

# Healthy Lifestyle Behaviors of an Adolescent with a Disabled Sibling: Qualitative Analysis

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## Abstract

**Purpose:** The management of a stressor such as disability and the way adolescents participate in the process are effective in the development of healthy lifestyle behaviors of adolescents. The research aims to define healthy lifestyle behaviors of adolescents siblings of children with disabilities.

**Design and methods:** The phenomenological type of research was conducted with adolescent siblings of children with disabilities from February to June 2021. The sample was selected by the snowball method. Data were collected by individual in-depth interview technique. Interpretive analysis method was used in the analysis of the data. The data were evaluated according to the method by two independent experts. A consensus was reached by the expert and the researcher in expressing the themes. Themes were named in line with the researcher's vision and mission.

**Results:** Five main themes were reached. These are acquiring a caregiver role in the sibling, unconditional family love, creating a need area in family love, loneliness, healthy life activities for acceptable physical development.

**Practice implications:** This research highlights the assumption that the presence of a disabled sibling affects family processes. Changes in family processes may affect the development of the disabled sibling, as well as affect both healthy lifestyle behaviors and the development of healthy adolescents. In order to increase the gains of healthy lifestyle behaviors of adolescents, adolescents and parents can be supported with education and the necessity of increasing the interaction between disabled siblings and adolescents can be prioritized.

**Keywords:** Nursing • Disability • Adolescence • Healthy lifestyle behaviors

## Introduction

Healthy lifestyle behaviors that emerge over time with the acquisition of health behaviors include continuous actions that are acquired during childhood and continue throughout adulthood, with physical, mental and social effects. Among the environmental factors that are effective in the acquisition and maintenance of healthy lifestyle behaviors in adolescents, the family factor has an important place [1].

Positive effects of strong healthy lifestyle behaviors in adolescents; health responsibility, self-development initiatives, active movement, health supporting nutrition, self-actualization, stress management and strengthening in interpersonal communication. Healthy lifestyle behaviors are the behavior that emerges as a result of the goals of promoting health and is pursued with the goal of preventing illness

and protection from diseases and the resulting healthy lifestyle behaviors are the actions that are acquired through the formation of identity in adolescence and continued in adulthood. Having a disabled sibling, together with the sense of responsibility in the care of the sibling of the adolescents, causes stressful, consuming and obstructive changes on their individual lives. In daily life, they are interested in meeting the physical needs of their siblings, active movement, strengthening communication channels, supporting their education, socializing and meeting their play needs. The fact that one of the family members has a disability, the continuation of dependent/semi-dependent care, deterioration in family processes, role confusion and the responsibility of healthy adolescent siblings in the care of their disabled siblings creates a stressful, obstructive and restrictive family system for adolescents in the development of self-efficacy. The attitude of the family in this process, the management of stressors and the way healthy adolescents participate in this process

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are effective in the development of healthy lifestyle behavior of adolescents who are in the process of gaining identity. With the literature review, it has been determined that the studies in this field are insufficient and the literature will be supported with the study. In addition, a study was conducted on the development of healthy lifestyle behaviors of healthy adolescent siblings of disabled children who benefited from rehabilitation centers for the first time in Mugla. According to the results of the study, it is planned to provide trainings to the adolescents and their families in the province of Mugla, who participated in the study and who have a need for education on healthy lifestyle development, to improve the healthy lifestyle of adolescents.

### Purpose of the study

Considering that the presence of a disabled sibling in the family has an effect on the functionality of the family and the roles and

responsibilities of the members, this study was conducted to examine the effect on the healthy lifestyle behaviors of healthy adolescents in the family. This study focuses on adolescents who have a disabled sibling and the effects of having a disabled sibling on healthy lifestyle behaviors [2].

## Materials and Methods

The research was carried out with reference to a rehabilitation center affiliated to the provincial national education in Mugla. There are approximately 150 children registered in this centre. The research started with the reference person from this center and reached 10 families with the snowball method. Participants feature was given in Table 1.

**Table 1.** Interview sample.

Participant	Gender	Age	Education	Sibling	Level of disability	Age of learned disability (Healthy sibling)	Healthy sibling learned who has person
A1	F	13	Secondary school	2	Mild	45208	Mother
A2	F	14	High school	2	Mild	45113	Mother
A3	M	13	Secondary school	2	Mild	45271	Mother
A4	F	13	Secondary school	2	Mild	45082	Mother
A5	F	15	High school	3	Moderate	Don't remember (triplet)	Mother
A6	M	13	Secondary school	2	Mild	Don't remember	Mother
A7	F	16	High school	2	Mild	8	Mother
A8	F	18	High school	3	Mild	45113	Mother
A9	F	14	Secondary school	2	Mild	45240	Mother
A10	F	20	Undergraduate school	3	Mild	45208	Mother

The sample size was determined using the snowball/chain sampling method. The study was carried out with individuals who were reached with the recommendation of the reference person selected by the institution.

Inclusion criteria of the participants in the study; having a smart phone and device to make online calls, using the zoom program. Exclusion criteria of the participants from the study; wanting to leave the research during the research process, having insufficient speaking and understanding Turkish, having a mental disability [3].

The data collection process was done online. The data were collected by filling out a semi-structured interview form in a 40-minute interview using the zoom program at the scheduled time with the adolescents who volunteered to participate in the research. A total of two interviews were conducted with each child. After reaching data saturation, the interviews were terminated. Research questions are given below.

#### Sample topic guide (Healthy adolescent siblings):

- What does the phrase "Healthy lifestyle behavior" mean to you?

- How is your relationship with your parents and sibling?
- Who told you that your sibling was disabled, and how did you find out about it?
- How did you feel when you first found out that your brother was a disabled person?
- How does it feel to have a disabled sibling right now?
- How has having a disabled sibling affected your life?
- Has having a sibling with a disability changed your domestic relationships?
- How has your healthy lifestyle behavior changed during this period?
- What are you doing to improve your healthy lifestyle behaviors?

### Data analysis

Data analysis was done with descriptive and thematic concept analysis. The analysis of data in qualitative research consists of the steps of identification with data reduction and reduction, classification with data display or presentation, inference and verification and connection steps. The data obtained from the interview are analyzed with the descriptive analysis method. The data

obtained in this method are summarized and interpreted according to the previously determined themes. The data can be arranged according to the themes revealed by the research questions. In this research, data are organized according to the themes revealed by the questions during the interview. With the thematic analysis method, the data in different themes in the study are examined in depth. The diverse ideas and meaning patterns expressed by the volunteer participants in the interviews are formulated according to the themes and analyzed and the results are verified with the literature [4].

## Results

With the examination of the descriptions of the interviews with the participants participating in the research, 7 top themes and sub-themes within these themes emerged. Themes are given in Figure 1.

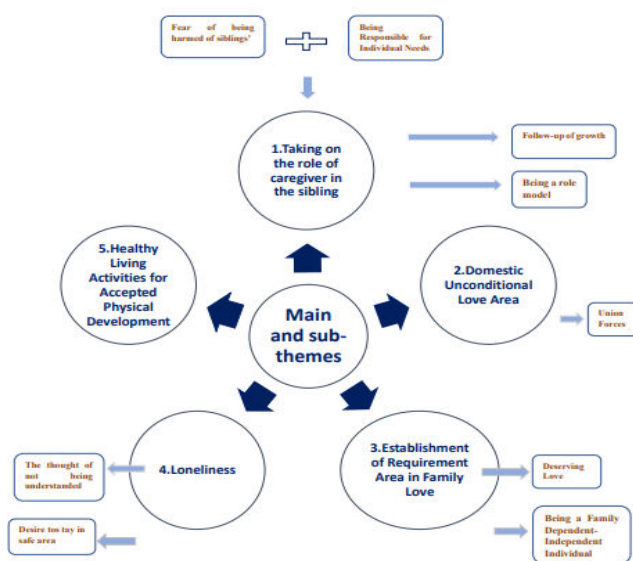


Figure 1. Main and sub-themes.

Table 2. Main theme 1 and sub-themes.

Main theme	Sub-themes
Taking on the role of caregiver in the sibling	Fear of being harmed of siblings
	<p>I sometimes (smile with pleasure) even when I go somewhere, I secretly watch them, to see what they are doing. I wonder if they are behaving badly, but they are behaving well</p> <p>My friends, let's go there sometimes according to his mind, let's go here, you know, I can't quit either. I stay very smart at home</p> <p>I am afraid that something will happen to him. I'm very worried</p> <p>I may have been a little stressed after my brother. That something will happen to him, something will happen. Actually, I always have a brother in the back of my mind, I am focused on my brother, I am anxious</p>
Being responsible for individual needs	
	<p>I felt like a mother. I always wanted her to attend her education regularly. In such cases, I bought it instead of my mother</p> <p>I always have to look after him. I'll do whatever he wants. If he wants to go out, we'll go out and come.</p>

## Taking on the role of caregiver in the sibling

The fact that the presence of a disabled child in the family dynamic is effective on the role sharing of family members stands out in the whole of the research. With this analysis, the main theme of assuming the role of caregiver in the sibling and sub-themes fear: The thought of being harmed, being responsible for their needs, following development, being a role model are formed [5].

In the research, it is seen that healthy adolescent siblings intensely experience the fear of being harmed by their disabled siblings and their individual needs being responsible. These feelings are effective in adolescents taking on the caregiver role that belongs to the parents. During the interview process, it is recorded by the researcher that the adolescents take on this role and follow the development of their disabled siblings and that they experience individual emotional transition processes on this development [6].

It is observed that emotional confusion and difficulties in peer relations occur in adolescents who develop parenting role imitation. In addition, it is analyzed that adolescents follow the development of their disabled siblings on the basis of parenting role imitation, and they develop skills in the field of being responsible for their own health, which is a healthy lifestyle behavior with their role-model behaviors (Table 2).

	<p>My mother has been working since I was a child and my father has been working, I don't have a very social life. I usually spend it with my siblings instead of spending it on my friends. Since my parents both work, I try to offer them the same experiences and places I have visited</p>
	<p>I am more conscious, I don't look at life like lay lay lom, I mature with him at a young age, I grow up with him too</p>
Follow-up of growth	<p>He couldn't get the letters out, for example, he did. Then he couldn't do math addition, now we are in addition, he is trying to achieve that too, he is making an effort."</p>
	<p>We are trying to be a little more careful about nutrition. It's portioning, we want to pay attention to what it eats, its content, etc</p>
Being a role model	<p>My brother is not allowed to eat salty. For example, it is forbidden to eat too fat or something. I eat the way he eats. He doesn't eat grocery items, including me. If I ate when it was just the two of us at home, I never ate when I was with my brother. Sometimes we go to the park and take walks like this</p>
	<p>I try not to eat too much junk food with my brother. Those with down syndrome are children who can hardly lose their weight a little later. That's why we don't get a lot of junk food at home, so we don't eat a lot of junk food either. It provided a positive effect on ourselves. We also make it more active physically. We try to be active all together</p>
	<p>Then sometimes I would try to play sports with him</p>
	<p>We are running, we are playing basketball or something</p>
	<p>For example, we used to go out for sports together in the evenings. My eating habits started very late. We fixed our eating habits together. I mean, I don't choose food anymore. Likewise, my brother's eating habits have improved</p>

**Fear of being harmed of siblings:** In the study, it is observed that the adolescents siblings adaptation skills to life outside the family are inadequate compared to their peers and they experience the fear that their siblings will be harmed due to their weakness in the face of difficulties.

Considering the statements of A1, A8, A9 and A10, it is seen that adolescents display a protective behavior towards their siblings due to the feeling of fear they experience and have difficulties in maintaining peer relations [7].

**Being responsible for individual needs:** In the study, it is observed that the siblings of the participants diagnosed with disabilities are responsible for their individual care needs and they direct their daily lives in line with these needs (A2, A6, A8). It is examined that the sense of responsibility in adolescents supports the acquisition of identity with its effect on the level of self-esteem and self-acceptance. In the study, the health gains of adolescents in the areas of activity/exercise, nutrition and spiritual development, where they experience an increase in health awareness, are analyzed (A8).

**Follow-up of growth:** In the study, it is observed that the family of healthy adolescents is in a process of change after the disabled siblings enter their lives and are diagnosed and in this process, they develop the ability to adapt to the developmental process by comparing the development of the disabled sibling with their healthy peers.

**Being a role model:** It is evaluated that A7, A9 and A10 regulate their nutrition and physical activity behaviors according to their disabled siblings. A1, A6, A8 positive gains in activity-exercise and feeding behavior are analyzed [8].

### Domestic unconditional love area

In the study, it is evaluated that healthy adolescents have a love bond with their disabled siblings and that being disabled plays an integrative role in the sibling relationship. It is analyzed that the relationship between siblings provides positive gain in stress management (Table 3).

**Table 3.** Main theme 2 and sub-theme.

Main theme	Sub-themes
Domestic unconditional love area	<p><b>Union forces</b></p> <p>My mother and father's relationship improved a bit, there were divorce matters, they got better. These things actually improved our family order so that it wouldn't affect my brother. Family ties got stronger. I tended to hurt myself continually. He comes to me, for example, I cry. What's up sister? Let's solve it together</p> <p>It helped us to get closer together as a family. We became integrated so that we could spend our lives with him and take care of him</p> <p>We overcame all obstacles with him. Well, we did not stop whoever came in front of us</p> <p>When I get very stressed, I play games with my brother to keep my spirits up</p> <p>We became more attached to each other he sometimes gets offended at me, then I say my sister, he comes and hugs me</p> <p>Troubles, stresses, economic troubles et We didn't feel like there was a problem. We always tried to give our love. I am preparing for the university exam I am very stressed. If I can't do it, sometimes I get angry, I cry at home and so on, but my brother is coming, don't cry sister he hugs me because I love you very much</p>

**Union forces:** In this theme, the sharing of healthy adolescents with disabled siblings with their disabled siblings is discussed. In the research, it is seen that adolescents express their relationships with their disabled siblings with the concepts of power and attachment. It is evaluated that the disabled sibling strengthens the family relationship in the family relations of A7 and A10. In the interview with A1, A3, A4 and A8, it is analyzed that the disabled sibling supports the adolescents when they experience emotional turmoil and difficulties and causes emotional well-being [9].

deterioration in family functionality. With the deterioration of functionality, it is seen that the love needs of the adolescents are shared by their parents with their disabled siblings and the adolescent is neglected in the emotional field. It is analyzed that the continuity in the functionality of the family positively affects the emotional and social development of the adolescent (Table 4).

### Establishment of requirement area in family love

In the study, it is examined that the meaning that parents give to disability affects emotional sharing with children and causes

**Table 4.** Main theme 3 and sub-themes.

Main theme	Sub-themes
Establishment of requirement area in family love	<p><b>Deserving love</b></p> <p>They justify my brother, sometimes they hold him, sometimes they hold me then I get angry (he tensed up when speaking). I always cry because of this anger. How did it affect (angrily) There was no sharing, no sharing with parents. There was discrimination on some days</p> <p>I never said I love you to my family, they didn't say. They didn't hug me. I mean, they were like that to my brother before he got sick, of course they changed after he got sick. They hug him and kiss him, but they never approached me like that</p> <p>I led a normal life. My family established the balance between that well. Instead of saying he is disabled and directing the attention to my brother, they showed equal interest to all of us</p> <p><b>Being a family dependent-independent individual</b></p> <p>They take care of them a lot, which they have to. For example, I think they like my sister more</p>

**Deserving love:** In the study, it is evaluated that the idea that siblings of adolescents who are diagnosed with disabilities by their parents need more love provides gains. It is examined that the love

needs of the adolescents are ignored because they are independent to the family compared to their disabled siblings [10].

It is observed that healthy adolescents have difficulty in expressing their feelings and tend to cry emotionally in interviews.

A2, state that the emotional sharing of their parents in the family is more intense with their disabled siblings. It is observed that adolescents are quite nervous and have difficulty in expressing their feelings during the interview. It is recorded in the interviews that the adolescent A7 shares risky behaviors during the developmental stages due to the oppressive and authoritarian parental attitudes of the family, has problems in peer relations, has unbalanced and unhealthy nutrition problems and cases of neglect and abuse. It has been investigated that family attitude tends to have self-confidence problems in healthy adolescents and to risky behaviors in healthy lifestyle behaviors [11].

Adolescent A10 states that there is no deterioration in family processes due to the tolerant and reassuring parental attitude in the family. A10's shares in the interview are examined that the emotional balance offered by the parents to the children supports the positive development in the lifestyle behaviors of healthy adolescents. A

positive development was achieved in the areas of activity-exercise, peer relations, nutrition and spiritual development of the participant; it is observed that identity acquisition has also improved in the academic field.

**Being a family dependent-independent individual:** A5 makes his sharing by crying. In the research, it is observed that the emotional turmoil experienced by the adolescent causes problems in eating disorder behavior and peer relations [12].

## Loneliness

In this theme, it is emphasized that healthy adolescent siblings have negative gains in their interactions within the family and in peer groups. It is analyzed that the problems of the participants in emotional and social development reveal inadequacy in the sense of trust in interpersonal relationships and communication difficulties (Table 5).

**Table 5.** Main theme 4 and sub-themes.

Main theme	Sub-themes
Loneliness	<b>The thought of not being understood</b>
	We went to the same school with my brother and people were constantly making fun of me (with a deep cry)
	My friends, you know, let's go there sometimes according to his mind, let's go here, you know, I can't quit either. I'm very confused at home. I don't think my close friends will understand (She talks with tears)
	<b>Desire to stay in the safe area</b>
	For example, he wanted to play with some of my friends, namely me, but I couldn't let him go. I was inviting him to the game too. If he didn't play, I wouldn't play either.
	I prefer to spend time with my siblings rather than with my friends, except for one or two people
	I sit and wait in a corner
	When I listen to music, I put on the earphones, go to a dark room, it's better for me, my sister. So, maybe I will cry, maybe I won't. I like the dark more

**The thought of not being understood:** In the study, adolescents defend the idea that because they do not have a disabled sibling, they cannot understand the feelings of their peer groups, they do not respect their experiences and it is unnecessary to continue communication with them for this reason.

It has been studied that adolescents have difficulties in maintaining peer relationships. In the interviews, it is analyzed that the communication problems they experience with their peer groups are effective in their emotional development and that the development is related to social relations and stress management.

**Desire to stay in the safe area:** In the research, it is seen that A1, A8 share most of their time during the day with their disabled siblings, depending on their responsibility relationship. It is stated that adolescents who have conflicts with their peer groups in this process tend to be in the background in their interpersonal relations and they want to stay in areas that can be safe for their siblings, thinking that their peers do not understand them and they may harm their siblings. In the interview, it is interpreted that the safe

space for adolescents is their individuality and the areas where their siblings are happy. It is believed that loneliness gives them the feeling that they are in a safe area [13].

In the study, it is examined that adolescents tend to be alone when they encounter stress and have difficulties in the emotional field. It is analyzed that adolescents have communication problems with their parents and peers and they experience the feeling of insecurity intensely.

## Healthy living activities for accepted physical development

In the study, it is interpreted that healthy living activities are important in order to ensure social acceptance with the influence of disabled siblings, as well as the idea of self-acceptance, peer acceptance and admiration in relation to the developmental characteristics of the physical development of adolescents (Table 6).



Table 6. Main theme 5 and sub-themes.

Main theme	Sub-themes
Healthy living activities for accepted physical development	If we eat products such as hamburgers and fast-food, we may lose weight or various diseases in our body. If we use healthy products, we naturally become taller. Well, our weight will be in place
	We need to consume our foods well, that is, we need to eat useful things, we should not consume too much junk food. Something like sports
	Eating a balanced diet, then sports, exercise

A3 and A6 are expressions of healthy lifestyle behaviors. Adolescents associate healthy lifestyle behaviors with nutrition and physical activity.

It is interpreted that healthy lifestyle behaviors of A7 support physical development and low body mass index and height are required for accepted physical development. It is concluded that there is a positive relationship between the concept of a healthy lifestyle and the physical development of adolescents. For this reason, it is analyzed that healthy lifestyle behaviors of healthy adolescents who have a disabled sibling are behavioral development related to nutrition and physical activity.

Discussion

Having a disabled child in the family affects the functionality of the family and the role sharing in the family. The findings in the theme of taking the role of caregiver in the sibling are consistent with the literature. The presence of a disabled child provides the development of healthy siblings sense of responsibility. In a qualitative study conducted by Freitag et al. in 2021, it is emphasized that adolescents with a disabled sibling show a complex emotional, social, cultural and cognitive development, moving away from favorite activities/games in healthy adolescent siblings when their sibling participates in the care process. In this study, it can be said that in line with the statements of the adolescents and within the scope of the theme of "taking the role of caring in the sibling, cognitive and emotional development along with the sense of responsibility developed positively and with this development, positive developments were achieved in the behaviors of being responsible for nutrition, physical activity and health [14].

In addition to its positive effects, there are studies suggesting that the degree of participation in the care of a disabled sibling is a source of stress, is associated with anxiety and depression levels, reveals psychosocial and behavioral problems and is perceived as an overload with conflict and communication difficulties in adolescents. In some, it is suggested that prosocial behavior emerges with positive gains in sibling interaction.

In the qualitative research conducted by Avieli et al. in 2019, it is emphasized that the healthy sibling is also responsible for the care of the sibling and plays the role of caregiver. With the development of metacognitive awareness in children, the development of a sense of responsibility is provided. There is a positive relationship between the level of sense of responsibility and the dimension of behavior. In the study, it is examined that the presence of a disabled child in the family has an integrative effect on the family members relationships. Findings in the theme of unconditional love within the family are consistent with the literature. In the qualitative research conducted by Avieli et al., it is emphasized that the disabled sibling creates a love area and supports the emotional

transition between parent and child [15]. In the research, it is interpreted that there is an imbalance in the emotional sharing of parents with children due to the concept of healthy and unhealthy having a disabled child in the family. The findings in the theme of formation of a need area in family love are compatible with the literature. In a qualitative study, it is emphasized that the healthy child is neglected and the healthy child moves away from the family in this process, with the thought that the disabled sibling needs the care and attention of the family more.

Adolescents who have a disabled sibling are at risk of facing mental problems such as anxiety and depression, as well as a sense of injustice in relation to excessive burden of responsibility and family attitude. In addition, children with disabled siblings perceive the responsibilities of their siblings in the care process as a necessity, as well as sharing between siblings and emotional bonds, sharing love and a protective relationship. Considering the positive effect of empathy and altruistic behavior, it is examined that adolescents who develop empathy in this interaction display positive attitudes in interpersonal relationships.

Peers are an important group for the development of the child during adolescence. In the study, it is examined that healthy adolescents who have a disabled sibling experience negativity in maintaining the relationship between peers. Findings in the theme of loneliness are consistent with the literature. It is a supportive factor in the positive interactive psychosocial development of children. In the literature, it is suggested that there is an interaction between difficult temperament and sibling relationship. Having a disabled sibling is effective on the difficult temperament development of children. In addition to these, school is an important tool for identity acquisition and psychosocial development in adolescence. It is suggested that healthy adolescents who have a disabled sibling have a low sense of belonging to school.

The functionality of the family and the peace of mind in the family resulting from the parent-sibling relationship of the adolescents are effective in the development of the physical and mental health of the adolescents. The findings in the theme of healthy life activities for accepted physical development and the literature are partially compatible. The literature is insufficient on this theme.

Adolescence is a period in which the need for childhood nursing care increases and should be managed with trainings and regular follow-ups. In this period, ensuring a healthy harmony with the disabled sibling, preventing the adolescent's tendency to risky behaviors, monitoring their development and developing healthy lifestyle behaviors are provided by pediatric nurse. While following the growth and development of the

adolescent during adolescence, they support the physical, cognitive, spiritual and social development of adolescents by increasing the quality of interaction between the adolescent-parent after the partnership with the parents.

In the study, it was seen that the presence of a disabled child in the family affected the family processes and the development of healthy adolescents was affected by the change in these family. The participation of healthy adolescent siblings in the care and treatment of their disabled siblings, their compliance with the that's and the attitudes and skills of the family affect the development of healthy adolescents. In order to have positive gains in the development of healthy adolescents and healthy lifestyle behaviors, family processes should be supported. Trainings should be planned by pediatric nurses in cooperation with rehabilitation centers in order to support the adolescent's cope with stress and acquisition of healthy lifestyle behaviors.

#### How might this information affect nursing practice?

This research is one of the few qualitative studies examining the healthy lifestyle behaviors of adolescents who have a disabled sibling. It is thought that the results of the research will be a qualified source for the literature about the achievements of the adolescents who have a disabled sibling in the family and the healthy lifestyle behaviors of the adolescents.

## Conclusion

In order to increase the adaptation of healthy adolescents to the process and their coping skills, the level of sharing and relationship with the disabled sibling should be maximized. In order for healthy adolescents to feel more valuable, they should participate in the rehabilitation center some days of the week and there should be supported by pediatric nurses. It is thought that there will be an increase in the positive gains in healthy lifestyle behaviors of healthy adolescents who are adapted to the care and treatment of the disabled sibling, whose disabled sibling and parent relations are strengthened and whose development is supported by pediatric nurses.

## Ethical Conduct of Research

This study was performed in line with the principles of the declaration of Helsinki. The ethical approval for the study was obtained from ofe of government university (15.03.2021/34) and institutional permission was obtained from the administrators of the participating schools. Also, a consent form was given to the adolescent to deliver to their parents to sign.

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manuscript. The authors have declared that they have no competing or potential conflicts of interest. The authors acknowledge the cooperation of the Turkish ministry of education, as well as the many principals, teachers, parents and students who participated in this study.

## Limitation of Study

In the study, adolescents who have 10 disabled siblings since they are within the scope of Muğla province were reached. It was analyzed that the majority of the children participating in the study were in the early adolescence period and their communication skills were insufficient compared to the participants in the middle adolescence period.

## Ethical Consideration

Mugla Sitki Kocman university medical and health sciences ethics committee-2 approval was obtained to conduct the study.

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