

# A Life in Purgatory: Being the Mother of a Bone Marrow Transplant Child

## Arafta Bir Yaşam: Kemik İliği Nakli Olan Bir Çocuğun Annesi Olmak

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### Abstract

Bone marrow transplantation is a therapy used for children who have certain diseases with high rates of morbidity and mortality as hematologic malignancies, immune deficiency and bone marrow failure. Bone marrow transplantation increase the chances of success in the treatment of this diseases and prolongs lifespan of children, it may also cause some systemic complications as well. During this rather difficult process, particularly for children, it is reported that among the family members, it is often the mother who is affected the most. Long-term attentive care creates a great burden for the mother. Moreover, concerns about whether transplantation will be successful or not, recurrence of the disease, loss of child, how life will continue after loss cause uncertainty, resulting in separation anxiety and existential anxiety for the mother. It is reported that mental illnesses such as depression, anxiety disorder and post traumatic stress disorder are common among those mothers whose children underwent bone marrow transplantations. In this process, which is traumatic for both the child and the mother, the role of the consultant liaison psychiatry (CLP) nurse together with the primary treatment team is important. Therefore, this review was written to explain the experiences, multidimensional problems of mothers whose children underwent bone marrow transplantation and to describe the role of the consultant liaison psychiatry nurse in this process.

**Keywords:** Bone marrow transplantation, child; mother, psychiatric nurse, consultation liaison psychiatry nursing

### Öz

Kemik iliği nakli çocuklarda başlıca hematolojik malignansi, immun yetmezlik ve kemik iliği yetmezliği gibi morbidite ve mortalite oranı oldukça yüksek hastalıklarda kullanılan bir tedavi yöntemidir. Kemik iliği nakli bu hastalıkların tedavisinde başarı şansını artırmasına ve yaşam süresini uzatmasına karşın, bazı sistemik komplikasyonları da beraberinde getirmektedir. Çocuk için oldukça zor olan bu süreçte en çok etkilenen aile bireyinin ise genellikle anne olduğu bildirilmektedir. Uzun süre özenli bakım verme annede bakım yükü oluşturmaktadır. Ayrıca nakilin başarılı olup olmayacağı, hastalığın tekrarlaması, çocuğu kaybetme, kayıptan sonra yaşamın nasıl devam edeceği gibi düşünceler annede belirsizliğe, ayrılık anksiyetesine ve varoluşsal kaygılara neden olmaktadır. Çocuğu kemik iliği nakli olan annelerde depresyon, anksiyete bozukluğu ve post travmatik stres bozukluğu gibi psikiyatrik bozuklukların oldukça sık görüldüğü bildirilmektedir. Hem çocuk hem de anne için travmatik olan bu süreçte primer tedavi ekibi ile birlikte Konsültasyon Liyezon Psikiyatrisi (KLP) hemşiresinin rolü önemlidir. Bu sebeple bu derleme, çocuğu kemik iliği nakli olmuş annelerin deneyimlerini, yaşadığı çok boyutlu sorunlarını açıklamak ve bu süreçte KLP hemşiresinin rolünü tanımlamak amacıyla yazılmıştır.

**Anahtar sözcükler:** Kemik iliği nakli, çocuk, anne, psikiyatri hemşiresi, konsültasyon liyezon psikiyatrisi hemşireliği

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**SINCE** it started to take its place in medicine in the 1960s, bone marrow transplantation has been used in children with diseases with high rates of morbidity and mortality as hematologic malignancies, immune deficiency, hemoglobinopathy, bone marrow failure (Önen 2014, Yeşilipek 2014). Bone marrow transplantation increases the chance of medical treatment success and extends life span of children, but it also brings some systemic complications in itself (Peykerli 2003, Koca and Akpek 2006, Packman et al. 2010, Tanzi 2011). Application of high-dose chemotherapy and immunosuppressives to child patient during the preparation regimen and bone marrow transplantation cause a number of physical complications such as mucositis, weight loss or gain, infection, nausea, vomiting, diarrhea, pain, pulmonary edema, hemorrhagic cystitis, etc. Also, graft versus host disease (GVHD), which occurs as an immunological reaction after allogenic bone marrow transplantation, is another important life-threatening physical complication (Manne et al. 2001, Koca and Akpek 2006, Tanzi 2011, Yılmaz et al. 2013, Yeşilipek 2014).

Such factors as physical complications, long-term dependence on others, social isolation due to the risk of infection, loneliness, the fear of recurrence of the disease, which may occur in the child following a bone marrow transplant, affect the child's mental health negatively. Some studies report that it is possible to observe psychiatric problems like generalized anxiety disorder, depression, hyperactivity and attention deficit, specific phobia, social phobia, enuresis nocturna, encopresis, post-traumatic stress disorder in children who had bone marrow transplantation (Packman et al. 2010, Taşkıran et al. 2016, Adanır et al. 2017).

Diagnosing the child with a life-threatening disease such as cancer and then performing a risky therapy as bone marrow transplantation is a traumatic experience both for the child and his family. It is reported that the most affected family member during the process of bone marrow transplantation of a child is usually the mother (Packman et al. 2010, Taşkıran et al. 2016, Baran 2018).

Most women identify themselves with their child along with maternity and begin to see the child as an extension of their own selves (Er 2006). Jacques Lacan, one of the post Freudian psychoanalysis theorists, associates this identification with the castration complex. According to him, the mother can overcome her castration complex by unconsciously accepting her child as her own phallus; that is, a part of herself (Tura 2005). Existentialism, on the other hand, relates a mother's identification with the child to fecundity and giving meaning to life. Fertility, which means fecundity and productivity, is an essential way of giving meaning to life. By giving birth, a mother strives at continuing her bloodline, or, her own existence. A mother may even see the child she brings into the world as "having something greater than her own self". Then, the mother feels highly responsible for protecting and ensuring the life-persistence of this great being, her child (Prinds et al. 2018, Korucu 2019). This increased responsibility may create a permeable border between the feelings of the mother and the child. This, on the other hand, could cause some mothers to perceive their children's experiences as their own experiences. For instance, such mothers may suffer from intensive stress in any medical intervention made on their child's body (Er 2006). In addition, such factors as the child's need for his/

her mother's love and affection during the process of bone marrow transplant, infection control and the cultural role of the mother cause the mother to undertake the care alone making her the most affected family member (Manne et al. 2001, Er 2006, Ersoy 2009, Yılmaz et al. 2013).

When the related literature is reviewed, it can be seen that the problems experienced by women whose children have bone marrow transplantation are generally approached from the aspect of psychological disorders (Manne et al. 2001, Nelson et al. 2003, Manne et al. 2004, Phipps et al. 2004, Vrijomoet-Wiersma et al. 2009, Barrera and Antenafu 2012, Virtue et al. 2014, Taşkıran et al. 2016). The number of studies focusing on the mothers' subjective experiences during the bone marrow transplant process of the child and conducting in depth interviews with mother is rather limited (Oppenheim et al. 2002, Forinder 2004, Matteo and Ceron 2015, Asadi et al. 2011). The present study aimed to review the problems that are/could be faced by the mothers of children who have bone marrow transplant and to touch the role of CLP nurses during this process. In addition, the writers of the present review have a research project conducted to lighten the care burden of mothers whose children have bone marrow transplant (Engin et al. 2019). In order to contribute to the literature, individual expressions of the participating mothers were included in the study after obtaining their written consent.

## **Problems faced by the mother during the child's bone marrow transplant process**

Diagnosis of a child with a serious disease like cancer usually causes the mother to experience hopelessness that can damage her belief in a secure world. Thus, the opportunity of bone marrow transplant as a treatment option comes as a great source of hope for the mother. However, it is quite difficult for parents to decide on bone marrow transplant, which can sometimes result in death and has significant side effects since bone marrow transplant represent a beginning only. The continuity of the child's life, which is the final goal of the treatment, cannot be fully foreseen by anyone (Matteo and Ceron 2015). In a study conducted by Forinder (2004), one parent defined bone marrow transplantation using the expression "A drowning man will catch a straw" (Forinder 2004). Briefly mother lives a "purgatory" life in the midst of concerns and thoughts about her child's healing (heaven) and losing her child (hell).

Bone transplant process of child is a very difficult experience for the his/her mother. Most of the time, the mother carries out the care of her child who undergo bone marrow transplantation alone (Manne et al. 2001, Er 2006, Ersoy 2009, Yılmaz et al. 2013). Caregiving is not a single form of help, but a multidimensional process involving physical-emotional-social assistance (Açar 2018). The mother meets child's several needs during the process of bone marrow transplantation ranging from the disease and hospital adaptation, mucositis and catheter care to infection control and personal care (Manne et al. 2001, Forinder 2004, Yılmaz et al. 2013). Mother's attentive care is not only limited to the hospital, but continues after discharge, as well because the child is at risk of infection after the transplantation,

especially within the first six months and may experience late complications (GVHD, etc.) (Yılmaz et al. 2013).

Infection is one of the most important reasons of death in children in bone marrow transplantation process. For this reason, the mother continues to give attentive care to her child after bone marrow transplantation (Yılmaz et al. 2013, Yeşilipek 2014). Yabroff and Kim (2009) reported that those who care for individuals with diseases such as lymphoma spend more than 10 hours a day only for care (Yabroff and Kim 2009). Considering that the individual being cared for is a child and that bone marrow transplantation is a process that requires special care, it is not wrong to say that the mother dedicates her entire life to care her bone marrow transplant child.

In addition to caring for the sick child during the bone marrow transplant process, the mother also tries to fulfill other responsibilities as caring for a donor sibling or other child (sometimes other children may be neglected), as well as maintaining the family, work and earning money. These heavy responsibilities eventually lead to deterioration of the mother's physical-psychological-social coherence and a decrease in her life satisfaction (Forinder 2004, Packman et al. 2010, Matteo and Ceron 2015, Baran 2018).

Among the most common symptoms and diseases in those who care for a person diagnosed with cancer include fatigue, insomnia, loss of appetite and weight (Stenberg et al. 2010), head, neck, shoulder problems, arteritis (Girgis et al. 2013), concentration disorder (Aranda and Hayman-White 2001), lower back and foot pain due to lifting heavy (Gribich et al. 2001) and severe symptoms. Although in literature there is no research in this context about the mothers whose children underwent bone marrow transplants, it is estimated that similar symptoms occur in mothers.

The mother goes an extremely emotionally challenging time period as well as physical stress during the process of the child's bone marrow transplant (Forinder 2004). For a mother, who tries to bring her own existence to eternity through her child, it is a great frustration when her child becomes ill (Yalom 2008). Moreover, concerns about whether transplantation will be successful or not, recurrence of the disease, loss of child, and in the case of a loss of her child, how life will continue cause uncertainty, separation anxiety and existential anxiety in the mother (Forinder 2004, Vrijomoet-Wiersma et al. 2009).

A mother whose child underwent a bone marrow transplantation remarks about her days in hospital; "Doctor and nurse, between the four walls, they always ask how the child is, which is the best way to follow, but as a mother, you also want to be asked after. You also look for someone to tell about and share your troubles. Everyone tells me "you're a mother and you should be strong", the first time when someone told me that it was a difficult situation and I could be weak at times, it felt nice. Of course, I don't think I can be weak from now on. It's another thing..." (Engin et al. 2019). In the study of Oppenheim et al. (2002), it was stated that it is not possible for a parents healthcare staff to understand them. Another mother shares her experience, stating: "I and my relatives are going through a very difficult time. For instance, we never get out of the patient's room and we have many concerns as the things we left behind, our family... I have a lot of weight on my shoulders,

and it's very distressing for my child not to show any recovery. I thought once my child was transplanted, she would be completely recovered... But life doesn't always go as planned. I'm going through a really bad time. When they said the transplantation didn't work, I felt terribly bad, cried for hours, and gave up on everything, I even thought about killing myself. I was in such a point that all hopes run out and the process after that scared me so much. I couldn't tell anyone what I was going through, even if I told them they didn't understand..." (Engin et al. 2019).

The above mentioned statements of mothers clearly show that mothers need psychological support during the bone marrow transplant process. The data in the literature also supports these statements. Many studies report that mothers whose children underwent bone marrow transplants are under intense stress and experience several mental illnesses such as anxiety, depression, post-traumatic stress disorder (Manne et al. 2001, Nelson et al. 2003, Manne et al. 2004, Phipps et al. 2004, Vrijomoet-Wiersma et al. 2009, Barrera and Antenafu 2012, Virtue et al. 2014, Taşkıran et al. 2016). In addition, factors such as the mother's being young, lacking social support, having low financial income and, if any, their previous mental illnesses increase the incidence of mental disorders (Manne et al. 2001, Nelson et al. 2003).

The mother's social life is also adversely affected during her child's bone marrow transplantation process. A mother, with her role as a caregiver, does not have any time for her own personal and social activities for a long time and has to leave her job or retire. This social isolation occurring over time makes the mother feel lonely. In order for the mother to cope with the feeling of loneliness, it is very important to receive support from her immediate environment and healthcare personnel (Forinder 2004). Because if they do not receive enough social support, the mother suffers more from depression and anxiety and thus experiences less social cohesion and life satisfaction (Nelson et al. 2003, Baran 2018). During the bone marrow transplant process of the child, the relationship between the spouses can also be damaged. Although some couples decide to break up, they continue to be married due to the child's illness, others get divorced (Forinder 2004, Çoban 2006). For example, a mother whose child had a bone marrow transplant said, "When I was looking after my child in the hospital, he cheated on me, I hate him..." (Engin et al. 2019)" expressing her anger towards her husband.

Another important problem experienced by mothers whose children have had bone marrow transplantation is the lack of necessary information about the disease and transplantation process. The results of a study carried out by Yılmaz et al. (2013) show that mothers whose children had bone marrow transplants have a high level of information requirements; especially about the procedures and process of the therapy including medications, side effects, diarrhoea, nausea, vomiting, fatigue, pain and skin care (Yılmaz et al. 2013). In the study conducted by Mayer et al. (2009), the vast majority of parents (81.5%) whose children underwent bone marrow transplants reported that they were using 'internet' as a source of information. For these reasons, it is very important that parents are informed by experts in their field about bone marrow transplantation (Mayer et al. 2009).

People are always more afraid of the things that they don't know and that they can't take under control. A mother whose child has a bone marrow transplant, said "Knowing how to take a better care of my child made me stronger" after the nurse informed her in detail about the transplantation and care process (Engin et al. 2019). In addition, parents may feel guilty from time to time that they decide to their child undergo bone marrow transplant. This is because the child sometimes feels pain, complications may develop and there is always a risk of death during the transplantation process (Forinder 2004). The mother can try to reduce her feeling of guilt by giving her child the best care in this case. For instance, the mother of a child who had bone marrow transplant expressed "Understanding what to do during and following the transplantation decreased my remorse" (Engin et al. 2019).

Among the above-listed multi-dimensional problems, it is perhaps the fact that the process is "uncertain" which worries the mother most and hurts her mentally. In the study carried out by Matteo and Ceron (2015), a mother whose child had bone marrow transplant described the process she went through saying "I live daily, monthly...I can't make any plans for the future..."(Matteo and Ceron 2015). Another mother in the same study defined the bone marrow transplantation process of her child as "It is like coming back from a cliff". In the study conducted by Zebrack et al. (2002), a mother whose child was receiving cancer treatment said "Cancer treatment is a bomb ready to explode, you never know when it will explode" (Zebrack et al. 2002). Uncertainty, which is rather difficult to cope with, causes the thoughts of incompetency and weakness through individual perceptions; feelings like anxiety, fear, anger, helplessness and guilt as well as such psychiatric conditions as depression and anxiety disorder (Öz 2001, Oppenheim et al. 2002, Asadi et al. 2011, Geçkin and Sahranç 2017).

Although mothers whose children have bone marrow transplant have psychiatric symptoms and disorders frequently, the number of interventional studies on mothers' problems is rather limited in the literature. Streisand et al. (2000) state that an intervention involving education, relaxation and communication skills is effective in reducing the stress experienced by parents whose children had bone marrow transplantation (Streisand et al. 2000). In the randomized controlled study conducted by Manne et al. (2016), it was reported that the intervention (informing, discussion feelings, problem solving, breathing exercises, imagination, progressive relaxation, social adaptation etc.) implemented with parents whose children had bone marrow transplant was effective in reducing the stress levels of the experimental group (Manne et al. 2016). Reviewing the national literature, it was seen that the number of studies aiming at determining the needs of caregivers of the individuals who had bone marrow transplantation is only limited (Aslan et al. 2006, Yılmaz et al. 2013) and no intervention was found to solve the existing problems.

## **Role of the CLP nurse during the bone marrow transplant process of the child**

a CLP nurse is responsible for the physical, mental and psychosocial care of individuals with physical complaints or a disease as well as their families. Coordination of healthcare services,

development of nurses and implementation of the scientific activities that would contribute to the field are among their other responsibilities. While fulfilling these responsibilities, a CLP nurse uses primarily clinical (consultation and liason), education, research and management roles (Kocaman 2005, Çam and Engin 2014).

A CLP nurse has a key role in supporting the mother during the child's bone marrow transplantation process. Her child's bone marrow transplant constitutes an important turning point in the mother's life. Most mothers go through a situational crisis in this period. Therefore, it would be beneficial that the CLP nurse makes a situational crisis evaluation for the child and the family. Some parents may use the denial defence mechanism to cope with their child's bone marrow transplant process. Some parents, on the other hand, cannot express their thoughts and feelings loudly even to themselves due to the feelings of guilt and anxiety. Parents who start treatment before fully accepting the process (Forinder 2004) can experience fear more deeply. Using their professional skills, CLP nurses must help mothers to share their feelings and thoughts, understand and accept the situation (Forinder 2004, Kocaman 2005, Çam and Engin 2014, Matteo and Ceron 2015).

A CLP nurse must always act honestly and have clear communication with the mother because parents may sometimes have ambivalent feelings for the health care team. In the study conducted by Oppenheim et al. (2002), a mother expressed her thoughts about the healthcare personnel as follows "They may kill my daughter or they may heal her." (Oppenheim et al. 2002). Moreover, some parents think that they are not sufficiently informed about bone marrow transplantation and its process by the concerning healthcare professionals (Asadi et al. 2011). This could cause parents to feel anger towards the healthcare team and feel themselves alone. Thus, a CLP nurse should act a bridge between the nurse and the mother. A CLP nurse must understand the thoughts and feelings of both sides. Nurses working at bone marrow transplant units may sometimes have difficulty understanding the thoughts and feelings of the patients' family. Nurses working at these units could show such symptoms as burnout, depersonalization, fatigue due to many factors like being face to face with death (especially because the one who dies is a child), long working hours, work related stress, heavy work load and they may develop mental disorders like anxiety and depression. Thus, psychoeducation and psychotherapy practices provided by the CLP nurse for the nurses working at bone marrow transplant units would help protect nurses' mental health and increase the quality of healthcare given to the child and the family (Kocaman 2005, Gallagher and Gormley 2009, Morrison and Morris 2017).

Another important responsibility of a CLP nurse is to offer psychoeducation to mothers whose child has bone marrow transplantation. Psychoeducation offered in line with requirements would raise the mother's awareness of her own thoughts and feelings, help determine the adaptive and maladaptive coping methods used, manage stress, anxiety and anger, notice strengths, increase the knowledge and self-confidence concerning the child's care, maintain relationships among healthy individuals and increase the quality of the care given to the child by the mother (Öz 2001, Zebrack et al. 2002, Forinder 2004, Kocaman 2005, Çam and Engin 2014, Manne et al. 2016, Matteo and Ceron 2015, Engin et al. 2019).

It is an important necessity that psychotherapeutic practices are offered by the CLP nurse to mothers whose child had bone marrow transplant. Most parents may feel deep mental pain thinking that they are losing their child as a result of the physical changes in the child during the bone marrow transplantation process (Oppenheim et al. 2002). The mother can be pulled to “now and here” through psychotherapeutic interventions. During the transplantation process, the mother’s mind is often engaged with worrying thoughts about the future. These worries may prevent the mother from realizing that her child is near her at that moment. A CLP nurse can make the mother stay in the present moment and help make new memories between the mother and the child despite the hospital environment. In addition, helping the mother spend time with her child by staying in the present moment could increase her psychological endurance and tolerance to uncertainty (Kars 2011).

A CLP nurse must help the mother to normalize the situation during the bone marrow transplantation process. The mother’s recognition that bone marrow transplantation is a common case experienced by many people would contribute to the process of normalization. The more the mother moves away from thinking that she is experiencing something extraordinary and normalize bone marrow transplant for the child, the better she would manage the acute crisis experienced (Forinder 2004). Moreover, taking the situation under control through normalization could make it possible to include bone marrow transplant into life history without causing trauma (Forinder 2004, Calhoun and Tedeschi 2006, Yalom 2008, Asadi et al. 2011).

In addition to all the above-mentioned interventions, CLP nurses can hold group therapy sessions bringing together families with similar experiences. This interaction could help the mother to normalize bone marrow transplant within her cognitive structure, understand the universality of pain and keep her hope alive. Some mothers whose children have bone marrow transplantation cling to their hope and see the transplant as the beginning of a new life (Oppenheim et al. 2002, Asadi et al. 2011). Some mothers may even experience post-traumatic growth. Despite the low number of studies in the literature, it is reported that some mothers get stronger, build closer interpersonal relationships and feel more grateful to life (Matteo and Ceron 2015, Forinder and Norberg 2014). Still some other mothers see bone marrow transplantation as an opportunity to understand the value of life and health (Asadi et al. 2011). It is considered that mutual sharing of these positive experiences and thoughts can help mothers give meaning to pain and accept it.

## Conclusion

The present review was written in order to explain/define the problems experienced by mothers whose children had bone marrow transplantation and the roles of the CLP nurse during this process. Many studies in the related literature clearly show that the mother faces emotional difficulties during her child’s bone marrow transplant process and need the care to be provided by the CLP nurse. There is a special need to train competent CLP nurses in this specific field both worldwide and in our country. It is thought that it would be highly beneficial to open postgraduate programmes in CLP nursing and organize special

psychoeducation activities, workshops and congresses for bone marrow transplant nursing in order to meet this need.

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**Authors Contributions:** The authors attest that they made an important scientific contribution to the study and have assisted with the drafting or revising of the manuscript.

**Peer-review:** Externally peer-reviewed.

**Conflict of Interest:** No conflict of interest was declared by the authors.

**Financial Disclosure:** The authors declared that this study has received no financial support.