Chapter 7

CAREGIVER BURDEN AND QUALITY OF LIFE OF PARENTS OF CHILDREN WITH HEMOPHILIA

Hamide Nur ÇEVİK ÖZDEMİR[1]

INTRODUCTION

According to the quick progress in the area of medicine and health technologies, the incidence of chronic diseases has raised with the continuation of the life expectancy (Can, 2010; Warner et al., 2014). Increasing chronic diseases in childhood cause many health problems (Abdel-Rahman et al., 2015). Chronic diseases can occur at any stage of human life and at any age. These diseases are health problems that do not heal completely, progress slowly and continuously, and increase the need for care by causing physical disabilities or permanent disability. Chronic diseases limit the life and environment of the individual and his/her family; makes individuals dependent on another person to meet their daily care needs. The increase in the demans of children and family members with chronic disease affects the quality of life (Can, 2010; İnci, 2006; Khair & Chaplin, 016) In this chapter, quality of life, caregiver burden and pediatric nurse's approach in life-threatening hemophilia in early childhood are discussed.

CAREGIVING

Caregiving is often grouped into formal and informal. The provision of health care and personal care services by health professionals (physician, nurse, dietitian, physiotherapist, patient caregiver, etc.) at the institution or at home is defined as formal care. Informal caregiving is helping the sick individual by family members in the institution or at home without the need for expertise, and meeting the needs of the sick individual (Berwig et al., 2017; Can, 2010). An informal (mother, father, grandmother etc.) caregiver is a individual who takes care of the patient's physical care without any compensation. Informal caregivers are also called primary caregivers. Family members, relatives and friends of the patient are included in this group (Berwig et al., 2017; Demirtepe & Bozo, 2009).

---

[1] Asst.Prof., Afyonkarahisar Health Science University, Faculty of Health Science, Department of Nursing, nur.ozdemir@afsu.edu.tr

Caregiving is considered an activity that has both benefits and burdens (Sullivan, 2004). The intimacy and love bond between caregivers and caregivers increases and a positive interaction is experienced. Care providers; they can also see caregiving as an increase in self-respect, conscientious relief, self-sacrifice, personal development and experience (Koch & Jones, 2018; Sullivan, 2004). However, the act of caregiving can cause many difficulties in addition to these positive features (İnci, 2006; Koch & Jones, 2018).

Caregiving has multidimensional effects on caregivers (Berwig et al., 2017). The act of caregiving may not always be carried out through volunteers or the most appropriate people to care. Most of the time, social roles and cultural characteristics are effective in taking caregivers' responsibility for caregiving. Sometimes, people's beliefs, values, sharing of roles in the family, cultural structure and value judgments of the society they belong to affect the perception of caregiving (Schulz & Sherwood, 2008).

The responsibility of care for the chronically ill individual in the family is predominantly carried out through one or two individuals. These individuals are usually spouses, mothers or fathers. It is shown in the literature that more likely to caregivers are women. Perception of gender, women's responsibility to do housework, women's more compassionate, sensitive, and caregiving skills are among the reasons why women take on the role of caregiver (Toledano-Toledano & Luna, 2020).

CAREGIVER BURDEN

The concept of family burden was first introduced to the literature by Grad and Sainsbury (1966). The burden has been defined as the cost and negative consequences to the family of mental patients. Since this date, the concept of burden has become a fact that has been commonly used in the area of health. The concept of load was first explained by Hoenig and Hamilton in 1966. They argued that care-related activities should be separated from care-related attitudes, feelings, and perceptions (Chou, 2000; Liu, Heffernan & Tan, 2020). For this reason, they divided the burden into two as subjective and objective burden.

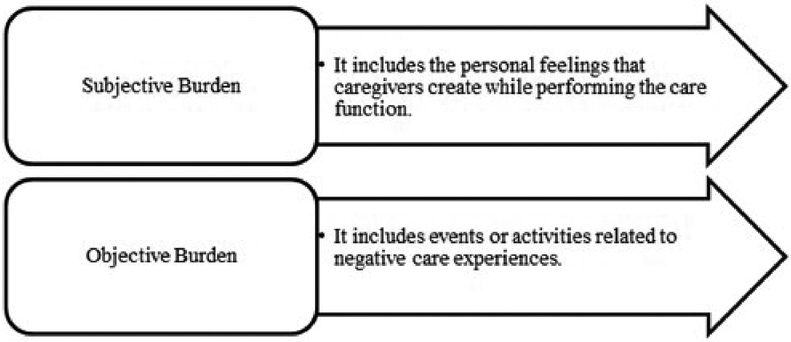


Figure 1. Caregiver Burden

Zarit, Reever and Bach-Peterson (1980) defined the concept of burden; He defined it as “a perceptual measure that affects the physical health, social life, emotional and financial status of caregivers”. They saw the burden as the result of a subjective and interpretive process. In this view, the burden of the caregiver is described as the caregiver’s subjective perception, personal reactions and the caregiver’s behavior (Chou, 2000; Zarit et al., 1980). Since the maintenance burden has a multidimensional structure, it is affected by alot of factors. The characteristics of the patient and caregiver, social factors, family relations and economic factors influence the care burden (Sullivan, 2004).

From the first moment the child is diagnosed with a chronic disease, the caregiver family member may encounter different sources of stress and difficulties at every stage of treatment and home care. While the caregivers experience feelings such as anxiety, fear, denial and uncertainty when the child is first diagnosed, they may experience intense depression, anxiety and anxiety when the home care process is started (Borjalilu et al., 2016; Nagelhout et al., 2018).

During the illness, the social life of the parent who cares for the child may be affected, and the general health status may deteriorate due to increased stress and depression (Borjalilu et al., 2016). In this context, being diagnosed with a chronic disease significantly affects both the child and the parents. Due to the needs arising from the care of their children, parents in the role of caregivers neglect their own health (Rubira et al., 2012) and state that they have to cope with many difficulties and need medical and psychological support (Nagelhout et al., 2018).

The increase in the demands of children with chronic diseases, especially in the home care process, increases the burden and responsibilities of the caregiver. Studies in the literature indicate that caregivers often experience health problems such as insomnia, depression, and fatigue. It also stated that parents who take care of the chronically sick kids need support in order to maintain family functions and family well-being (Koch & Jones, 2018; Nagelhout et al., 2018; Rubira et al., 2012). Also, because of the character of the chronic disease, frequent hospital check-ups and long hospitalizations interrupt the daily lives of caregivers and may lead to problems of social isolation and alienation (Koch & Jones, 2018).

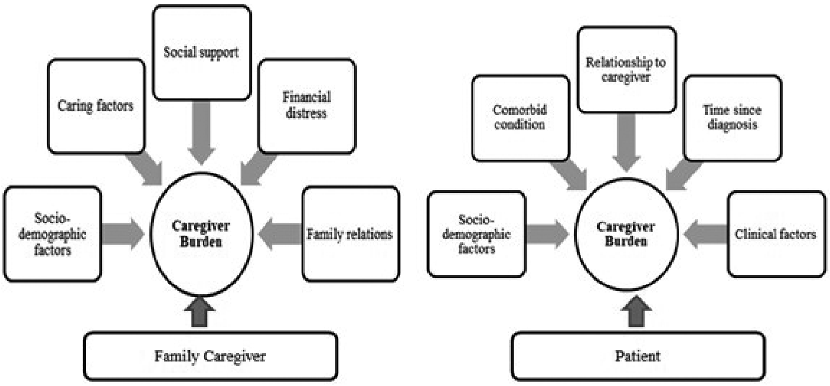


Figure 2. Factors affecting the caregiver burden of the family

Burden of Care in Hemophilia

Hemophilia is one of the chronic diseases that affects the child and the parent and causes radical changes in their lives. Hemophilia is an X-linked autosomal recessive disease characterized by a deficiency of coagulation factors. Hemophilia A is seen in one out of every 5000 male infants and Hemophilia B in one out of every 10000 male infants. While the incidence of hemophilia A is 1/10,000, the incidence of hemophilia B is 1/50,000. In the hereditary disease showing X-linked recessive inheritance, female individuals are carriers and male individuals show a clinical Picture (Green 2006; Kavaklı, 2011; Montgomery & Scott, 2008). The violence of the disease is classified as severe, moderate and mild. The clinical picture varies depending on the duration and frequency of bleeding (Wagner et al., 2020).

The presence of hemophilia is a difficult situation for both the child and their parents. Children with hemophilia may impose a psychosocial burden on their parents at all developmental stages. Being under constant medical supervision, bleeding, limitation of movement, problems arising from treatment affect the quality of life of these children. Caring for a child with hemophilia can impress the emotional and physical health of the caregiver, resulting in a burden of care (Shaw & Riley, 2008; von Mackensen, 2019). Parents may have to quit their job to take care of their children. They may need to go to hospital appointments regularly for treatment. This can be costly and time consuming for them (Myrin-Westesson et al., 2013; Shaw & Riley, 2008).

Caregiving is a multidimensional concept with physical, social and emotional dimensions. Families take an active role in the care of their child with hemophilia. For this reason, restrictions occur in the social lives of caregivers and the burden of care increases (Alahan et al., 2015; Sevgi, 2021). When the studies in the literature were examined, Von Mackensen et al. stated that hemophilia affects their lives in 66.2% of caregivers, and 57.6% of them impose some restrictions on the lives of children. In addition, 26.8% reported that hemophilia affected their economic life. DeKoven et al. in this cross-sectional study, it was stated that the heaviest burden for caregivers was the child's pain, followed by emotional stress and economic situation. Lindvall et al. found a higher burden of care in caregivers of children who developed factor inhibitors in their study. In addition, caregivers reported that the disease negatively affected their lives economically. Wharfe et al. in their study, it was stated that the burden of care was high. There is a need to evaluate the social support status of children with chronic diseases along with the quality of life and caregiver burden of their parents (Sevgi, 2021).

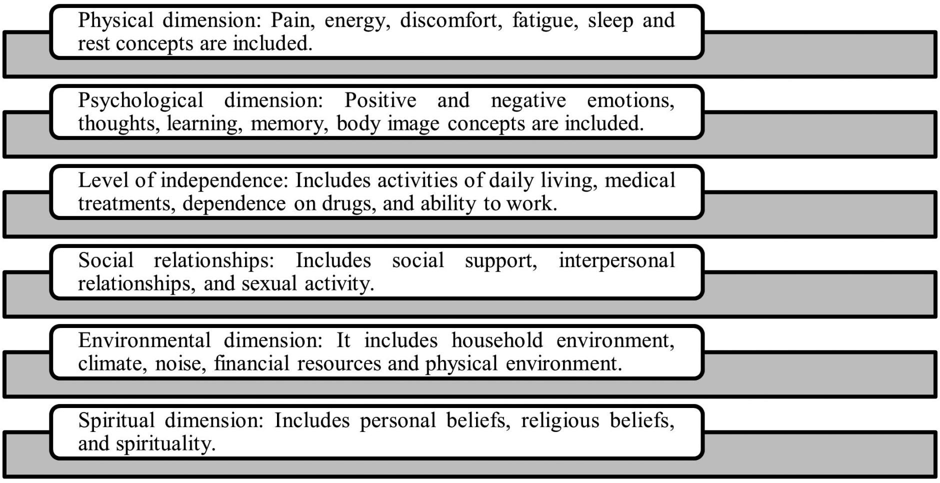
Hemophilia patients and their parents are affected emotionally, socially and financially throughout their life during the disease process. Parents have to deal with the feeling that the hemophilic child is always at risk of bleeding. For this reason, the pediatric nurse has an important role in coping with the repercussions of the hemophilia disease in the lives of the parents, who play the role of caregivers, as well as effectively maintaining the medical treatment of the child with hemophilia (Şenol, Seyfioğlu & Kavaklı, 2008).

Quality of Life

The World Health Organization (WHO) defines the quality of life: "Within the cultural structure and value system in which the individual lives; aims, expectations, criteria and perception of social relations (WHO 1995). Well-being differs from person to person. Physical, mental and social well-being can be perceived by people in different ways (Memik et al., 2007).

There are objective and subjective domains in the assessment of quality of life. People who are in the same situation objectively may subjectively perceive their quality of life differently. In the objective field; The individual's living conditions, social relations, environmental functionality and what he can do are evaluated. In the subjective area, the physical, emotional and social functionality of the individual is evaluated (Wallender et al., 2001). Quality of life is a multidimensional concept. The quality of life includes components such as the individual's cultural structure, values, perception of health, and well-being. Quality of life can be evaluated under physical and psychological dimensions, level of independence, social relations, environmental and spiritual factors. The relevant factors are presented in Figure 3 (İnceoğlu, 2019; Varni et al.. 2002)

To measure the quality of life of the personel and their relatives; It is important to state the quality of life of patients before and after treatment, and to appraise the effectiveness and side effects of medical interventions (Memik et al., 2007; Varni et al., 2002).



Physical dimension: Pain, energy, discomfort, fatigue, sleep and rest concepts are included.

Psychological dimension: Positive and negative emotions, thoughts, learning, memory, body image concepts are included.

Level of independence: Includes activities of daily living, medical treatments, dependence on drugs, and ability to work.

Social relationships: Includes social support, interpersonal relationships, and sexual activity.

Environmental dimension: It includes household environment, climate, noise, financial resources and physical environment.

Spiritual dimension: Includes personal beliefs, religious beliefs, and spirituality.

Figure 3. Factors related to quality of life

Quality of Life in Hemophilia

It is known that chronic diseases and their treatment affected directly the quality of life as they cause changes in the lifestyle of the individual and their families. Having a child with a chronic illness increases the burden of caregivers and reduces their quality of life (Wisniewski et al., 2013). The presence of inhibitor, pain, arthropathy and treatment complications in hemophilia can affect the patient and their relatives psychologically and economically. This affects not only the quality of life of patients with hemophilia, moreover the quality of life of their caregivers (DeKoven et al., 2014; Gringeri et al., 2004).

Hemophilia is a disease that affects the relationship of the diagnosed child with family members, friends and social environment. As in all children with chronic disease, quality of life and functionality are important in hemophilia patients. In addition to physical changes such as bleeding findings, hemarthrosis, and pain that occur in children with hemophilia, there are barries in coping with the illness and adapting to the disease process (Çavuşoğlu, 2019). Changes in attitudes towards the child, deterioration in social relations, environmental and psychological problems, and increased psychosocial and economic care burden negatively affect the quality of life in parents who have children with hemophilia (Kantarcıoğlu & Evim, 2018; Kodra et al.,2014). The burden of care and the factors affecting the quality of life of the families of children with hemophilia are shown in figure 4.

When a child is diagnosed with a chronic illness, family members grieve because of the child's condition and their own inner feelings. The family's reactions to chronic illness, stress levels and coping methods affect the quality of life of both the child and the family. For this reason, health professionals should carefully evaluate the impacts of the illness on the family and child (Sezer, 2019).

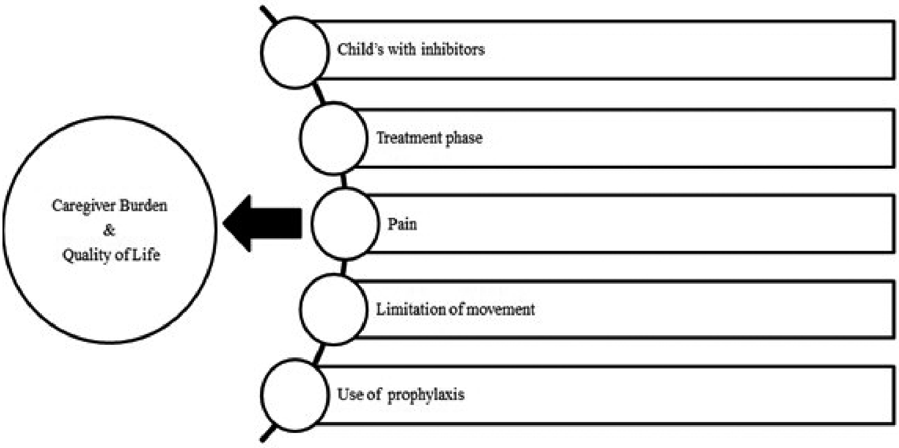


Figure 4. Factors Affecting Quality of Life and Caregiver Burden

The Role of the Pediatric Nurse in the Assessment of Care Burden and Quality of Life

The pediatric nurse plays a key role in providing care to the child with chronic disease and his family. It is the task of the pediatric nurse to define the necessity of the child and parents, to determine the care needs, to provide solutions to the difficulties related to care and to support the family. The pediatric nurse not only evaluates the symptoms of the child diagnosed with chronic disease; It deals with the child and his family in a wide scope with his roles as educator, counselor, advocate, collaborator and researcher (Çevik Özdemir & Şenol, 2019; Chaves et al., 2018; Şenol, 2018).

In line with the family-centered care philosophy of the pediatric nurse, the role of assessing the care burden, quality of life and family functions in caregivers of children with chronic diseases and strengthening intervention and coping strategies for these (Çevik Özdemir & Şenol, 2019). In this direction, the pediatric nurse evaluates the knowledge and attitudes of the child and his family about the disease, treatment and care during the care process of the child with chronic disease. Examines the objective and subjective outcomes of caregiving burden on family members. Defines in which areas the caregiver has difficulties, plans and presents evidence-based nursing interventions aimed at eliminating these difficulties and increasing the quality of life (Chaves et al., 2018).

In order to determine the strengths experienced by caregivers of children with chronic diseases, first of all, it is necessary to evaluate the burden of care and to describe the factors associated with the burden of care. In the caregiving process, apart from the burden perceived by the caregiver, quality of life and social relations should be evaluated together (Koch & Jones, 2018; Warner et al., 2014). In studies, scales should be used to present the quality of life and care burden concretely and to describe the components related the care burden (Rubira et al., 2012; Sullivan, 2004). The sensitivity of pediatric nurses to the family who takes care of the child is effective in revealing the difficulties experienced by the caregivers. Identifying and supporting the care burden of parents increases the quality of care. In parallel with this, it is thought that the quality of life and well-being of other members of the family will increase (Abdel-Rahman et al., 2015).

The pediatric nurse should ensure that the complications that may develop in the child with hemophilia are reduced, the self-care power and the socio-economic support of the parents are increased. In improving the quality of life of children and families, educating the family about home care, providing cooperation with the personnel providing home care services, have an important place in the effective implementation of hemophilia care (Alahan et al.,2015; Şenol, 2006; Yüzer et al., 2010)

So that decrease the care burden of families and develop the quality of life, pediatric nurses;

Evaluate the caregiver's relationship with his family,
Define family roles and functions,
Examine the objective and subjective outcomes of caregiving,
Identify the factors affecting the caregiver's quality of life,
Social support systems should be established for caregivers,
A training plan should be created and counseling should be provided in line with the needs of the parents,
It should reduce the complications that may develop in the child with hemophilia, increase the self-care power and socio-economic support of the parents.

CONCLUSIONS

The psychosocial and economic care burdens of parents who have children with hemophilia increase and their quality of life may be adversely affected. Pediatric nurses have important roles in increasing the quality of life of the child and her family, reducing the burden of care, and planning trainings about home care. The sensitivity of pediatric nurses to the parent who takes care of the child is effective in revealing the difficulties experienced by the caregivers. It is necessary to determine the care burden and quality of life of parents and to apply nursing interventions to reduce care burdens to increase the quality of care.

REFERENCES

Abdel-Rahman, R. A., Ismail, G. M., Sayed, H. A., Sharaa, H. M. (2015). Stressors and coping strategies among family caregivers having children with lymphoma at children's cancer hospital Egypt. *Med. J. Cairo Univ,* 83 (1), (s. 35-43).

Alahan NA, Aylaz R, Yetiş G. (2015). Kronik Hastalığı olan çocuğa sahip ebeveynlerin bakım verme yükü. İnönü Üniversitesi Sağlık Bilimleri Dergisi, 4 (2): 1-5.

Berwig, M., Dichter, M.N., Albers, B., Wermke, K., Trutschel, D., Petersen, S.S., Halek, M. (2017). Feasibility and effectiveness of a telephone-based social support ıntervention for ınformal caregivers of people with dementia: study protocol of the Talking Time Project. *BMC Health Services Research*, 17, (s. 280).

Borjalilu, S., Shahidi, S., Mazaheri, M. A., Emami, A. H. (2016). Spiritual care training for mothers of children with cancer: Effects on quality of care and mental health of caregivers. *Asian Pac J Cancer Prev*, 17 (2), (s. 545-552).

Can, T. (2010). BAKAS caregiving outcomes scale'in (BAKAS bakım verme etki ölçeği) Türkçe'ye uyarlanması, geçerlilik ve güvenirliği (Yayınlanmamış doktora tezi). Pamukkale Üniversitesi Sağlık Bilimleri Enstitüsü, Denizli.

Çavuşoğlu H. (2019). Çocuk Sağlığı Hemşireliği, 13. Baskı. Ankara, Sistem Ofset Basımevi, 113-27.

Çevik Özdemir, H. N., & Şenol, S. (2019). Bakım yükü değerlendirme ölçeklerine sistematik bir bakış. *İzmir Katip Çelebi Üniversitesi Sağlık Bilimleri Fakültesi Dergisi*, *4*(2), 61-68.

Chaves, M. O., Ribeiro, G. P., Amorim, K. A. (2018). The role of the nurse in caring for the child with cancer: integration review. *Hospital & Palliative Medicine International Journal*, 2 (4), (s. 225-229).

Chou, K. R. (2000). Caregiver burden: a concept analysis. *Journal of pediatric nursing*, *15*(6), 398-407.

DeKoven M, Karkare S, Lee WC, Kelley LA, Cooper DL, Pham H, Powers J, Wisniewski T. (2014). Impact of haemophilia with inhibitors on caregiver burden in the United States. Haemophilia, 20 (6): 822-30.

Demirtepe, D., Bozo, Ö. (2009). Bakıcı iyilik ölçeği'nin uyarlama güvenirlik ve geçerlik çalışması. *Türk Psikoloji Yayınları*, 12 (23), (s. 28-37).

Green D. (2006). The management of acquired haemophilia. Haemophilia. 12:32-36.

Gringeri A, von Mackensen S, Auerswald G, et al. (2004). Health status and health-related quality of life of children with haemophilia form six West European countries. *Haemophilia*, 10(Suppl 1): 26- 33.

İnceoğlu, Ş.(2019). *Kanserli çocuğu olan annelerin bakım verme yükü ve yaşam kalitesi* (Master's thesis, Lisansüstü Eğitim Enstitüsü).

İnci, F., Erdem, M. (2008). Bakım verme yükü ölçeği'nin Türkçe'ye uyarlanması geçerlilik ve güvenilirliği. *Atatürk Üniversitesi Hemşirelik Yüksek Okulu Dergisi*, 11 (4), (s. 85-95).

Kantarcıoğlu AÇ, Evim MS. (2018). Bursa'da pediatrik talasemi, hemofili ve lösemili olgu annelerinin aşırı koruyucu ebeveyn tutumları ve duygu durumlarının değerlendirilmesi. Güncel Pediatri, 16 (3): 37-50.

Kavaklı K. (2011). Hemofililer. İçinde: Anak SS, Aydoğan G, Çetin M, İrken G, Kemahlı S, Öztürk G, Yeşilipek MA editörler. Pediatrik Hematoloji, 1 nci baskı, İstanbul, İstanbul Tıp Kitabevi, 479-494.

Khair, K., & Chaplin, S. (2016). The impact on parents of having a child with haemophilia. *The Journal of Haemophilia Practice*, *3*(2), 4-14.

Koch, K.D., Jones, B.L. (2018). Supporting parent caregivers of children with life-limiting illness. *Children*, 5, (s. 85).

Kodra Y, Cavazza M, Schieppati A, Santis MD, Armeni P, Arcieri R, Calizzani G, Fattore G, Manzoli L, Mantovani L, Taruscio D. (2014). The social burden and quality of life of patients with haemophilia in Italy. Blood Transfus, 12 (3): 567-75.

Lindvall K, Von Mackensen S, Elmstahl S, Khair K, Stain AM, Ljung R, Berntorp E. Increased burden on caregivers of having a child with haemophilia complicated by inhibitors. Pediatr Blood Cancer 2014, 61 (4): 706-11.

Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International journal of nursing sciences*, *7*(4), 438-445.

Memik, N. Ç., Ağaoğlu, B., Coşkun, A., Üneri, Ö. Ş., & Karakaya, I. (2007). Çocuklar için yaşam kalitesi ölçeğinin 13-18 yaş ergen formunun geçerlik ve güvenilirliği. *Türk Psikiyatri Dergisi*, *18*(4), 353-363.

Montgomery RR, Scott JP. (2008). Hemorajik ve trombotik hastalıklar. İçinde: Behrman RE, Kliegman RM, Jenson HB, eds. (Çeviri ed. Akçay T.) Nelson Pediatri, Cilt 3, Ünite 7, Bölüm 468. Nobel Tıp Kitabevleri,.

Myrin-Westesson L, Baghaei F, Friberg F. (2013). The experience of being a female carrier of haemophilia and the mother of a haemophilic child. *Haemophilia*, **19**(2): 219- 224.

Nagelhout, E.S., Linder, L.A., Austin, T., Parsons, B.G., Scott, B., Gardner, E., Spraker- Perlman, H., Verma, A., Fluchel, M.N., Wu, Y.P. (2018). Social media use among parents and caregivers of children with cancer. *Journal of Pediatric Oncology Nursing*, 35 (6), (s. 339-405).

Rubira, EA., Marcon, S.R., Belasco, AG., Gaiva, M.A., Espinosa, MM. (2012). Burden and quality of life of caregivers of children and adolescents with chemotherapy treatment for cancer. *Acta Pau Enferm*, 25 (4), (s. 567-73).

Schulz, R., Sherwood, PR. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, 108(9), (s. 23-27).

Sevgi, T. (2021). Hemofilili çocuğa sahip ebeveynlerin bakım yükünün algılanan sosyal destek ve yaşam kalitelerine etkisinin incelenmesi(Yayınlanmamış doktora tezi). İnönü Üniversitesi Sağlık Bilimleri Enstitüsü, Malatya.

Şenol S, Seyfioğlu U, Kavaklı K.(2008). Hemofili hastalarına bakım verenlerin umutsuzluk ve depresyon düzeylerinin incelenmesi. Ege Pediatri Bülteni, 15(3): s. 187- 196. 11.

Şenol S. (2006). Hemofili hastalarında kapsamlı bakım ve hemşirelik rolü. Türkiye Klinikleri J. Int. Med. Sci. 2(2).

Şenol S. (2016). Hemofili tanılı çocukta tedavinin uygulanması ve bakım ilkeleri. Turkiye Klinikleri J Pediatr Nurs-Special Topics, 2(2):8-14.

Şenol, S. (2018). Tarih boyunca pediatri hemşiresinin rol ve işlevleri. *Türkiye Klinikleri J Pediatr Nurs-Special Topics*, 4(1), (s. 1-7).

Sezer, T. A. (2019). Kronik hastalığa sahip çocuk-ergen ve ebeveynlerinin yaşam kalitesi algıları. *Sürekli Tıp Eğitimi Dergisi*, *28*(2), 127-136.

Shaw D, Riley GA. (2008). The impact on parents of developments in the care of children with bleeding disorders. *Haemophilia*, 14: 65- 67.

Sullivan, M. T. (2004). Caregiver strain index. *Dermatol Nurs*, 16(4), (s. 385-386).

Toledano-Toledano, F., & Luna, D. (2020). The psychosocial profile of family caregivers of children with chronic diseases: A cross-sectional study. *BioPsychoSocial medicine*, *14*(1), 1-9.

Varni, J., Burnwinkle, T. M., Katz, E. R., Kathy, M., ve Dickinson, P. (2002). The PedsQL in Pediatric Cancer. American Cancer Society.

von Mackensen, S., Myrin Westesson, L., Kavakli, K., Klukowska, A., Escuriola, C., Uitslager, N., ... & Khair, K. (2019). The impact of psychosocial determinants on caregivers' burden of children with haemophilia (results of the BBC study). *Haemophilia*, *25*(3), 424-432.

Wagner B., Krüger S., Hilberg T., Ay C., Hasenoehrl T., Huber D. F. X, Crevenna R. (2020). The effect of resistance exercise on strength and safety outcome for people with haemophilia: A systematic review. Haemophilia. 26(2):200-215.

Wallander JL, Schmitt M, Koot HM (2001) Quality of life measurement in children and adolescents: issues, instruments and applications. J Clin Psychol, 57:571-585.

Warner, B. E. L., Kirchhoff, A. C., Nam, G. E., Fluchel. M. (2014). Financial burden of pediatric cancer for patients and their families. *Journal of Oncology Practice*, 11(1), (s. 12-18).

Wharfe G, Buchner-Daley, L, Gibson T, Hilliard P, Usuba K, Abad A, BomaFischer L, Bouskill V, Floros G et al. (2018). The Jamaican haemophilia registry: Describing the burden of disease. Haemophilia, 24 (4): 179-86.

WhoQol Group. (1995). The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social science & medicine*, *41*(10), 1403-1409.

Wisniewski T, Petrilla A, Holot N. et al. (2013). Health-related quality of life in haemophilia patients with inhibitors and their caregivers. *Haemophilia*, 19: 287– 293.

Yüzer S, Yiğit R, Taşdelen B. (2010).Çocuğu hastanede yatan annelerin aldığı sosyal destek ile depresyon düzeyleri arasındaki ilişki. Anadolu Hemşirelik ve Sağlık Bilimleri Dergisi, 9 (4): 54-62.

Zarit, S. H., Reever, K. E., Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20, (s. 649-655).