state, focus on concepts of distress and anxiety, mother-newborn relationships and implications of hospitalization.

Methods: Publications on the topic of maternal experiences during their newborn NICU hospitalization were collected and revised. In total 15 studies were analyzed and discussed. Analysis and discussion was done on the basis of clinical literature regarding topics of distress, anxiety and attachment from the lens of psychodynamic ideas.

Discussion: Mothers in NICU exhibit significant anxiety and distress. The felt anxiety is diffuse, overwhelming and constant during the stay at the hospital. The hospital staff should pay attention and care to the mothers, rather than dismiss them as bystanders. Strategies involving emotional distress recognition and interventions are vital aspects of NICU nursing care. Closeness and near proximity of the mother to the infant should also be enforced, if the newborn's condition allows it.

Conclusion: Improving communication between mothers and hospital staff is of uttermost importance. Interventions such as educational videos, informative lectures and physical contact in NICU departments to improve maternal hospitalization experience should be encouraged.

Table of Contents

Introduction	5
1. Stress and Distress.....	6
1.1 The Physiological Theories of Distress	6
2. Anxiety.....	9
2.1 The Neurobiology of Anxiety	9
2.2 The Psychodynamic Approach	10
3. Mother-Newborn Relationship	12
3.1 Object Relations Theory	12
3.2 Significance of Separation.....	12
4. Hospitalization	14
4.1 NICU and Infant Stays at NICU	14
4.2 Maternal Experiences During Newborn’s NICU Hospitalization.....	14
5. Hospital Interventions Improving Maternal Experiences.....	18
6. Conclusion.....	20
7. Discussion	21

Introduction

According to the EFCNI, [31] one in ten newborns is born prematurely each year, adding up to about 500,000 preterm newborns in Europe alone. Preterm newborns are susceptible to serious health complications during the newborn period, as well as morbidities extending into later life. These infants are often admitted to the neonatal intensive care unit (NICU) as they require specialized care. Mothers and newborns have a unique attachment which forms the basis for biopsychosocial health of the infant. Hospital stays for mothers whose infants are admitted to the NICU are difficult. The term difficult refers to the presence of a multitude of symptoms as well as negative emotions. These mothers are prone to experiencing significant levels of distress and anxiety. In order to examine the difficult state, this thesis is exploring concepts of distress and anxiety, the mother-newborn relationships and implications of hospitalization. Identifying experiences of these mothers may aid in creating adequate support during the hospitalization, as well as facilitate better care of the infant after the release from NICU. In this thesis, the term mother is an umbrella term for any primary caregiver in the light of the absence of a biological mother or the choice of such.

1. Stress and Distress

The general population regards stress as a singular process with a negative effect on the body. In contrast, medicine looks at it from a more differentiated point of view. Medicine regards stress as a physical demand on the organism, and divides it into two subtypes. Distress as a negative demand on one hand, and eustress as a positive demand on the other. Stress was first introduced by H. Selye and will be discussed in this paragraph. Eustress can be described as the “good” or positive stress. It offers an appropriate number of demand for the individual and thereby acts as a motivator. Distress on the other hand, is the “bad” or negative stress. Too many stimuli or demand lead to a mental overload that lowers the performance.

A short period of stress is not harmful as it keeps us alert in dangerous situations and helps us perform our daily tasks. Long-term exposure to stress causes a problem. It leads to a shift from eustress to distress due to the organisms overwhelm of stimuli. Distress leads to increased cortisol levels released from the adrenal gland. Cortisol effects include glucose formation, immunosuppression, increased insulin resistance, blood pressure elevation, and inhibition of bone formation. Though these effects are extremely important for preparation of the “fight or flight”, long term exposure in distress may cause hypertension, dyslipidaemia, decreased immune system, insulin resistance, bone disease, etc., In addition, the constant exposure and over activity of cortisol leads to a disturbed neuronal metabolism which changes the balance in the production and reduction of several neurotransmitters (serotonin, dopamine, noradrenaline), which may lead to development of depression.

1.1 The Physiological Theories of Distress

As introduced by H. Selye, stress is identified as a performance-increasing reaction to the bodily and the psychological demand of the body to different stressors. This psychological demand is nowadays referred to as “stress”, while the stress reaction in the Selye-ian sense is referred to as burden.

The first and the most immediate reaction towards stress is an activation of the sympathetic nervous symptoms in order to mobilize the physical functions to optimize reaction towards danger. This reaction is referred to as the “fight and flight”. The activation of the sympathetic nervous includes acceleration of the heart rate, increased force in myocardial contraction, vasodilation of arteries in working muscles, vasoconstriction of arteries in non-working muscles, dilation of bronchi and pupils, increased ventilation, reduction of digestive activity, released glucose from the liver [29]. These reactions occur due to the release of

catecholamines, specifically noradrenalin and adrenalin, from the adrenal gland, and are aimed to prepare the body for rapid metabolic change and physical movement. In the absence of stress, the parasympathetic nervous system is active and regulates homeostasis, however, both systems do not necessarily function simultaneously as there is no physical arousal and relaxation possible at the same time [29].

The CNS also plays a part in stress, for example, parts of the limbic system are directly responsible for the biochemical processes that contribute to the stress response. Amygdala is where fear is first recognized by the brain. When there is a threat present, the hypothalamus exhibits several functions, being the activation of the autonomic nervous system, the stimulation of secretion of ACTH, production of ADH, and stimulation of the thyroid gland. The hypothalamus also controls appetite, it is also known to be a pain and pleasure center, these functions explain why during acute levels of high stress appetite decreases. The neocortex is the most developed part for cognitive decision making and gives humans the ability to analyze, imagine, be creative, have intuition, logic, memory and organization [29]. Due to the high level of the neocortex, it can override the lower brain structures, and thus conscious thought can influence emotional response and intervene in some functions of the autonomic nervous system [29]. Based on this principle, coping skills and relaxation techniques can be acquired. Researcher Bruce McEwen conducted research indicating that at first a stressful encounter is engraved into the memory bank (as to prevent it), however, repeated episodes of stress decrease the memory capacity by weakening hippocampal brain cells [29]. Long term stress is thought to diminish neuronal connections in the brain, eventually leading to decreased brain size [29].

From the endocrine system glands involved in stress response are: pituitary gland, thyroid and adrenal glands. The pituitary gland plays a vital role, as it produces hormones that lead to hormone releases from other organs. Due to the stimulation from the pituitary, the adrenal gland releases several hormones, most important in the stress response are glucocorticoids. Cortisol generally prepares the body for the “flight or flight” and is responsible for triggering mobilization of free fatty acids, proteins and amino acids, initiates gluconeogenesis and increases serum glucose levels, decreases insulin production, promotes muscle wasting, increases arterial blood pressure, as well as suppresses the immune system, etc. Long term stress stimulates all these functions, and may cause hypertension, dyslipidemia, a weakened immune system, these outcomes and many more are harmful to the body. Due to the stimulation from the pituitary, the thyroid gland increases the general metabolic rate via the secretion of thyroxine and triiodothyronine. Thyroxine is influential enough to double one’s rate of metabolism [29]. The effects are the increased workload of the heart muscle, increased

gastrointestinal activity (which in prolonged stressful situations may lead to gastritis, stress ulcers) and in some situations cerebation, which is associated with anxiety and/or insomnia [29].

2. Anxiety

Elizabeth L. Auchincloss describes “anxiety (as) an affect characterized by the painful experience of apprehension and anticipation of danger” [25]. Anxiety could be compared to fear to an extent, as both anticipate a threat, and both can keep us safe from harm. However, there is a core difference between the two, fear is a reaction to external danger, while anxiety is a response to danger emerging from within (psyche) [23]. Generally, at one time or another, all people have experienced anxiety since it is a normal part of existence, the human life and condition. The rather typical somatic occurrence of tachycardia, sweaty palms, a stomach ‘turning’ are familiar, as well as the racing and obsessive thoughts. Anxiety affects over one fourth of the entire population and women are twice as likely to report anxiety symptoms [24]. It can be displayed in different ways, one path of looking at anxiety is that of a motivator for completion of tasks and deadlines, as not reaching those goals may leave us in danger of getting a bad mark, getting fired, losing status, etc., the cause of feeling anxiety in these situations is that the outcome may be threatening to us. In other cases, anxiety can be disturbing and may interfere with our daily lives, preventing us from concentrating on tasks, sleeping, and generally decreasing the quality of life; here, the anticipation of danger may be too overwhelming, and often irrational [24]. There are various factors that may predispose people to experiencing anxiety. “Some that can be mentioned are genetics, brain organization, chemical imbalances, drug and alcohol abuse, physical illness, as well as intrapsychic conflicts and early developmental issues” [24;417]. Such factors may make persons more prone to experiencing the destructive side of anxiety, and seriously affect how they cope with life situations and how they generally function in the society.

2.1 The Neurobiology of Anxiety

Various brain regions play a role in anxiety. The majority of the regions involved in anxiety are part of the basic fear network, being the prefrontal cortex, thalamus, hippocampus and the amygdala, as well as its projections to brain parts that play a role in the autonomic, endocrine, and the behavioral responses to fear [30]. The brain structure considered to play a remarkable role in processing fear-related stimuli is the amygdala, and neuroimaging research shows that its abnormal function is majorly involved in anxiety disorders, for instance that a heightened activation of the amygdala is seen in PTSD patients when provoked to recollect about the traumatic event [30]. A 2003 study by Massana G. et al., [11] concerning the amygdalar atrophy detected by volumetric MRI, showed that patients with panic disorders

appeared to have lower bilateral amygdala volume in comparison to those in the control group not suffering from panic disorders. This could suggest that activity, function, as well as the structure of amygdala may be attributed to some anxiety disorders [30].

Apart from brain structure participation in anxiety and in anxiety disorders, neuroendocrine and neurotransmitter factors are important. Increased activity in brain regions responsible for emotional processing in those with anxiety disorders could result from reduced inhibitory signaling by GABA, or increased excitatory neurotransmission by glutamate [10]. “In the central nervous system, classic neurotransmitters often are packaged and co-released with neuropeptides, many of which are expressed in limbic reactions where they can influence stress and emotion circuitry” [10;552]. Neuropeptides with especially strong links to psychopathology are cholecystokinin, galanin, neuropeptide, vasopressin, oxytocin, and corticotropin releasing factor [10].

Systemic diseases can also play a role in triggering anxiety symptoms. For instance, patients with hyperthyroidism may have symptoms of tachycardia, difficulty managing emotions, insomnia, increased agitation [24]. Anxiety symptoms can be provoked by hormonal imbalances. Patients with adrenal tumors may present with complaints of anxiety and anxiety attacks, which are difficult to distinguish from a panic attack; in such cases the symptoms of anxiety are primarily caused by the adrenal tumor, and not a psychological reaction to the tumor [24].

2.2 The Psychodynamic Approach

From a psychodynamic standpoint, anxiety is at the core of the theory of affects, and is crucial in understanding mental conflicts [26]. Anxiety can be explained as a result of an unknown, unrecognized factor coming from the environment or from the psyche, and may be provoked by changes from the environment or by some rousing of the unconscious, which is repressed [28]. In psychodynamics, mainly the latter conflict is analyzed. Freud coined several theories about anxiety. The earliest theory stated that anxiety was a “manifestation of repressed libido” [28: 8], the next theory suggested that the cause of anxiety was the reoccurrence of the experience of birth [28]. The third theory is the one that became a widely accepted in psychoanalysis. It states that there are two types of anxiety, primary anxiety and signal anxiety, which are both the response of the ego to “an increase of instinctual or emotional tension” [28:8]. Signal anxiety acts as an “alerting mechanism which forewarns the ego of an impending threat to its equilibrium” and primary anxiety acts as “the emotion which accompanies

dissolution of the ego” [28:8]. The role of signal anxiety is to prevent the primary anxiety from being acknowledged or experienced, by enabling the ego to use defenses [28]. The Freudian theory of anxiety is nowadays part of orthodox psychoanalysis, and seldom used in psychosomatic settings.

An example for anxiety with its underlying unconscious quality can be seen in the analysis of panic attacks. Anxiety, here, is an indicator for the unconscious fear of the emotion of anger, arguably due to its interpersonally dividing effect on the intrapsychic motive of separation [2].

In order to reduce anxiety, humans use defense mechanisms. One of the reasons for using defense mechanisms is to protect ourselves from powerful, threatening emotions [27]. Phoebe Cramer reviewed the current state and mentioned several empirical findings in her paper [4]. Some of Cramer’s findings state that defenses are unconscious, they are present in normal personalities, defenses are increasingly used in times of distress, they reduce the conscious experience of negative emotions, they operate via the autonomic nervous system, and that defenses become pathological when used excessively [4].

Anxiety may be experienced differently depending on the personality structure. Psychotics are more likely to experience anxiety at the level of annihilation, [24] which could be regarded as a threat to self, and even to the existence itself. It could be described as impending doom, or an anticipation of a disaster [24]. This could be explained with the scattered personality structure of the psychotic personality organization, their disorganized inner world, as well as their hesitation about their right to exist independently. For them, anxiety is extremely overwhelming, the defenses used may distort reality. With psychotic anxiety, these people have low capacity for maintaining friendships and relationships, including a therapeutic relationship [24]. Neurotics have a different experience of anxiety, they have an integrated self, they are in touch with reality and have an observing ego. Neurotics’ reality testing is intact, which makes them experience anxiety on a different level from psychotics, as they can be reflective and realistic [24].

3. Mother-Newborn Relationship

3.1 Object Relations Theory

The object relations theory explains primary need for attachment in infants and children, and the potential damage done if that need is not met. The term object refers to something that is outside the self, “something that the self perceives, experiences, desires, fears, rejects or takes in” [24:120], in psychodynamic theory it usually refers to people. Object relations theory is a work of a group of psychodynamic thinkers from England and the U.S, multiple studies were conducted that looked at the concept of object relations in infants and children. “Bowlby (1969) concluded that attachment is a primary, biological, and absolute need in human beings, necessary for the survival of the species” [24:136]. Bowlby emphasized that the problem of not having a mother is not only due to the lack of functional care [24]. He believed that having a mother is an utter need for the human race, and that losing one can cause great suffering and grief in children [24]. Early attachment is important for more than just physical survival, it is needed for the development of a person’s healthy inner world, which is significantly influenced by the quality of early relationships. Another analyst has looked at the importance of attachment. Donald Winnicott’s ideas focused on the significance of the quality of relationships, and how the nature of object experiences influence development [24:126]. Winnicott argued that at the very beginning, mothers should be completely “consumed” by their infants and provide them with absolute love and attention, he referred to it as “primary maternal preoccupation” and believed it is needed to ease the shock of transitioning into a separate extra-uterine life from the intra-uterine one [24]. The aim of this preoccupation is for the newborn to feel complete safety, belonging and love for at least some time [24]. It is with this healthy early attachment that a child will eventually be able to separate from the mother/caregiver gradually and challenge-free, and later form wholesome relationships with others.

3.2 Significance of Separation

In 1946 Spitz published a study concerning psychological harm of the children who did not receive emotional care [24:125]. He observed approximately a hundred infants whose mothers were in a penal institution; for six to eight months after birth the infants were with their mothers, after which a three-month separation from the mothers followed, during which the children were provided with solemnly functional care from the nursing staff and were not

cuddled or held [24]. After some time, the children exhibited loss of interest in the surrounding environment and became apathetic, generally withdrawing [24]. Some of the children developed “anaclitic depression,” presenting with extreme withdrawal from the environment. Spitz introduced the term “anaclitic” to refer to deprivation of the loved object, the term is currently used to describe a personality type characterized by disturbances of gratifying interpersonal relationships (loss of object, neglect). The word “anaclitic” itself refers to a strong emotional disturbance on another or others. A portion of these children became anorexic, lethargic and unresponsive to objects; many children had developmental abnormalities of motor skills and language at the age of 18 months [24]. This is a rather extreme end of emotional neglect of newborns, however, it is of value when discussing early life attachments.

4. Hospitalization

Mothers with newborns in NICU exhibit clinically significant symptoms of anxiety and distress, feelings of helplessness and isolation from the newborn, and the inability to protect the infant from pain and thus act out the parental role [15, 6]. This prevalence of poor psychological well-being in these mothers emphasizes the importance and need of contribution from the NICU nursing staff, “neonatal care providers have a unique relationship with mothers and a golden opportunity to identify symptoms and provide appropriate referrals and support” [20;320]. The skills to identify and understand the concept of aversive emotional states in NICU mothers may aid in creating beneficial screening systems aiming to recognize the mothers requiring emotional support and intervention [20].

4.1 NICU and Infant Stays at NICU

The NICU provides care for newborns with special medical needs. The department contains advanced technology and has trained health care professionals. Not all hospitals have a NICU department, thus neonates with special needs may need to be transported to hospitals which have NICUs. Newborns in need for NICU hospitalization are premature (born before 37 weeks of gestation), have low birth weight (<2.5kg), heart defects, infections, birth defects. Twins, triplets and other multiples tend to have low birth weight and are often admitted to the NICU [32]. Delivery factors may also contribute to NICU admission, such as fetal distress/asphyxia, breech presentation, forceps or cesarean delivery [32].

Hospital stays of infants in NICU are often not short, for instance, in a study looking at length of stay in NICU of infants after 34 weeks of birth in the UK, the average length of stay in infants who were intrauterine growth restricted at birth was 12.5 days and those without IUGR 8.2 days [7]. As to be expected, in very preterm infants (in all neonatal units in England) the median length of stay is much lengthier, in those born at gestational age of 29 weeks stay for 53 days on average, those born at 30 gestational age stay for 42 days, and those born at 31 weeks stay for 34 days on average [19]. Such numbers highlight the importance of help for these mothers as their experiences of anxiety and distress can be rather long lasting.

4.2 Maternal Experiences During Newborn’s NICU Hospitalization

The birth of a new child is a challenging time for mothers. Mothers of infants who are admitted to the NICU begin their parenthood in an unfamiliar, extremely stressful environment.

These mothers are prone to experiencing high levels of distress [3,6,17,20]. In studies comparing the NICU experience of both parents, mothers have been reported to be more distressed than the fathers [6]. The distress is thought to be related to the condition of the newborn, the NICU environment, and isolation from the baby, both physical and emotional [17]. Mothers feel responsibility for the child's health outcome, and worry that the infants will have growth and developmental issues [17]. Such reported patterns greatly contribute to continuous feelings of distress during the NICU experience. The mothers reported that the inability to establish a normal, healthy parenting role is the predominant source of distress [17]. Feelings of stress were decreased with the presence of hospital staff's support and open communication, allowing the parents to care for the newborn, as well as being informed about the child's health [17]. Turan et al. conducted a study to assess the effect of stress-reducing nursing interventions on the stress levels of the parents of NICU admitted premature infants [21]. The intervention was a 30-minute long informative lecture, conducted during the first week of admission, concerning their infants and the general NICU environment [3]. In addition to the informative lecture, the parents in the intervention group were introduced to the department and the department staff, and were given answers to any questions the parents had [3]. The control group solemnly experienced routine unit procedures. After the infant's tenth day in the NICU, parent's perceived stress scale scores were measured. The results showed that distress levels of the mothers in the intervention group were significantly lower than in mothers in the control group [3]. Phillips and Tooley (2005) reported that mothers that were unable to see, touch, or have proximity to the NICU infants felt significant distress [17,18].

NICU mothers are also at a high risk for significant anxiety symptoms [6]. The mothers present with high rates of aversive emotional states, with significant symptoms of anxiety disorders; these symptoms negatively affect the mother's quality of life as well as the infant's development [20]. In a study concerning anxiety in NICU mothers, 28% met the diagnostic criteria for acute stress disorder one week after the infant was admitted to the ICU [9]. These numbers suggest a high prevalence of feelings of anxiety in these mothers. Both parents experience significant anxiety when their newborns are in the NICU, but mothers tend to have a more diffuse anxiety and find the NICU experience as well as post-NICU period more stressful than fathers [6]. The sources of heightened anxiety levels in mothers with newborns in NICU are the lack of a comfortable environment where the mothers can fulfill physiological needs and take care of the newborns (such as feeding, putting them to sleep, etc.), the ill condition of the newborn, little information concerning treatment and medical procedures, flawed communication with the hospital staff, as well as the lack of social support [15].

Amongst the mothers with newborns in NICU, mothers who have received little information about the newborns condition, versus those mothers who were informed of their children's condition, higher anxiety levels were recorded [15]. Social support from the staff, as well as support from close family should also be strongly encouraged. From the mothers whose infants were in the NICU, those who reported little or no support systems showed significantly higher state anxiety levels than the mothers who reported having support systems [15]. It is important for the mothers to be close to the infants and complete activities such as feeding, touching and holding the infant; as through these activities, anxiety levels can be reduced through the development of competence and parenting roles [22].

Since NICU visits are uncommon and states of exception, in case of NICU admission a separation between a mother and a child occurs. Those mothers may experience delayed maternal attachment [17]. Generally early separation of the infant from parents complicates the infant-parent relationship as the parents should see the infant and have proper physical contact with it to enable early attachment and bonding [8]. Feldman et al. (1999) found that the illness of the newborn as well as the mothers' personality traits both influence the maternal attachment, this suggests that mothers who are depressed or anxious are more likely to develop disturbances of mother-newborn attachment [8]. This is of great significance, as mothers with NICU newborns are highly anxious and distressed. Some of the things that the parents found helpful was parental participation and close proximity to the child [17]. Coming from this, it is of crucial importance for the hospital staff to identify the needs, understand the experience of the mothers, and attempt to improve their satisfaction, which will give rise to healthy attachment and bonding [17]. In a study by Cronin et al., mothers whose wishes of closeness to the newborns were granted have reported feeling more responsible, confident and familiar with the baby [5].

In a study conducted by K. Nyström et al, (2006) [16] mother's experiences of separation from newborns were looked at. Narrative interviews were carried out one to two months postpartum where mothers were asked to reflect upon their experiences during the stay at the NICU. Eight women's interviews were recorded, all their newborns were full-term, and stayed in the NICU between two and ten days. These mothers had many reflections about the hospitalization, with three reoccurring major themes: being an outsider, lack of control, and caring. The mothers reported the theme of feeling like outsiders, and subthemes of relating to this were: "despair, powerlessness, homelessness and disappointment" [16;227]. Some of these feelings were conveyed through crying a lot, sleeplessness, anorexia, and wanting to be with the babies; these recurrent narratives were interpreted as despair [16]. Despair was also

demonstrated as the distressing experience of being away from the newborn. Powerlessness was narrated as the mother's will to take responsibility for the newborn, but feeling like she is unable to as others were making the decisions for her. Moreover, the inability to stop the newborn's crying (for example after procedures) played a role in the feeling of powerlessness. The feeling of homelessness came from narratives of NICU proximity to the postpartum ward, mothers felt like going to the different floor was a barrier for the visits, and not having their newborns in the postpartum unit made the mothers feel as if they did not belong to the postpartum unit, contributing to the feeling of homelessness. Disappointment was narrated as the outcome of the complete unpreparedness to the complications that occurred with the newborns. Mothers reported that seeing other mothers with healthy newborns was unfair and painful to them. The lack of information and the inability to openly communicate with the nurses also contributed to the feeling of disappointment; even though the children were not seriously ill, the mothers were still yearning for emotional support from the NICU staff and the postpartum department staff.

Further on, lack of control was connected to descriptions of threat, guilt, and insecurity [16]. Threat was described as experiencing fear and worry and anticipation for something worse to happen, despite reassurances from doctors about the newborn's condition. Guilt was expressed by the mothers as feeling as they were at fault for the child's suffering, and trying to recollect what they could have contributed to the child's condition during the pregnancy. "Insecurity included a feeling of loneliness, a lack of commitment from the staff, and a sense of bothering the staff." [16;278] The mothers were unsure if all the procedures the child went through were necessary, and if they were left alone and cried, all this contributed to insecurity.

"From the theme of caring, the following subthemes emerged: trust, love, anxiety, relief and closeness" [16;278]. Trust was narrated as the feeling of faith and confidence in the medical staff who were empathetic. When the mothers were close to the newborns, the feeling of "love was expressed through gratitude, intense closeness, and joy inspired by the newborns" [16;278]. Anxiety was narrated by the mothers by thinking the newborn might be harmed during the separation, and relief was expressed when the mothers understood the child was not seriously ill. The mothers felt closeness to the newborns, and also commented that newborns shouldn't be separated from the mothers, but if they are, there should be a place for the mother in NICU as well [16].

5. Hospital Interventions Improving Maternal Experiences

Several studies show that open communication and information from the hospital staff improves maternal experiences during the NICU stay [6,15,17]. Wigert et al., (2006) found that the feeling of inclusion or participation was expressed by the mothers when they experienced open communications and discussions with the NICU staff, and were treated as individuals with individual needs [22]. Studies by Melnyk et al looked at the Creating Opportunities for Parents Empowerment (COPE) model and its use for mothers with NICU infants [13,14]. “The COPE model is an educational and behavioral intervention about preterm infant development, strategies for interaction and care, and preparation for discharge to home” [3;32]. The 20 mothers that received the COPE intervention have shown to have significantly less stress as measured by the PSS: NICU related to the sights and sounds of the NICU, as opposed to the 22 mothers in the control group. The infants of mothers in the intervention group also scored significantly higher on the cognitive assessment tools at three and six months [3]. In a research conducted by Matricardi et al, [12] mothers and fathers of 42 preterm infants admitted to the NICU in Italy were studied. The intervention group was taught how to observe and massage their infants in order to improve and encourage parental engagement in infant care [12]. The Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU) to assess the difference between the intervention and the control groups. The results have shown that the intervention group had significantly lower stress levels related to NICU sights and sounds, the appearance and behavior of the infant, and parental role alteration. They also found that mothers had higher stress levels related to parental role alteration than fathers. The research also showed that upon discharge, the mothers had a significant reduction in the stress of role alteration [12].

Browne and Talami [1] conducted a study involving mothers of preterm infants born at 36 weeks’ gestation or earlier, who were admitted to the university hospital NICU in Oklahoma, USA [1]. Three groups were created out of the 84 participants, two interventional groups and one control. The first group (n=28) was given information about infant reflexes, attention, motor skills, and sleep-wake states using the Assessment of Preterm Infant Behavior and the Mother’s Assessment of the Behavior of her Infant, based on the Brazelton Neonatal Behavioral Assessment Scale to observe and to elicit infant responses [1]. The second group (n=31) was given some general information concerning premature infants through educational slides and tapes, and a book concerning prematurity. The third group (n=25) was a control group, and only took part in a general discussion about preterm infant care. The results of the study showed that the first and the second (interventional) groups had significantly improved knowledge scores and nearly significant lower Parenting Stress Index scores than the control group. It was also

shown that 28% of all the participating mothers had Parenting Stress Index of above the published high normative range [1].

6. Conclusion

NICU hospitalization is a distressing experience for the mothers. Distress is attributed to the ill condition of the newborn, the unfamiliar NICU environment and separation from the newborn. Mothers show significant signs of anxiety in part caused by lack of information and communication with the NICU staff about the hospitalized infant. Improving communication between mothers and hospital staff is of uttermost importance. Interventions such as educational videos, informative lectures and physical contact in NICU departments to improve maternal hospitalization experience should be encouraged.

7. Discussion

Mothers in NICU exhibit significant anxiety and distress. Anxiety felt by the mothers with newborns in NICU is diffuse, constant during the stay at the hospital, and overwhelming. Hospital staff tends to dismiss the mother in the light of the infants' treatment. The hospital staff should pay attention and care to the mothers, rather than dismiss them as bystanders. Strategies involving emotional distress recognition and treatment are vital aspects of NICU nursing care. These strategies improve the mother's well-being and increases the ability to communicate with the department staff, as well as the perceived relationship with the infant. The lack of information about the newborn's condition greatly affects the mothers, causing them to exhibit significant amounts of distress and anxiety. Research supports the benefits of improvement in the communication between the medical staff and mothers since it decreases anxiety and distress. Open communication with the staff may improve the mother's experience during an already difficult situation, and could contribute to a better mother-child relationship after the infant's release from the NICU, as the mother's distress may be reduced, allowing her to be calmer and more focused on the newborn. Closeness and near proximity of the mother to the infant should also be enforced, if the newborn's condition allows it. If the mother will be able to act out at least some of the parental role and care for the infant, some confidence may be established in turn decreasing the levels of distress. During the postpartum phase, not only is it important for the mother to be near the newborn for the production of milk, but also to build a healthy mother-child relationship, to adapt to the parent role, as well as to reduce stress of the newborn who is away from the mother. Helping the mothers establish early access to attachment to newborns in NICU settings could aid the relationship, and help the mothers feel less helpless by the inability to consume the child with care and love during those crucial early times.

In regard to the importance of social support in personal relationships, the hospital staff should be able to identify the mothers lacking the support, as they likely exhibiting higher distress. The families could be informed about the importance of support of the mothers, or communication could be aided by the medical staff in order to improve the social support network of the mother.

The significance of early newborn-mother attachment and its vital role in biopsychosocial development leads to two essential questions: is the lack of emotional care of the newborn influencing hospitalization and future development? And is the effect of hospitalization on the mothers influencing attachment and future relationship with the child?

The NICU newborns are lacking the emotional care which supports them in feeling safety and union, making their environment potentially frightening and alien.

Mothers have shown to experience more distress than the fathers, this could potentially be attributed to the inability of the mother to perform early attachment to the newborn. According to Winnicott, in order to reduce the stress of the newborn child when starting an extra-uterine life, mothers should be consumed and involved in them. A mother who is not able to do so due to unexpected NICU separation could be feeling distressed at the inability to do so. It should be mentioned, that Winnicott's ideas are culture bound and coined during the 1950's, where stay at home mothers were the norm and idealized. In current time, many mothers have to or choose to work shortly after delivery. If his theories are to be applied, the question stands: are the newborns in our times, who do not get complete "preoccupation" doomed to feel unsafe and unloved even in the absence of NICU setting?

Shortcomings of the previously discussed research with its symptom orientated approach lack a psychodynamic perspective with qualitative interviews. In order to prevent, better care for, and provide support for infants in NICUs, in addition to accessing state anxiety, further research identifying structural deficits in mothers should be done. Given the earlier discussion on attachment and its significance during NICU settings, it should be a goal of research to show early shortcomings of attachment by structural deficits in mothers, and thereby access if NICU admissions could be influenced by the mother's personality organization instead of solemnly focusing on the acute setting. Thereby keeping in mind that mothers with a structural deficit will be profoundly distressed during NICU settings and unable to care for the child. In case the mothers receive support, it is questionable if mothers with severe structural deficits can provide good care for the newborn. Even though it seems unlikely that newborns are already influenced by the personality organization of their mothers, identifying the structures possibly during pregnancy could help prevent future hospitalization.

The study of Kerstin Nyström et al. is one of the only studies discussed which gives an insight into the subjective emotions and experiences of the mothers rather than a symptom based approach. However, it should be noted that the sample might be too small (eight participants), and that in the given hospital, the mothers were encouraged to see and take care of their newborns with any possibility, and were allowed to spend time with the newborns whenever they wanted to. This study could be representing a rather narrow sample, where contact is allowed and encouraged, as in many hospitals that is not the case.

Discussed interventions performed by the hospital to reduce maternal distress and anxiety are effective, though the populations involved were not diverse and did not mention

any socioeconomical differences. In addition, the newborns of this study were born prematurely, but no severely ill newborns.

To explore further possibilities and limitations research should be focus on specific subgroups such as age, religion, ethnicity, social support among the family of mothers as well as psychodynamic entities such as defence mechanisms, personality organization to evaluating the prevalence of symptoms and the efficacy of interventions. Initiating evidence based interventions in hospitals with NICU departments to improve maternal hospitalization experience should be encouraged, which can in turn facilitate better attachment between mothers and newborns.

Bibliography

I Journals

1. Browne J, Talmi A. Family-based intervention to enhance infant parent relationships in the neonatal intensive care unit. *J Pediatr Psychol.* 2005; Dec;30:667-677. PubMed PMID: 16260436
2. Busch FN, Milrod BL, Singer MB. Theory and technique in psychodynamic treatment of panic disorder. *J Psychother Pract Res.* 999;8(3):234-42. PubMed PMID: 10413443.
3. Chertok, Ilana R. Azulay PhD, RN, IBCLC; McCrone, Susan PhD, RN, PMHCNS-BC; Parker, Dennelle MSN, RN, FNP-BC; Leslie, Nan PhD, RN, WHNP. Review of Interventions to Reduce Stress Among Mothers of Infants in the NICU. *Advances in Neonatal Care.* 14(1):30-37, February 2014.
4. Cramer, P. (2008), Seven Pillars of Defense Mechanism Theory. *Social and Personality Psychology Compass.* Vol 2,5: 1963-1981. doi: 10.1111/j.1751-9004.2008.00135.x
5. Cronin C. First time mothers: identifying their needs, perceptions and experiences. *Journal of Clinical Nursing* 2003 Mar;12(2):260-7.
6. Doering LV, Moser DK, Dracup K. Correlates of anxiety, hostility, depression, and psychosocial adjustment in parents of NICU infants. *Neonatal Network.* 2000 Aug;19(5):15-23. PubMed PMID: 11949109.
7. El-Sheikh A, Francis A, Gardosi J. Comparative analysis of length of stay in neonatal intensive care after 34 weeks in singleton babies with and without intrauterine growth restriction. *Archives of Disease in Childhood - Fetal and Neonatal Edition* 2011;96:Fa71.
8. Feldman R, Weller A, Leckman FJ, Kuint J, Edelman IA. *J Child Psychol Psychiatry.* 1999 Sep;40(6):929-39.
9. Jubinville J, Newburn-Cook C, Hegadoren K, Lacaze-Masmonteil T. Symptoms of acute stress disorder in mothers of premature infants. *Adv Neonatal Care.* 2012 Aug;12(4):246-53. doi: 10.1097/ANC.0b013e31826090ac.
10. Martin, Elizabeth I et al. The neurobiology of anxiety disorders: brain imaging, genetics, and psychoneuroendocrinology. *Psychiatric clinics of North America* vol. 32,3 (2009): 549-75. PubMed PMID:19716990.
11. Massana G, Serra-Grabulosa JM, Salgado-Pineda P, Gasto C, Junque C, Massana J, Mercader JM, Gomez B, Tobena A, Salamero M. Amygdalar atrophy in panic disorder patients detected by volumetric magnetic resonance imaging. *Neuroimage* 2003 May;19(1): 80–90.
12. Matricardi S, Agostino R, Fedeli C, Montirosso R. Mothers re not fathers: differences between parents in the reduction of stress levels after a parental intervention in a NICU. *Acta Paediatr.* 2012; 102:8-14.
13. Melnyk BM, Alpert-Gillis L, Feinstein N et al. Improving cognitive development of low birth weight infants with the COPE program: a pilot study of the benefit of early NICU intervention with mothers. *Res Nurs Health.* 2001; 24:373-389. PubMed PMID: 11746067.
14. Melnyk BM, Feinstein N, Alpert-Gillis L et al. Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics.* 2006;20:35-41. PubMed PMID: 17043133

15. Mizrak B, Deniz AO, Acikgoz A. Anxiety levels of mothers with newborns in a Neonatal Intensive Care Unit in Turkey. *Pak J Med Sci.* 2015;31(5):1176-81. PubMed PMID:26649009
16. Nyström, K. and Axelsson, K. Mothers' Experience of Being Separated From Their Newborns. *Journal of Obstetric, Gynecologic, & Neonatal Nursing.* 2002 May-Jun;31: 275-282. PubMed PMID: 12033540.
17. Obeidat HM, Bond EA, Callister LC. The parental experience of having an infant in the newborn intensive care unit. *J Perinat Educ.* 2009;18(3):23-9. PubMed PMID: 20514124
18. Phillips SJ, Tooley GA. Improving child and family outcomes following complicated births requiring admission to neonatal intensive care units. *Sexual and Relationship Therapy.* 2005;20(4):431–442.
19. Seaton SE, Barker L, Draper ES, Abrams KR, Modi N, Manktelow BN, on behalf of the UK Neonatal Collaborative. Estimating neonatal length stay for babies born very preterm. *Arch Dis Child Fetal Neonatal Ed.* 2018 Mar 27. pii: fetalneonatal-2017-314405. doi: 10.1136/archdischild-2017-314405
20. Serge LS, McCabe JE, Chuffo-Siewert R, O'Hara MW. Depression and anxiety symptoms in mothers of newborns hospitalized on the neonatal intensive care unit. *Nurs Res.* 2014 Sep-Oct; 63(5):320-32. PubMed PMID: 25171558.
21. Turan T, Basbakkal Z, Özbek S. Effect of nursing interventions on stressors of parents of premature infants in neonatal intensive care unit. *J Clin Nurs.* 2008;17(21):2856-2866. doi: 10.1111/j.1365-2702.2008.02307
22. Wigert H, Johannson R, Berg M, Hellström AL. Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scandinavian Journal of Caring Sciences.* 2006 Mar;20(1):35-41. PubMed PMID 16489958.

II Books

23. Akhtar, S. (2014). *Sources of Suffering.* London: Routledge 2018.
24. Berzoff, J., Flanagan, L. M., Hertz, P. *Inside Out and Outside In: Psychodynamic Clinical Theory and Psychopathology in Contemporary Multicultural Contexts.* Rowman & Littlefield Publishers, 2011.
25. Elizabeth L. Auchincloss M.D. *The psychoanalytic Model of the Mind.* American Psychiatric Pub, 2015. Pg .271
26. Elzer Matthias, Alf Gerlach. *Psychoanalytic Psychotherapy: A Handbook EFPP Monograph Series.* Kernac Books, 2014.
27. McWilliams, N. *Psychoanalytic Diagnosis: Understanding Personality Structures in the Clinical Process.* 2nd edition. Guilford press 1994.
28. Rycroft, Charles. *Critical Dictionary of Psychoanalysis.* Second ed., Penguin, 1998. Pg.8
29. Seaward B.L. *Managing Stress.* Jones & Bartlett Publishers 2013. Chapter 2: Physiology of Stress.
30. Toth, M. and Zupan, B. (2007). Neurobiology of Anxiety. In *Handbook of Contemporary Neuropharmacology* (eds D. R. Sibley, M. Kuhar, I. Hanin and P. Skolnick). doi:10.1002/9780470101001.hcn023

III Electronic Information

31. Definition & Epidemiology – EFCNI. *EFCNI*, European Foundation for the Care of Newborn Infants, 2017, www.efcni.org/health-topics/keyfacts/definitionepidemiology/.
32. The Neonatal Intensive Care Unit (NICU). Stanford Children's Health - Lucile Packard Children's Hospital Stanford, Stanford Children's Health, www.stanfordchildrens.org/en/topic/default?id=the-neonatal-intensive-care-unit-nicu-90-P02389.

Pledge

I, Alisa Bobrova, pledge that this scientific thesis, titled “Distress and Anxiety in Mothers with Newborns in Neonatal Intensive Care Unit” was written by me independently. All other data, definitions and quotations used in my thesis have been given references. The text of this written work neither in its entirety, nor its parts has ever been submitted to another committee for presentation and it has never been published in its entirety.

Signature

Alisa Bobrova
Name Surname

Date: 12th November 2018