



Evaluation of quality of life of healthy siblings of children with chronic disease

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Abstract

The quality of life determination of children with chronic disease is closely related to treatment success. Quality of life assessment studies revealed that it was not limited to the individual, the quality of life of the family members also had to be assessed. Along with the child being diagnosed with chronic illness, some changes occur in the family structure, and in family roles. Quality of life assessment studies in healthy siblings generally indicate a global influence. These children live in different senses such as closure, aggression, depression, anxiety, guilt, and isolation. Psychosocial impact (short or long-term) of healthy siblings have been associated with disease type, severity, disease duration, age, sex, and ability to cope. Further comprehensive studies among healthy siblings of children with chronic disease about quality of life are needed. Building support groups (especially family support groups) to express feelings and thoughts freely for healthy siblings can positively affect the well-being and self-esteem of the child.

Keywords: Chronic disease, healthy sibling, quality of life

Introduction

In the light of the advances obtained in the diagnosis and management of many pediatric diseases that could result in mortality in the past, children can live longer and reach adult ages. In the last century, it has been shown that a change from infectious diseases to chronic diseases has occurred in the morbidities that are observed most commonly in children and young adults. The term 'chronic disease' encompasses congenital and acquired diseases that inhibit the physical and mental development (1). Chronic disease is a condition in which a morbidity or weakness spreads over a long time period or recurs and stability is affected negatively, leading to social, physical, emotional, and professional limitations (1). Although chronic disease was described as "morbidity which shows very little variance or pro-

gresses slowly lasting for six months or longer" in the 1990s, it has been described as "conditions which last for at least three months or which do not have a probability of recovery" since 2007 (2). It is thought that the frequencies of chronic diseases including mainly diabetes, cancer, and asthma are increased worldwide and chronic diseases affect 13-27% of the community (3). In a portion of chronic diseases, "disability" and "physical limitations" may also accompany morbidity. The World Health Organization (WHO) defines disability as "any restriction or limitation of ability to perform an activity in the manner or within the range considered normal for a human being." Disability is a mental or physical limitation or weakness that restricts daily activities including learning, movement, vision, sensory functions, and breathing for longer than six months (4). In children, chronic diseases are classified as mild (limitations

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in activity are absent), moderate (limitations in some activities are present) and severe (frequently disturbing together with limitations in activities) according to their impact on physical status (5).

Clinical and Research Effects

Definition and assessment of quality of life in children

The WHO has defined 'health' as absence of morbidity and "a state of complete physical, mental and social well-being." Though quality of life is a multi-dimensional phenomenon affected by different factors, it is the way individuals perceive their states within the whole of the culture in which they live and their value judgements in relation to their targets, expectations, standards, and interests considering the WHO's definition. Quality of life is affected by an individual's physical health, psychological state, degree of independence, social relations, beliefs, and environmental characteristics (6). The main objective of specifying quality of life is to determine how satisfied individuals are in terms of their own physical, mental, and social functions, and to what extent absence or presence of the characteristics they own in relation to these aspects of life disturb them.

In recent years, "quality of life" has been considered an important determinant in the follow-up and management of chronic diseases in children and adults. Specification of quality of life in the diagnostic and therapeutic stages in children with chronic disease is also closely related to treatment success and prognosis. Studies related to the assessment of quality of life have not been limited to individuals with chronic disease and revealed that family members should also be assessed. The concept of "family quality of life" emerged primarily and sibling studies were also conducted in subsequent years (7-12).

Various quality of life scales have been developed for the standardization and comparison of quality of life. These scales enable the assessment of psychosocial well-being and general life satisfaction and examination of social status, as well as the assessment of a healthy or sick individual's physical status. Considering the differences in health and sickness states between adults and children, new scales were needed to be developed to assess quality of life in children. Initially, questionnaires completed by parents were used in quality of life scales and subsequently, scales that assessed the responses of sick and healthy children who could express themselves

were developed. The most commonly used quality of life scale was developed by Varni et al. (13) at the end of the 1990s. It was shown that this scale could be used in healthy children, patients, and adolescents in populations in schools and hospitals. The quality of life scale was expanded for different age groups in the form of questionnaires to be completed by children themselves and/or parents and its validity and reliability studies in many languages have been conducted.

The effects of children with chronic disease on family structure

Making a diagnosis of chronic disease in a child is not a condition that is solely related to the child. Long-term and sometimes life-long care may be needed in the case of chronic disease in childhood and adolescence. The lives of all family members are shaped around this diagnosis and this leads to differentiation in their life styles. Families of children with life-threatening chronic disease (genetic, metabolic or neurologic) may experience significant difficulties (14-16). These families are obliged to enter a route that they do not know beforehand and to live with great uncertainty. Families' futures are shaped depending upon their children and their expectations for the future begin to diminish or may change with a child's chronic disease. All family members including mainly the parents spare significant time and resources in order to take care of the sick child (14). Prolongation of the life of the child with a chronic disease, increased requirement for health care, and need for short-term or long-term hospitalizations during acute attacks lead to an increase in the anxiety and distress experienced by the family. The continuing requirement for health care and changes in health status may affect the family's functionality to a great extent. Families may maintain their values and objectives by readjusting the intrafamilial roles and activities, but these changes in lifestyle may lead to negative effects on the psychosocial health of the healthy siblings and family members (17).

It has been reported that the presence of a sick child in a family improves togetherness of the family (7, 18, 19). Family members become closer to each other, withdraw from social life, and may become stronger against various experiences they have. The family may attain a continuously protective and safe position. Sometimes, these close relations may cause excessively protective behavior and lead to separations between family members (7, 18, 20, 21). Therefore, chronic diseases are related to transformation of the

entire family and individual family members. This transformation may be manifested in different ways. The father and siblings may function as the mother at home (alone or together) because the mother stays with the sick child during hospitalizations (19). New duties and responsibilities for family members at home or in hospital may lead to limitations in their lives and this picture frequently results in stress. Relatives (e.g. grandparents), friends, and neighbors help as necessary, but they cannot establish a responsibility relation as a nuclear family member (21). The picture of stress experienced in families may also cause the sick child to feel responsible. Another important problem that negatively affects togetherness in coping with the chronic disease is financial difficulties experienced by the family, and this may affect the quality of life of all family members.

Evaluation of healthy siblings of children with chronic disease

Fraternity is the most intensive relation between individuals, and is a condition that markedly affects personality development and determines identity in children and adolescents, normally lasting for a lifetime (9). Having a sibling with chronic disease constitutes a risk for psychological health and well-being in children. It has been identified that chronic disease or a status of disability affects healthy siblings, renders them more susceptible to mental diseases and weaker psychosocial functions, and these effects also continue in adulthood (21-25). Many problems including anxiety, depression, symptoms of posttraumatic stress, lower quality of life values, and/or peer problems may be observed in these children (7, 11, 23, 26). It has been shown that healthy siblings are affected more prominently in terms of psychological functions, especially in cases where chronic disease is severe and life-threatening (26). In studies conducted with healthy siblings, it was shown that these children experienced different emotions including withdrawal, aggression, depression, anxiety, guilt, confusion, and isolation. These children may overreact to changes in family life, experience separation anxiety, and think that they are outside the family order. As loneliness and concerns related to personal health status increase, the risk of low self-esteem, poor self-concept, and poor academic performance increases. As a result, families may fail to satisfy the needs of the other siblings because they mostly focus on the child who is sick (27). Healthy siblings may potentially become forgotten, disregarded, and neglected children. In a study conducted with siblings of children with cancer, it was

shown that healthy siblings experienced stress “similar to the stress experienced by the sick child” (27).

Children and adolescents who grow up with a sibling who has a chronic disease become more sensual and sensitive with personality characteristics expressed in terms including patience, compassion, and empathy, and probably become more easygoing, more open to communication, and socially more competent (7, 18, 19, 20, 26). Healthy children try to meet their own needs while helping and supporting their sick siblings and experience conflicts (19-20).

Children who have a sibling with a chronic disease may also experience significant difficulties in schools. This is identified as “school problems” or “decreased academic performance” (7, 18). Van Riper (18) defined this condition as “school phobia.” According to Alferder et al. (7), these children feel a desire to stay with their sick siblings instead of going to school. Alderfer et al. (7) showed a reduction in attention, memory, and performance capacity in sibling studies.

Factors that impact on quality of life in healthy siblings of children with chronic disease

The reactions and influences of healthy siblings of children with chronic disease may show variance between children (23, 28, 29). Studies evaluating quality of life in healthy siblings of children with chronic disease generally show that there is complete influence (23). In the study conducted by Wolfe et al. (30), it was shown that siblings of children with mental disease experienced mostly psychosocial stress in adulthood and their lives became upside down. In contrast, there are also studies showing that siblings of children with chronic disease with disability have better relationships and increased empathy (31). Factors that affect different results in psychosocial influences have been identified as the type and severity of chronic disease, the time passed since the time of diagnosis, the age and sex of the healthy sibling, and the ability of the healthy sibling to cope (17).

The type of chronic disease is among the main determinants that influence quality of life in healthy siblings of children with chronic disease. In some studies, healthy siblings of children with different chronic diseases were evaluated in a mixed manner, whereas other studies evaluated healthy siblings of children who had a single chronic disease group (28, 32). Assessments performed by collecting chronic diseases together are frequently

based on specifying the general effects of chronic diseases on family life and standard recommendations, rather than on the specific effects and outcomes of the chronic disease. In special approaches for a morbidity, it becomes possible to see the effects of chronic diseases on family life and the differences between various chronic diseases. Fisman et al. (33) found that parents defined more behavioral problems in healthy siblings of children with pervasive developmental disorder compared with the normal population. Similarly, Giallo and Gavidia-Payne (34) found that the parents of these children reported more frequent behavioral problems (especially emotional and social problems) compared with normal. This impact is greater in children than in adolescents. In another study conducted over a period of longer than three years, it was shown that adaptation problems occurred more commonly in siblings of children with pervasive developmental disorder (35). In a meta-analysis that included siblings of children who had various chronic diseases including cancer and diabetes, it was observed that the siblings had greater anxiety and depression, lower peer activity, lower cognitive developmental scores, and poorer functional outcomes (23).

Childhood cancers severely affect the whole family including the siblings of the child. During the process of active chemotherapy, healthy siblings may experience social and emotional influences because of their sick sibling. They frequently experience problems related to school attendance. In childhood cancers, psychosocial effects on healthy siblings continue for a long period after cancer treatment is completed, and affect quality of life, even if the child with cancer survives (36-38). In some studies, no difference was found between patients who had childhood cancer and their healthy siblings in terms of distress, guilt, and psychosomatic symptoms in behavioral, educational, and social areas (7, 27, 29). In recent years, it has been thought that the definition of cure of disease in children with cancer should encompass all family members. It is not difficult to understand why siblings of children with cancer experience emotional and social problems. At least one parent is needed to stay with the sick child in hospital or at home. There is increased parental distress because of physical and emotional inaccessibility. Changes in family life and in the roles of family members may disrupt the siblings' daily functions and some siblings may undertake more housework and responsibilities. These changes may limit post-school and other social activities. In addition, healthy siblings worry that their sibling will

die and experience difficulties when they witness the physical changes occurring in the sick sibling. Siblings of children with cancer experience emotional distress and some behavioral problems, but these signs are not generally at a clinical level. Positive effects of cancer experience including increased maturity, responsibility, independence and empathy have been reported (39). Healthy children of these families experience problems in social communication with relatives and friends because of their parents' decreased affection and communication. In addition, they become isolated because of limitations in resting, playing, and having fun, and have contact with friends less often. On the other hand, these children face fear, anxiety, distress, despair, nervousness, and guilt.

It has been shown that the severity, as well as the type of morbidity may have influences on quality of life of healthy siblings. Among children with congenital muscular dystrophy, a difference between the psychological findings in healthy siblings was found between those who needed and did not need wheelchair (40). In this study, it was shown that increased severity of morbidity increased the psychological influence in healthy siblings because use of wheelchair was an indicator of advanced stage morbidity or progression of morbidity. It has also been shown that intensive diagnosis, follow-up and treatment, and need for frequent interventions in the child with chronic disease cause the negative effects on quality of life of healthy siblings to be more prominent (22). In cases where the morbidity needs closer follow-up and invasive interventions including cancer and cystic fibrosis, healthy siblings are affected more negatively compared with morbidities for which only medical treatment is needed and interventions occur less frequently. However, it has also been shown that psychosocial influences are similar in healthy siblings of children with chronic disease with a high risk of mortality (AIDS, cancer, cystic fibrosis, sickle cell anemia) and in healthy siblings of children with chronic disease with a low risk of mortality (diabetes, rheumatic diseases, gastrointestinal diseases, asthma). Therefore, there is no clear consensus on the impact of the severity of disease or poor prognosis on the quality of life in healthy siblings (23).

It is also thought that the time period since the time of diagnosis may have an influence on the quality of life in healthy siblings, in addition to the severity and prognosis of the chronic disease (7). It was shown that healthy siblings of children with cancer were influenced to a

great extent in the first month after the diagnosis was made and the impact decreased six months after the diagnosis (12). Although the time period since diagnosis progressed positively in healthy siblings of children with cancer, it was reported that this time period had no effect on the changes in quality of life in healthy siblings in chronic diseases including epilepsy or diabetes (41). In some studies, however, it was shown that the influences decreased as the disease age advanced, in healthy siblings of children with epilepsy and diabetes (42-43). Further studies are needed because the time period since diagnosis shows differences between disease types.

It is thought that the sex of healthy siblings of children with chronic disease may also have influences on quality of life, and the influences of chronic diseases on boys and girls and their reactions may be different (7, 12, 28). Healthy brothers mostly have externalization problems including aggression and hyperactivity, whereas healthy sisters define internalization problems including anxiety, depression, and lonesomeness (12). This difference arises from sex differences observed in development of psychopathologies rather than a response to chronic diseases; boys generally show their reactions with externalization, and girls show their reactions through internalization (44). Some studies suggest that sex difference has no influence on the quality scores other than psychopathological symptoms (empathy, emotional symptoms, attachment problems) (45). It is thought that internalization signs observed in healthy sisters are related to taking on the responsibilities including helping for housework, caring for sick siblings, and taking on the role of the parents (23, 28, 40). Taking on cleaning and cooking at home when parents are in hospital results in becoming an early 'parent' for the sister who has not yet become an adult physically and culturally. It has been shown that taking on the responsibility of a parent early can lead to depression and anxiety in such girls (46).

Age been shown as another factor that influences quality of life of the healthy siblings of children with chronic disease. Studies related to the age of healthy siblings generally investigate the relationship with psychopathological symptoms (47). Healthy adolescent siblings who are older than the child with cancer may experience anxiety, insecurity, lonesomeness, traumatic stress, and emotional influence to a greater extent compared with younger siblings (7, 12). Healthy siblings who are younger than the sick child mostly show exter-

nalization findings, including aggression and hyperactivity. Changes related to the age of the healthy sibling have been found to be related to the disease type and the degree of responsibility of the healthy sibling at home (taking on the responsibilities including cleaning of the house, caring for other siblings, and cooking as the child's age gets older) rather than the child's age (17). Parent's taking care of the sick child in hospital or at home to a greater extent may cause younger children to feel ignored and they may show behavioral changes to attract their parents' interest (48). Adaptation responses to the family order, which is disrupted because of children with chronic disease, may also show differences between older and younger children. It is difficult to differentiate if the differences in these responses occur as a reaction to the chronic disease or as a result of internalization or externalization arising from the healthy child's age (44).

Psychosocial, psychopathological, and long-term effects in healthy siblings of children with chronic disease

Increased risks in terms of psychopathological conditions have been shown in quality of life studies conducted with healthy siblings of children with severe chronic disease. The majority of studies showed that growing up with a sibling who had a chronic disease resulted in emotional experiences to a great extent and could influence quality of life. These emotions of siblings may be in the form of internalization or externalization (23-25, 34, 49). Healthy siblings frequently become introverted and quiet. These emotional experiences may be related to drawing less interest from parents, other family members and friends, because the focus is the sick child. The significant decrease in accessibility to parents markedly influences healthy siblings (7, 18, 19, 20, 26, 27). As a result, they may feel themselves alone, insignificant, ignored, left out, neglected, and rejected (7, 11, 18-20). All these influences may result in emotional deprivation (18-20). In the future, these intensive emotions may transform to sadness, grief, and anger if the affected family member dies (7, 11, 18-20, 23). If the disease causes a defect related to appearance, symptoms related to the feeling of shame may also emerge in the healthy sibling (20). Some investigators reported that healthy siblings had vulnerability associated with a feeling that they had faults and responsibility related to the cause of their sibling's disease (7, 19, 20).

In siblings of children and adolescents with chronic disease, a feeling of injustice, which is expressed as jealousy and envy, predominates behind the feeling

of potential-normal depression (7, 19). It is thought that this may be caused by decreased interest of the parents, inequality in application of rules, and excessive tolerance (19). Siblings frequently think about and try to solve the question of why their parents' reactions are different. Nonetheless, healthy children and adolescents who have a sibling with chronic disease are unsuccessful in suppressing these emotions and cannot draw away from these thoughts (19). In some studies, it was emphasized that the feeling of anger was very pronounced in healthy siblings (7, 19, 20, 26). In contrast, other studies reported that they expressed this anger in different ways with eagerness, restlessness, and hyperactivity (18, 19). The way of expressing these feelings is most frequently reflected as aggressive reactions including fighting with peers (23, 26).

Numerous symptoms have been identified in healthy siblings of children with chronic disease. These include eating problems and weight loss, which are expressed as 'child with poor appetite' or overeating and sleep problems. Among sleep problems, different findings including awakening exhausted and having nightmares may be observed (18, 50). Healthy siblings of children with chronic disease have been reported to be more prone to accidents (50). In addition, it has been reported that a part of the healthy siblings of children with chronic disease have headache and some experience enuresis at any age (50). Healthy siblings may express only a few physical symptoms even in severe conditions when they are really sick (18). Murray et al. (50) showed that children whose siblings had cancer received less healthcare service than the control group. However, the anxiety they feel for their siblings influences their lives in many aspects. Alderfer et al. (7) reported that there was no difference between children whose siblings had cancer and their peers in terms of physical functions. However, it is known that siblings of children and adolescents with cancer feel anxiety about their own health (7). Siblings are anxious about the health status of the sick child at least as much as they are anxious about their own health (19). Murray et al. (50) reported that healthy siblings feared that their sick sibling's disease would also occur in themselves. Although we have these data about healthy siblings of children with cancer, data about siblings of children with other chronic diseases are limited or lacking. Only van Riper et al. (18) reported that healthy siblings of children with other chronic diseases also experienced anxiety about having the same disease and fear of death.

Growing up with a sibling who has chronic disease also influences personal and social development of children and adolescents. Self-concept encompasses the individual's personal attitudes, intellectual and cognitive skills and personal characteristics that specify self-identity. Some investigators proposed that siblings of children and adolescents with chronic disease had low self-respect (18, 20, 50). It is thought that the inconsistent results between studies may be related to the complexity of self-identity. The development of self and self-identity is partially related to the presence of a brother or sister who is sick. These findings have only been expressed descriptively and an adequate explanation has not yet been made. Siblings develop a sense of responsibility and they feel proud because they help their sick siblings. However, this excessive burden has influences (11, 18).

Adolescence is characterized by anxiety related to identity and adaptation in the growing child and a desire to be separate from the rest of the family because of personal and emotional conflicts. This period itself needs effort and creates stress. Living with a sibling who is disabled or has a chronic disease and caring for them influences the healthy sibling negatively. Relationships with friends become complicated and this condition may even cause teasing and bullying (51). Adolescents come into contact with the rest of the family in a limited time period and cannot find an opportunity to share their feelings related to their sick sibling. This is a vicious cycle. In addition, conflicts in the family increase in this period and the child emotionally withdraws from the family and this condition causes the child to feel guilt, which leads to an increase in serious psychosocial problems (52).

The states of healthy siblings of children and adolescents with chronic disease have mostly been described by their parents. However, reports from the siblings' own perspectives are rare or ignored. Instead, typically the points of view of siblings and parents or points of view of only siblings were included in studies. Both of these approaches are insufficient in terms of demonstrating the experiences of children and adolescents appropriately. In conclusion, the world of siblings is interpreted by adults. Therefore, it is important to understand experiences of siblings through their own points of view and obtaining information related to their world. Currently, it is known that growing up with a sibling who has disability or a chronic disease causes both positive and negative effects.

However, negative effects emerge instantly, whereas positive effects emerge in adolescence or adulthood. It has been proven that establishing support groups for these siblings where they can freely express their emotions and thoughts, positively affects the child's well-being and self-identity, especially when families participate in these support groups together with their children. Spending time away from home, even for a short time, decreases stress, increases self-respect, and has a positive influence for healthy siblings of children who have disability or a chronic disease. Studies suggest that some interventions including education programs organized for parents and healthy siblings of children with chronic disease are effective in increasing these children's knowledge level and compatibility and decreasing behavioral problems. Information related to the effects of childhood cancers on families gradually increases, but studies related to healthy siblings are still limited. It has been stated that applying education and support programs to siblings of children with cancer provides a decrease in anxiety, distress and behavioral problems and is helpful in developing social competence of healthy siblings of children with cancer. Investigators have reported that intervention programs organized for parents and healthy siblings of children with cancer will provide improvement in quality of life of healthy siblings with physical and psychosocial aspects. Conducting more comprehensive studies related to quality of life of healthy siblings of children with chronic disease and establishing support programs will be guiding. The time since diagnosis and disease severity/disease mortality rate may cause different effects on quality of life in healthy siblings of children with chronic disease because of treatment approach differences. It will be helpful to examine disease classes separately in studies related to children with chronic diseases.

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