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Promoting Positive Mental Health of Families with Children with Autism Spectrum Disorder

Literature Review

Helsinki Metropolia University of Applied Sciences

Bachelor of Health Care

Degree Programme in Nursing

Thesis

21.4.2017

Authors Title	Nea Nykopp, Katariina Partanen Promoting Positive Mental Health of Families with Children with Autism Spectrum Disorder – Literature Review
Number of Pages Date	29 pages + 2 appendices 21.4.2017
Degree	Bachelor of Health Care
Degree Programme	Degree Programme in Nursing
Specialisation option	Nursing
Instructor	Liisa Montin, PhD, RN, Senior Lecturer
<p>The purpose of this thesis was to describe the methods on how to promote positive mental health of families with children with autism spectrum disorder (ASD). The aim was to use the acquired knowledge to promote the positive mental health of families with children with ASD. This thesis answers the questions: 'what are the factors related to the positive mental health in families with children with ASD' and 'what type of methods are available in order to promote the positive mental health among families with children with ASD'.</p> <p>Databases CINAHL and Medline were used as the sources for data collection. A total of fifteen articles were chosen for analysis. Literature review was chosen as the method of execution.</p> <p>The results showed that parents of children with ASD experience higher levels of stress than parents of typically developing children. Experiencing high amounts of stress may lead to worse psychological issues, such as depression and mood disorders. The severity of the disorder plays a major role in the parents' mental health. Therefore it is crucial to use all resources available to maintain positive mental health within the family. Sufficient knowledge about the disorder is an essential factor to obtain the competence needed to care for a child with ASD. The use of health care services and professional guidance is beneficial for the whole family. In addition, siblings and grandparents can have a positive impact on the family's mental health. Social support assists in coping with the hardship involved when caring for a child with ASD. The use of creative therapeutic methods, such as music therapy or mindfulness practices have proved to have positive effects on families.</p> <p>Although various strategies and treatments are available to promote the positive mental health of families with children with ASD, further research should be conducted in order to provide more individualized care for the families.</p>	
Keywords	autism spectrum disorder, positive mental health, family

Tekijät Otsikko	Nea Nykopp, Katariina Partanen Positiivisen mielenterveyden edistäminen perheissä, joissa on autistilapsi – Kirjallisuuskatsaus
Sivumäärä Aika	29 sivua + 2 liitettä 21.4.2017
Tutkinto	Sairaanhoidaja AMK
Koulutusohjelma	Hoitotyö
Suuntautumisvaihtoehto	Sairaanhoidaja
Ohjaaja	Liisa Montin, TtT, sh, lehtori
<p>Tämän opinnäytetyön tarkoituksena on ollut kuvata menetelmiä siitä, miten positiivista mielenterveyttä voidaan edistää perheissä, joissa lapsella esiintyy autismin kirjoa (eng. autism spectrum disorder, ASD). Tavoitteena oli hyödyntää kerättyä tietoa positiivisen mielenterveyden edistämiseen perheissä, joissa on autistilapsi. Opinnäytetyö vastaa kysymyksiin: 'mitkä tekijät vaikuttavat positiiviseen mielenterveyteen perheissä, joissa on autistilapsi' ja 'minkälaisia menetelmiä on saatavilla, joilla voidaan edistää positiivista mielenterveyttä perheissä, joissa on autistilapsi'.</p> <p>Kaiken kaikkiaan 15 tutkimusartikkelia valittiin analysoitavaksi CINAHL- ja Medline-tietokannoista. Kuvaava kirjallisuuskatsaus valittiin opinnäytetyön toteutustavaksi.</p> <p>Tulokset osoittavat, että autistilapsen vanhemmat kokevat enemmän stressiä kuin normaalisti kehittyneiden lasten vanhemmat. Jatkuva stressi voi aiheuttaa vanhemmissa vakavia psykologisia oireita, kuten masennusta tai mielialahäiriöitä. Myös autistilapsen vamman vaikeus on vahvasti kytköksissä vanhempien mielenterveyteen. Onkin tärkeää, että vanhemmat pystyvät hyödyntämään kaikkia saatavilla olevia resursseja ylläpitääkseen koko perheen hyvinvointia. Autistilapsen hoitoon tarvittavan osaamisen saavuttamiseksi on tärkeää omata kattava tietämys oireyhtymästä. Sosiaali- ja terveystalvet, sekä potilasohjaus ovat hyödyllisiä koko perheelle. Sosiaalisen tuen saamisella on merkittävä vaikutus etenkin autistilapsen vanhempiin. Etenkin sisaruksilta sekä isovanhemmilta saatu tuki vaikuttaa positiivisesti koko perheen hyvinvointiin. Erilaisilla luovilla terapiamuodoilla, kuten musiikkiterapialla ja mindfulnessilla, on huomattu olevan positiivisia vaikutuksia perheisiin joissa on autistilapsi.</p> <p>Vaikka autistilapsille, sekä heidän perheilleen, on tarjolla useita eri hoitomuotoja, uusia terapiamuotoja tulisi aktiivisesti kehittää ja tutkia, jotta jokaisella perheellä olisi mahdollisuus saada juuri heille sopivaa hoitoa ja tukea.</p>	
Avainsanat	autismin kirjo, positiivinen mielenterveys, perhe

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1 Introduction

World Health Organization (WHO) defines mental health as a part of general health, forming a foundation for physical, psychological and social development. It is a state of well-being where an individual acknowledges their own abilities and strengths, can adjust to everyday challenges and is capable of being a contributing member of the society. (WHO 2014.) The very basis of mental health is founded at an early age and is very much affected by the child's surroundings and relationships with family members. Any imbalances in parents' mental health can severely affect a child's well-being and sense of security. (THL 2014.)

This thesis involves the concepts autism spectrum disorder and positive mental health. Positive mental health is an asset and an essential part of an individual's health and well-being. It plays a significant role in a person's daily performance. (THL 2015.) The main focus of the thesis is the positive mental health of families with autistic children and to identify the methods available on how to promote it.

Autism Spectrum Disorder (ASD) is a general term used for various neurodevelopmental disorders. It is used to describe autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), Rett syndrome and Asperger syndrome. (Autismi- ja Aspergerliitto ry.) Abnormal behavior and characteristics of autism are often recognized around the time a child would typically begin to learn how to talk and interact with other people. A diagnosis is usually given within the child's first two years of life and the disorder continues into adulthood. (Autismiliitto 2016.) The condition is commonly characterized by problems with social interaction and communication, as well as repetitive behavior. ASD is often associated with other conditions, such as anxiety, ADHD, depression, gastrointestinal problems and epilepsy. (WHO 2016.)

The child's diagnosis usually comes to the parents as a surprise. While having an explanation for a child's abnormal behavior can be a relief, adjusting to a completely new way of living can be frightening. Parents often have deep concerns

about their child's future and how well they will be perceived and treated by others. (Autism Speaks 2016.)

As opposed to the nature or severity of the child's disability, it is more often the availability of support systems and the family's financial situation that affect the whole family's adjustment and overall quality of life (THL 2016). According to Kela's regulations, a diagnosis alone does not determine whether a child is entitled to disability allowance (Kela 2016). The right for financial support, and the amount of support is based on how much care or treatment is required (Autismi- ja Aspergerliitto ry). If the child does not receive active treatment, through for example rehabilitation or therapy, obtaining financial aid can be a long struggle (Kela 2016).

2 Background

Globally, about 1 in 160 children have Autism Spectrum Disorder (WHO 2016). It is estimated that 40% of the population obtain intellectual abilities that are above or on the average level. Approximately one third of people with ASD cannot communicate verbally, but are able to learn other means of communicating. (Autism Speaks 2016.)

The prevalence of ASD is increasing globally and the factors causing this include environmental and genetic factors (WHO 2016). There are numerous risk factors associated with the genetic predisposition to autism. These include the parents' age at the time of conception, maternal illness while pregnant, and complications during birth. While these factors do not cause autism on their own, a combination of these can increase the risk of genetic predisposition. Autism is typically caused by a combination of environmental factors and risk genes that influence the early stages of brain development. (Autism Speaks 2016.) There is no cure for the condition, but evidence-based psychosocial interventions, like behavioral treatment, can help with communication and social behavior (WHO 2016).

ASD has an effect on the individual's daily activities and participation in society. Some may require lifelong care and support while others are able to live independently. (WHO 2016.) It has been studied that children with ASD can often present more challenging behavior, and a high percentage of children with ASD also have some level of learning difficulty (Roberts & Pickering 2010: 27). Children with a severe case of the condition can be demanding, especially if the support and access to services for the families are insufficient (WHO 2016).

Various studies have been executed on families with children that have ASD, due to the significant increase of the condition and the lack of resources available for families.

3 Purpose, aim and study questions

The purpose of the thesis is to describe the methods on how to promote the positive mental health of families with children with autism spectrum disorder.

The aim of the thesis is to use the acquired knowledge to promote the positive mental health of families with children with autism spectrum disorder.

The study questions were:

- What are the factors related to the positive mental health of families with children with autism spectrum disorder?
- What type of methods are available in order to promote the positive mental health among families with children with autism spectrum disorder?

4 Data collection method, data collection and data analysis

4.1 Literature Review

A descriptive literature review was used as a method of execution. The purpose of a literature review is to create an objective and thorough summary by using the most recent, reliable data regarding the topic. Not only is it essential to gather information that is already known about the subject but also identify the areas where further research is needed. (Carnwell & Daly 2001.) A well-executed literature review utilizes information from multiple sources in order to provide the reader a comprehensive overview on the matter. Proper structuring and clear writing with consistent and understandable terminology are vital in terms of improving the readability of the review. (Cronin, Ryan & Coughlan 2008.)

4.2 Data collection

Two databases, CINAHL and Medline, were used as the main sources for the data collection for this thesis. In addition, other sources were used, for example WHO and THL guidelines.

Various terms were used in the searches to best suit the concepts involving the topic. Different combinations of the search terms were used to collect a variety of articles to answer both of the study questions. Similar search terms were applied in both CINAHL and Medline with varying results. Although the same amount of searches were performed in both databases, CINAHL proved to be more efficient concerning the study questions and purpose of the thesis. Alterations to the search mode on CINAHL were also made by switching between “boolean search” and “find any of my search terms”. Many of the articles were found in both databases, which was taken into consideration when forming the search table. Each article was documented only once.

Alterations to the original search limitations were made due to the lack of hits, especially in Medline. Initial limitations included year of publication from 2010 to 2017, as well as choosing articles that had both abstract and full text available. The articles were first chosen based on the title alone, after which they were further selected based on the abstract and then the full text. A total of 15 articles were taken into analysis after careful deliberation. (Table 1.)

4.3 Data analysis

In this work, the data was analyzed according to the study questions. The material chosen for analysis was carefully read and the data answering the study questions was then collected. The findings obtained from the articles were categorized and the main titles used in this thesis were formed. The two main categories are the factors related to positive mental health and the methods promoting positive mental health. Underneath the main categories, subcategories were created to present the data in the most effective way possible.

Table 1. Database search

Database	Search terms (AND,OR, *)	Limitations	Hits	Chosen by title	By abstract	By full text
CINAHL	“Autism Spectrum Disorder AND methods AND famil* AND parent* AND child*”	Year of publication 2010-2017, abstract and full text available	264	36	18	7
CINAHL	Autism Spectrum Disorder AND positive mental health AND parent* AND children AND education	Year of publication 2010-2017, abstract and full text available	163	16	7	1
CINAHL	“Autism* AND famil* AND parent* OR child* AND promot* AND positive mental health”	Year of publication 2010-2017, abstract and full text available	213	32	23	6
Medline	“Autism* AND famil* AND mental health”	Abstract and full text available	95	15	11	1
Total			735	99	59	15

5 Results

This thesis answers the questions ‘what are the factors related to the positive mental health in families with children with autism spectrum disorder?’ and ‘what type of methods are available in order to promote the positive mental health among families with children with autism spectrum disorder?’. The results were divided into two main categories to correspond to the study questions mentioned above.

5.1 Factors related to positive mental health in families with children with autism spectrum disorder

5.1.1 Parental stress

As autism spectrum disorder affects the entire family's daily life, it is crucial for the family to learn to adapt to the new situation and routines (Bilgin & Kucuk 2010). The earlier the diagnosis of ASD is given, the better the child's prognosis is. Early interventions can begin, which have been shown to reduce the severity of the disorder. Caregivers who have received the diagnosis for their child earlier have also had better reactions towards the disorder. (Keenan, Dillenburger, Doherty, Byrne & Gallagher 2010.)

Parents often experience stress during the diagnostic process as they find the given information difficult to understand and take in. Many feel that the advice provided during the planning of treatment could have been presented more clearly and more information could have been provided, especially concerning the family's rights to financial support. (Keenan et al. 2010.)

Forward planning is a significant part after diagnosis and almost all caregivers noted that they did review their care plans every eight to nine months. A small percentage of the caregivers stated that they were not aware of when or how frequently their child's plans were revisited. When asked about how they felt about their child's care plans, most were satisfied, but many felt that they could have been executed better. Although nearly all caregivers had been given the chance to participate in reviewing or going through the child's care plan, some stated that they had not been included. Half of the caregivers who had the chance to participate felt that their opinions were often overlooked and not included in the making of the care plan, while the other half felt their opinions were taken seriously. (Keenan et al. 2010.)

The undisciplined behavior of autistic children may cause issues between family members and in the community. The parents tend to feel guilt and shame for how

the child behaves. (Hall 2012.) The parents of children with autism spectrum disorder report experiencing more stress when raising their child compared to parents with typically developing children. Even parents of children with other developmental disabilities do not report experiencing as much stress as parents of children with autism spectrum disorder. (Zablotsky, Bradshaw & Stuart 2012.)

Members of the community often do not have sufficient knowledge about autism which can lead to the parents feeling embarrassed or that their parenting skills are being judged. The condition can be misleading, because physically the child looks like a typically developing child, but acts in a disorderly way. Friends and family members may also have insufficient knowledge about autism. (Hall 2012.) Not knowing the cause of the child's condition can be difficult for family members to grasp and accept. Speculations can in turn cause additional stress for the parents of the autistic child. (Margetts, Couteur & Croom 2006.) Many parents can find a family members' resisting or belittling of the diagnosis frustrating. As parents are also trying to cope with the child's condition, worrying about the feelings and opinions of others can be too much for them to handle. (Blanche, Diaz, Barretto & Cermak 2015.)

Mothers of autistic children are more often affected by their problem behavior than fathers. The more severe the child's autism disorder is, the more stressful it is for the parents. As the stress becomes worse, the autistic child is often negatively affected by this, increasing their disorderly behavior. The more severe the child's tantrums and behavior are, the more stressed the mothers get. Autistic children are more likely to be aggressive and self-injurious, which has a huge impact on the parents' well-being as well. (Hall 2012.)

5.1.2 Psychological problems

Untreated parental stress can lead to severe psychological issues among parents with children with ASD. Parents of children with ASD have an increased risk of experiencing depressive symptoms and episodes. Children of depressed parents are also more likely to experience depressive symptoms than those with non-

depressed parents. In addition children of depressed mothers have a higher risk of forming behavioral health issues and mood disorders. (Zablotsky et al. 2012.)

A study focusing on the experiences of Turkish mothers with autistic children indicated that many of them feel emotionally drained. One participant described her life a “nightmare”, due to the extreme social isolation brought on by the child's ASD. Many experienced their child's condition as a lifelong struggle, which often made them feel helpless. (Bilgin & Kucuk 2010.)

When examining the association between ASD and maternal mental health it was discovered that the mother's mental health is a significant factor in the overall well-being and functioning of the family unit. Contributing factors for lowered mental health were found to be associated with the amount of resources available. Mothers from low-income households and the mothers of black children experienced higher levels of stress and depressive symptoms than mothers of white children. Additionally college educated or employed mothers had a reduced risk of mental health problems. Mothers of only one child reported having more depressive symptoms compared to those who had three or more children. (Zablotsky et al. 2012.)

The severity of the child's condition and the existence of psychiatric conditions in either the child or the parent play a major role in the parents' mental health. Comorbid conditions increased the risk of impaired mental health among mothers of ASD children. Mothers of ASD children with one comorbid condition were 3.2 times more likely to develop mental health issues than mothers of typically developing children, whereas mothers with children with two or more additional conditions were 4.8 times more likely to experience depressive symptoms. (Zablotsky et al. 2012.)

5.1.3 Resources

Society is compelled to provide support services in the community for families with a child with autism due to the hardship these families experience. Although society is obliged to provide services, support is not available for all families that need assistance. Families that live in areas where there are no support systems tend to rely on their other family members or community for strength. (Hall 2012.)

Many parents feel that school and child care personnel are untrained to work with children with ASD, which complicates the process of finding proper services for the child. Limited knowledge about ASD among school staff members can have negative consequences in terms of interaction with the child. At school, children with ASD can often end up being excluded from academic assignments and receive less or no take home assignments. (Hall & Graff 2010.)

The accessibility of services may be restricted in families with lower socioeconomic status. Raising a child with autism costs twice the amount as a typically developing child which can cause financial strain for the family. In Latino families, difficulties in obtaining services were often caused by language barriers, limited education, lack of health insurance, insufficient funds and lack of transportation. Hence Latino children with ASD are typically diagnosed much later or sometimes left completely undiagnosed. (Blanche et al. 2015.)

Latino parents reported a lack of mutual understanding with the service providers which often led them feeling excluded from the treatment process. Many parents felt that after receiving the diagnosis of ASD they did not receive enough information or material on how to treat or manage the condition. Variety of the written material in languages other than English was also limited. (Blanche et al. 2015.)

The frustration of not receiving sufficient information from healthcare professionals led many parents to advocate for their child. Parents felt that they needed to be demanding and persistent in order to obtain proper treatment for the child. While also emotionally exhausting, advocating for the child gave the parents a

sense of empowerment and pride over their own accomplishments. (Blanche et al. 2015.)

Some parents, especially those with newly diagnosed children, found comfort in self-studying about the condition by reading books, while other parents felt that the books did not provide them any new information. Many parents used the Internet to communicate with other parents and access information; some even creating web pages related to ASD. (Hall & Graff 2010.)

5.1.4 Family relationships

A limited amount of studies have been published about the experiences and feelings of typically developing children regarding their autistic sibling. However, a few studies have researched this subject, finding various results. (Hastings & Petalas 2013.) One of these studies aimed to get a better understanding of sibling relationships where one child was autistic and the other typically developed. Two families from different cultures participated; one European American and one Asian American family. (Sage & Jegatheesan 2010.)

The parents of the European American family had a positive outlook on their son's autism and believed that he could achieve as much as any other child. The typically developing child was educated about his brother's autism by his parents. This enabled him to build a stronger relationship with his brother, as he was able to better comprehend his behavior. The typically developing child felt that he knew his autistic brother better than anybody, including his parents, because he spent the most time with him. (Sage & Jegatheesan 2010.)

Results from the Asian American family were very different than those obtained from the European American family. The Asian American family perceived the child's disability as karma from their ancestors. Fearing that their other son might reveal their autistic child's diagnosis to the community, the parents kept the diag-

nosis a secret from the typically developing child for two years. The typically developing child's knowledge about autism was quite low and he did not seem to understand what the condition truly was. The brothers interacted together, but they did not communicate. They did not seem to understand each other much and the mother often had to intervene in various types of situations. (Sage & Jegatheesan 2010.)

Another study researched siblings' self-reported behavior issues to see if they correlated with having another sibling with ASD and their mother's mental health. The study assessed the behavior problems of the child with ASD, maternal depression, and the siblings' own emotional, as well as behavioral issues. The results showed that the longer the family had known about the ASD diagnosis, the less problems there were between the siblings. Also, having a brother instead of a sister with ASD resulted in less conflicts between the siblings. The mothers noted that if there were more behavior issues with the child with ASD, the siblings' relationship was not as close and loving. (Hastings & Petalas 2013.)

The sibling's self-reported behavior and emotional problems were not affected much by having a sibling with ASD, but peer problems were. The typically developing children felt that their autistic sibling could embarrass them in front of their friends which sometimes caused difficulties in their friendships. Overall, the results indicated that typically developing children with an autistic sibling are not at high risk to develop emotional or behavioral problems. (Hastings & Petalas 2013.)

Grandparents' impact on the family has also been researched. A study involving six grandparents examined their experiences and the challenges they faced with their autistic grandchild. The results implied that grandparents frequently experience overwhelming stress due to their worry over two generations. Not only were the grandparents concerned of the well-being of their grandchild, but of their adult child and their spouse as well. Many also perceived their role as a grandparent difficult, as they wanted to help and be involved as much as possible without undermining the parents of the autistic child. (Margetts et al. 2006.)

Knowing how hectic and stressful taking care of an autistic child can be, many grandparents offered to act as advocates for the struggling parents. Grandparents were often involved in finding and obtaining services for their grandchild, thus reducing the burden on the parents. (Margetts et al. 2006.)

5.2 Methods for promoting positive mental health in families with children with autism spectrum disorder

5.2.1 Social support

Social support helps families with autistic children develop their coping and adjustment skills. Having the efficient support helps decrease the parents' stress, promoting their quality of life. Most often the most influential support is received from a spouse, but friends and church also have a great impact. (Hall 2012.) Support from family members, especially grandparents, has been shown to reduce stress in parents with ASD children. Parents who receive support from grandparents are also more likely to receive help from other family members or friends. (Margetts et al. 2006.) Research also suggests that neighborhood support has a positive effect on families with autistic children. Having a closer bond with neighbors can help the family improve their mental and physical health. (Zablotsky et al. 2012.)

Educating the public, friends, and other family members about autism would be an effective way to decrease the stress of the families with autistic children (Hall 2012). For example, in the study by Sage & Jegatheesan (2010), a typically developing child with an autistic brother had an extensive understanding of autism and was able to apply this knowledge to support his brother in their daily life. Because he understood that his brother's behavior was caused by autism, the typically developing child was more patient with his brother and felt he understood him better. (Sage & Jegatheesan 2010.)

5.2.2 Professional guidance

Patient education programs, like counseling can have great effects on parents of children with autism spectrum disorder. Knowledge and proficiency in caring for a child with ASD can develop, decreasing stress levels and boosting the parents' competence regarding the care of a child with ASD. A study conducted in China assessed the efficiency of a multidisciplinary parent education program created to enhance the health-related quality of life (HRQOL) of parents of a child with ASD. Family functioning, competence, and positive coping styles were evaluated. Sessions on dealing with hardship were led by a special education teacher who had a child with ASD herself. The results indicated that there were improvements in mental HRQOL, but no effect on the physical HRQOL. There were positive effects on family functioning and positive coping styles as well. A family that functions well is able to cope with the burden of caring for an autistic child. The competence evaluated in the study included their ability to care for their autistic child and how they regulated and maintained their family. The results indicated that the multidisciplinary parent education program could have positive effects. (Binbin, Sun, Yi & Tang 2014.)

5.2.3 Therapeutic methods

In the past two decades there has been a significant increase in the use of **assistance dogs** for children with autism. Not only can dog ownership increase the physical activeness of their owners but also improve the psychological aspect of those at risk of social isolation. (Smyth & Slevin 2010.)

A study conducted in Ireland examined the effects of having an assistance dog in families with an autistic child. A qualitative research method was utilized to get the most comprehensive view on the matter. The sample group consisted of five Irish mothers and two fathers, all of whom already had an assistance dog in their family to support the needs of their autistic child. (Smyth & Slevin 2010.)

All of the participating parents found the presence of the assistance dog beneficial, not only for the autistic child, but for the entire family. Parents reported major improvements in safety, the child's motor skills, as well as in the relationships within the family. Parents also felt that the assistance dog often worked as an icebreaker in social situations and when meeting new people. (Smyth & Slevin 2010.)

The autistic children found comfort in the companionship provided by the assistance dog. In stressful situations the child would more often seek consolation from the dog instead of going to the parents. Parents suspected this to be due to the lack of social skills, common for autistic children. By either barking or pacing, the assistance dog could notify the parents if something was wrong with the child. Through the dog's constant tracking and providing companionship to the child, the parents felt an increased sense of security in the house. The assistance dog also provided useful distraction for the child, resulting in fewer tantrums and meltdowns. (Smyth & Slevin 2010.)

Public outings with the autistic child improved significantly by the use of an assistance dog. With the dog being attached to the child with a harness, the dog managed to prevent potential hazards in traffic, as autistic children often lack a sense of danger. (Smyth & Slevin 2010.)

Despite the primarily positive effects of the assistance dog, most parents had some concerns regarding the maintenance aspect of dog ownership. Some parents found the additional time consumed by training, grooming and toileting of the dog troublesome due to their already busy schedule. Many parents were also worried that their child's lack of reserve could potentially result in harmful situations, as the child might not understand that not all dogs are assistance dogs. However, all parents were unanimous in that the positive effects of having an assistance dog were far more superior than the negative. (Smyth & Slevin 2010.)

Comic-strip conversation (CSC) is a story-based intervention that aims to help children process and understand problematic situations through visualization. Pre-set rules and symbols for different concepts, for example, for listening or talking, are typically used to assist the construction of CSC. As the child draws, the adult guides the intervention by performing questions related to the situation being discussed, such as “what happened” or “where were you”. The intervention is completed by discussing and writing down potential solutions to the problem and weighing the pros and cons of each solution. (Vivian, Hutchins & Prelock 2012.)

The potential use of comic strip conversations as a parent implemented intervention was examined with two parents and their 8-year-old daughter with ASD participating in the study. Prior to the study the parents were interviewed to get a better understanding of the family's needs and concerns regarding the study. The parents were asked to use the CSCs with their child for six weeks and videotape each intervention. Both parents took part in the implementation of the CSCs, taking turns with the child. The parents only managed to videotape three of the interventions as the child would often refuse to be recorded. Nevertheless, these recordings together with the given checklists, indicated that the parents were able to successfully execute the CSC intervention. The researchers found that the parents' strong dedication to the study, as well as their calm, relaxed delivery of the interventions made the implementation of the interventions so effective. (Vivian et al. 2012.)

The parents reported that before taking part in the study they had not seen significant improvements in their child's behavior. After just one week of using CSC interventions the parents felt they had a better understanding of their child and their thought process. As the parents found the CSC method effective, they felt more positive and confident when dealing with the consequences of their child's behavior, for example at school. They also wished to have the method used at the child's school to minimize the occurrence of problem behavior. Parents found the execution of the CSC intervention attainable. They felt that the method was time-saving and simple enough to execute, to fit into their schedule. Parents also

saw potential of using the CSC method in the future, with possibly performing the interventions outside of home as well. (Vivian et al. 2012.)

While studies examining the effects of **mindfulness practice** have shown positive results, there have been relatively few studies focusing on its effects on the families of children with ASD. Despite the topic being new, the previously conducted studies have shown significant benefits regarding the parent-child relationship. Mindful parenting has been linked to lowered levels of parental stress and depression, as well as increased involvement in child care, especially with the fathers of ASD children. Previous studies have also shown mindfulness practice to have a positive impact on the behavior of children with ASD, reducing aggression and self-injury, and increasing the compliance towards parents. (Hwang, Kearney, Klieve, Lang & Roberts 2015.)

The potential of mindfulness has been studied in terms of promoting the relationship between mothers and their children with ASD. Six mother-child pairs participated in a two-stage study with the children's age ranging from 8-15 years. During the first stage of the intervention, the mothers attended an eight week mindfulness program consisting of weekly sessions. During these sessions the mothers received both theoretical and practical guidance on how to practice mindfulness in daily situations. After completing the first stage of the study, the mother-children duos had a two month self-practice period. Based on what they had learned, the mothers proceeded to teach the mindfulness activities and techniques to their children. In stage two of the study, the participating children received three parent-mediated mindfulness sessions which took place at their home. The authors of the study took part in the weekly visits, supporting the mother's teaching, while gradually decreasing the amount of guidance each visit. The mothers were encouraged to take part in online discussions after each mindfulness session to share their experiences regarding the process. (Hwang et al. 2015.)

After completing the study, five out of the six mothers reported a decrease in parental stress. The parents also noticed positive effects in their children, with

lowered anxiety and problem behavior. Four mothers reported a significant reduction in their child's aggressiveness. Positive effects in mothers included an increased sense of empowerment brought by teaching mindfulness to their child. Some mothers continued to teach the mindfulness methods to their whole family. The long study period proved to be challenging for the mothers. Mothers found the regular practice with the child difficult, especially during the self-practice period. The findings indicated that the more actively the mother was involved in the mindfulness practice, the better results were received from the intervention. (Hwang et al. 2015.)

A family-centered music therapy treatment was conducted for children with a more severe case of autism spectrum disorder to test if music therapy improves their social involvement or participation. The hypotheses included that the therapy would have improvements and also that the parents of the children would undergo positive changes involved in the relationship with their child. This study included 23 participants between ages 3 and 6 and had very limited verbal skills. All participants were already attending a family centered early childhood intervention program as well. (Thompson, McFerran & Gold 2013.)

An experienced music therapist conducted the sessions, which lasted 30 to 40 minutes. During the sessions, methods such as improvisation, songs, and movement to music were used. To help situate the child into the session, a greeting song was played. The activities throughout the session included different types of social communication, like focusing on facial expressions and learning to behave in a more socially appropriate manner. (Thompson et al. 2013.)

Notable improvements were seen after the sessions; children's social involvement at home and in the community increased. Despite these improvements, the autistic children still remained in the lowest ratings of their typically developing peers. The parents experienced improvement regarding the relationship with their child, including their responses and attitude towards them. Their emotional reactions towards their child became more optimistic. Interaction with the child in-

creased resulting in the parents feeling more connected with their child. The parents were able to focus on the child and not just the diagnosis. Music had a great impact on the children and the parents noted that it helped motivate their child. The children played with others, shared, and were more cooperative with others in social situations. There were conclusive effects on the families who participated in the family-centered music therapy. The experiences the parents received throughout the study helped them utilize what they had learned in numerous different situations. (Thompson et al. 2013.)

Overall, family-centered music therapy provides a motivational environment for social interaction and actively engaging with music can help develop important interaction skills in the children with severe ASD. (Thompson et al. 2013.)

Repetitive behavior is often associated with children with autism and can obstruct learning and social skills, thus negatively affecting the child's development. Treatment can be essential to benefit the child and guide their behavior. A treatment called Family-Implemented Treatment for Behavioral Inflexibility (FITBI) was conducted to treat the repetitive behaviors with children with autism. The treatment involved instructions, behavioral teaching methods, and treating the behaviors. The aim was to teach caregivers to view repetitive behaviors in a different way and to show them exercises that they could benefit from and use in their daily life. (Boyd, Mcdonough, Rupp, Khan & Bodfish 2010.)

FITBI was conducted in 12 weekly sessions. The sessions included training and teaching the caregivers how to use the method with their child and then the child was placed in situations that would provoke the child to engage in repetitive behavior. They were then taught how to get the child to interact more appropriately. The child was taught how to engage in another behavior, for example, physically directing them to act more appropriately. Parents continued to use this method at home throughout the study. (Boyd et al. 2010.)

The results showed a reduction in the amount the child engaged in repetitive behavior, and the children behaved more appropriately. The parents were able to

use the method at home after the treatment was over without constant guidance from a therapist. FITBI proved to be a type of intervention that could help with autistic children's repetitive behaviors. Although it may not be suitable for all children, it can provide positive results and is also cost-effective. (Boyd et al. 2010.)

5.2.4 Religion and spirituality

Faith can be a great source of comfort and hope for the families. Many parents find their faith in God helpful in terms of accepting and coping with the child's diagnosis. (Blanche et al. 2015.) Having a spiritual connection can also be an effective way to handle stress (Hall 2012). Despite the family's acknowledgement and acceptance that there is currently no cure for ASD, relatives may find consolation in trusting that the child's condition is part of God's or a superior being's plan (Blanche et al. 2015).

The experiences of Latino families with children with ASD were studied. Their results indicated that the strong belief within Latino families was often associated with passiveness when seeking medical treatment for the child with ASD. Due to their faith in a higher power, many families considered the child's diagnosis as part of their fate, which they could not affect. As a result families did not question the information given by healthcare professionals or seek for additional information. (Blanche et al. 2015.)

Although parents experience their faith as an important coping mechanism, undermining the child's condition can potentially delay the diagnostic process, resulting in a poorer prognosis (Blanche et al. 2015).

6 Discussion

6.1 Discussion of the results

Results obtained from the articles supported the two study questions of the thesis: (1) what are the factors related to the positive mental health of families with children with autism spectrum disorder? (2) what type of methods are available in order to promote the positive mental health among families with children with autism spectrum disorder? A vast amount of information regarding the title and study questions was found. Dividing the discussion into two categories based on the main findings felt the most fitting, as the topic is so broad.

6.1.1 Factors related to positive mental health

As seen in the results, it is clear that parents of autistic children are under an enormous amount of stress. Not only is the stress they experience greater than of parents with typically developing children but also compared to parents of children with other developmental disabilities. Parents find the diagnostic process extremely stressful, as the information provided to them is often unclear or insufficient. They also experience that after receiving the diagnosis for the child they are not given enough information on how to manage and cope with the child's condition. The problematic or disorderly behavior of the child often evokes shame and embarrassment in the parents. Parents often fear the reactions of other people towards their child and having their parenting skills judged. Parents, especially mothers with autistic children are more likely to develop other psychological problems, most commonly depression and anxiety.

The amount of resources available for autistic families has been strongly correlated to the occurrence of parental stress and mental health problems. Families often experience difficulties in obtaining the right services and treatment for their autistic child. As taking care of an autistic child is more expensive than of a typi-

cally developing child, the financial strain can be restricting. These types of problems are particularly common in families with lower socioeconomic status. Insufficient funds, lack of health insurance and transportation to health care facilities can complicate or completely prevent families from receiving treatment for the autistic child. Other than financial hardships, many families find the insufficient information of school personnel and care providers frustrating. The lack of knowledge regarding ASD and how to manage an autistic child, can lead to the child being given less attention or assignments at school. Parents commonly search for additional information independently, as they often feel that even health care professionals do not have sufficient knowledge on ASD. Their information is typically obtained from other parents with ASD children, books or the internet.

It can be concluded that the relationships of siblings differ widely. While many siblings can have a positive and caring relationship despite having an autistic child in the family, some seem to have a more negative and secluded relationship. Different factors including parenting style, cultural background and knowledge about autism all have an effect on the nature of the sibling relationship. Unlike mothers of autistic children, the typically developing siblings do not have an increased risk of developing emotional or behavioral problems.

Accepting the diagnosis of ASD can be a long and difficult process for family members. Relatives can sometimes undermine or completely resist the diagnosis, creating tension within the family.

6.1.2 Methods used to promote positive mental health

There are diverse methods to promote the positive mental health in families with autistic children. Some methods may be more efficient than others, depending on the family. All families often need additional assistance to help them cope and deal with the high levels of stress. Different coping strategies are available. Firstly, social support is widely available for families. A spouse's support may be

the most influential, but church, family, and friends can have a major impact as well, improving the family's overall quality of life. Educating loved ones about the disorder decreases the stress of the families. Professional guidance for the parents of the autistic child has been shown to have positive effects and increasing the parent's competence of the disorder greatly affects the family functioning. Religion and spirituality can be meaningful and substantial in some families. Having faith in a higher power has the potential to ease the acceptance and coping aspects of the disorder.

Creative methods, such as the use of assistance dogs for children with autism, can improve the child's skills and create a better atmosphere within the family. Although the maintenance aspects of dog ownership were found somewhat difficult, the assistance dog proved to have great benefits for the families. Children have an easier time communicating through visualization. Comic-strip conversation is one method that benefited the parents. The parents felt they had a better understanding of their child with ASD and the child's behavior improved. Mindfulness is a fairly new therapeutic method, but has been proven to be useful in decreasing parental stress and the children's aggressive behavior. Some of the mothers found the method difficult to execute with the child with ASD, but the more involved the mothers were, the better the results were. Music can also have great impact on families with autistic children. Family-centered music therapy improves the child's social skills and the parents felt more connected to their child. The music helped motivate the child and the parents' reaction and emotion towards their child became more positive. Lastly, a treatment for the repetitive behaviors was conducted, which helped guide the child's behavior, thus decreasing the child's repetitive behavior.

6.2 Discussion of the ethical considerations

In the literature review, the ethical considerations include, no fabrication, misrepresentation, plagiarism, or misappropriation (TENK 2012). In this thesis, all of

these factors were acknowledged and avoided during each step of the work process.

Both the selection of the articles and the writing of the thesis were done with the study questions and purpose in mind. In order to get the most accurate results possible, the collected data was represented truthfully without any information being altered or favored in any way. All relevant findings obtained from the articles were reported without intentional manipulation or misinterpretation. The results acquired from the studies also remained consistent throughout the entire thesis.

Plagiarism was avoided by carefully summarizing the key findings of each article used. This was done in an objective, unbiased manner that did not affect the original results of the articles. Credit was given to the rightful authors and all sources used for the thesis were properly cited and referenced. Data searches done in CINAHL and Medline were carefully documented and all articles used in the thesis were acquired from the searches presented in Table 1. Upon completion the thesis was submitted to Turnitin to further assure that the work was not plagiarized.

6.3 Discussion of the validity of the thesis

There are certain standards for validity, which include the purpose, control, audience, and format (Dudovskiy 2012). Including and considering the criteria mentioned above, the validity of the final thesis is assured. Two databases, Medline and CINAHL were used to find articles for the thesis. Medline is part of Ovid, which is a larger database organization. Medline offers over 5,500 biomedicine and life science journals in almost 40 different languages. It provides the latest bibliographic citations and author abstracts. CINAHL refers to the cumulative index to nursing and allied health. It is a database that provides authentic and reliable literature that is related to nursing and health.

All search terms used in the databases fit the themes and concepts of the thesis. The articles obtained from the data searches were critically evaluated, and only those that supported the two study questions, were selected. This ensured that all literature used for the thesis was relevant and related to the topic. The results reported in this thesis are also aligned with the study questions and purpose. The interpretation of the study results remained the same since the beginning of the writing process in the fall of 2016.

Having two authors increases the validity of the thesis, as the risk of misinterpretations and other significant errors is lowered. The articles used for the thesis originated from four continents; Australia, Asia, Europe and North America. Therefore it was possible to conduct a more comprehensive review on the topic.

7 Conclusion and recommendations for nursing practice

As the prevalence of autism spectrum disorder (ASD) continues to increase, the need for better understanding on the well-being and coping methods in families with autistic children is required. Based on the studies, families experience that health care professionals have insufficient knowledge regarding the treatment of their autistic child. Caregivers involved in the diagnostic process often find the information provided to them too brief or difficult to understand. Many also found that no information regarding how to cope with the disability or manage the child's behavior was given. Immediate family members, such as grandparents, feel they require more information about ASD as well, as it would allow them to support the family more effectively and improve their own understanding of the child's behavior.

Parental stress and other psychological issues caused by a child's autism were some of the key findings in this literature review. The stress experienced by parents was visible in most of the articles used. Mothers of autistic children are more affected by stress and mental health problems, as they are often the primary caregivers of the child. Parental stress is typically not just caused by the child's

condition itself, but is a combination of multiple factors, such as lack of resources or social support.

Families with autistic children have various coping methods. Social support provided by close family members, friends or community members is often perceived the most valuable source for strength. The guidance provided by healthcare professionals and the use of therapeutic interventions, can potentially lower parental stress, improve the family's quality of life and decrease the child's negative behavior.

As cultural backgrounds may affect family dynamics and the coping methods used, a more culturally-appropriate approach is required when treating families with autistic children. Families require clear guidance on the treatment options available and how to manage the child's problematic behavior. Because grandparents and other close family members are often affected by the child's condition, more information should also be provided to them. The potential of creative coping methods should be further studied, as not all of the methods suit all families.

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Table 2. Framework for analyzing research data

Author(s), year and country where the study was conducted	Purpose	Participants (sample size)	Data collection and analysis	Main results
Bilgin & Kucuk, 2010, Turkey	To analyze and categorize the experiences of Turkish mothers with an autistic child.	43 mothers with an autistic child.	Deductive content analysis. Data were grouped into categories based on common themes.	The mothers felt burden and lonely. Some felt they became closer with their spouse. The diagnosis was hard for the mothers to accept and many experienced financial problems. They used various coping methods. They wanted their child to have social skills in the future and they felt that the school should meet the child's needs.
Binbin, Sun, Yi & Tang, 2014, China	To assess the effectiveness of a multidisciplinary parent education program designed to improve health-related quality of life in caregivers of children with ASD.	42 participants with a child diagnosed with autism spectrum disorder.	A quasi-experimental study and analysis was based on the results of a pilot study.	There were improvements in mental health related quality of life and positive effects on family functioning and positive coping styles. The parents' competence could increase as well.
Blanche, Diaz, Barretto & Cermak, 2015, USA	To describe the experiences and difficulties faced by Latino families when taking care of a child with ASD.	15 Latino parents from 13 families with ASD children were interviewed.	The data was collected by using in-depth semi structured interviews, which were conducted in the language of the parents' preference (Spanish or English). The interviews were either recorded or notes were used to transcribe the results.	Four main themes surfaced from the parent interviews; dealing with the child's diagnosis, social isolation and stigma, accessibility to services and maternal challenges as the primary caregiver.
Boyd, McDonough, Rupp, Khan & Bodfish, 2010, USA	To assess how well the Family Implemented Treatment for Behavioral Inflexibility (FITBI) works, which included teaching caregivers to view repetitive behaviors using a neurodevelopmental model and how to conduct FITBI sessions, as well as teach how to use FITBI in their children's everyday routines.	5 preschool aged children diagnosed with Autistic Disorder.	Baseline and treatment probe sessions were conducted. There was stimuli to evoke the child's repetitive behavior.	There was a significant reduction in the children's repetitive behaviors.

Author(s), year and country where the study was conducted	Purpose	Participants (sample size)	Data collection and analysis	Main results
Hall, 2012, USA	To examine the behaviors of children with autism, community support and family coping, as well as the associations amongst them.	38 parents of children with autism.	A descriptive, correlational, cross-sectional study. Childhood Autism Rating Scale, Social Support Index, Family Crisis Oriented Personal Evaluation Scale, and Demographic Form were used.	Parents with children with autism need more community support and coping methods. The families often used reframing coping strategies and spiritual support was commonly used as a coping mechanism.
Hall & Graff, 2010, USA	To gain understanding on the views of parents with ASD children on how they experience the behaviors of their children and the accessibility of services.	9 primary caregivers of children with ASD; 7 mothers, 2 fathers and 2 grandmothers.	A 90-minute focus group interview which was recorded and transcribed.	Parents experienced the stress of taking care of the ASD child overwhelming. Some parents felt embarrassed about the child's behavior problems, which often led to social isolation. The amount and the quality of the health care services were seen as inadequate, with many parents feeling they know more about ASD than the physicians. Parents wished to have more information about different treatment options and needed financial support to cover for the care fees. Additional information was often sought from the Internet and books or by exchanging thoughts with other parents with ASD children.
Hastings & Petalas, 2013, UK	To examine whether siblings' self-reported behavior problems and sibling relationships were associated with the psychological adjustment of both their brother/sister with ASD and also their mother's mental health.	Siblings and their mothers from 94 families of children with autism spectrum disorder.	Regression analysis to explore family systems relationships, with sibling self-reports predicted by the behavior problems scores for the child with ASD and by maternal depression.	Siblings' behavioral and emotional problems were unrelated to their mothers' mental health and the behavior issues of their sibling with ASD.

Author(s), year and country where the study was conducted	Purpose	Participants (sample size)	Data collection and analysis	Main results
Hwang, Kearney, Klieve, Lang & Roberts, 2015, Australia	To explore the potential use of mindfulness practice in children with ASD and their mothers.	6 mothers and their child with ASD.	Various measures were used to examine the effects of the mindfulness program; the Freiburg Mindfulness Inventory (FMI), the Parenting Stress Scale (PSS), the Beach Family Quality of Life (FQOL) and the Child Behavior Checklist (CBCL).	Five out of the six mothers reported a decrease in parental stress after the completion of the mindfulness program. The method had positive effects on the children as well, decreasing anxiety and thought problems.
Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2009, UK	To assess the needs and experiences of parents of children diagnosed with ASD.	67 multi-disciplinary professionals and 95 parents who reported on 100 children.	Questionnaires were completed by the participants.	Diagnosis took too long and future planning wasn't successful. Plans for the future were looked at regularly, but not parental views, monitoring procedures, or intervention data. Improvements regarding diagnosis and forward planning are needed.
Margetts, Couteur & Croom, 2006, UK	To describe the experiences of grandparents in families with children with ASD.	6 grandparents of children with ASD; 5 grandmothers and 1 grandfather.	All grandparents were interviewed separately. The hour-long interviews followed a semi-structured format. Notes were taken during each interview which were later transcribed. Each interview was followed up with a telephone call to minimize errors or misunderstandings in the responses.	The grandparents experienced a great amount of stress and worry for both their grandchild, as well as their own adult child. Grandparents were often unsure of their role in the family, as they did not want to undermine the child's parents. They also felt their knowledge of the child's condition and their treatment was inadequate.
Sage & Jegatheesan, 2010, USA	To assess how a typically developing sibling viewed their other sibling who was diagnosed with autism spectrum disorder.	2 families with different cultural backgrounds participated. Both had an autistic child as well as a typically developed child.	Interviews and a draw-and-tell technique for the sibling involved.	The families differed a lot from each other. One brother viewed their autistic brother positively, while the brother from the other family more negatively.

Author(s), year and country where the study was conducted	Purpose	Participants (sample size)	Data collection and analysis	Main results
Smyth & Slevin, 2010, Ireland	To describe the experiences of ASD families of having an assistance dog.	5 mothers and 2 fathers of ASD children were interviewed.	Individual, semi-structured interviews. The interviews were recorded by taping or field notes.	All parents found the presence of a service dog beneficial to them, their child and the entire family. The parents reported improvement in the child's behavior problems, family relationships and motor skills. They also found that the assistance dog increased the overall safety of the child, therefore decreasing the stress of the parents.
Thompson, McFerran & Gold, 2013, Australia & Norway	To explore whether music therapy improves the social engagement of children with severe autism spectrum disorder.	23 children with severe autism spectrum disorder.	A randomized controlled trial using quantitative and qualitative data.	The children's involvement at home and in the community improved. Parents responded in a more positive way towards their child.
Vivian, Hutchins & Prelock, 2012, USA	To research the possibility of using comic-strip conversations as a parent-implemented intervention.	2 parents and their 8-year-old daughter with ASD.	Both quantitative and qualitative data were collected.	The participating parents were successful in implementing the interventions at home. The parents reported significant improvement in their daughter's behavior. Parents felt the CSCs helped them get more discussion with their daughter and work through problematic situations more effectively.
Zablotsky, Bradshaw & Stuart, 2012, USA	To examine the association of maternal mental health and ASD.	56,547 mothers of children between the ages of 3-17.	National Survey of Children's Health (NSCH) was used and a telephone survey was utilized.	ASD increases their mother's risk for mental illness, most notably depression. Lower income families, as well as mothers of black children experienced more stress than others. The severity of the child's condition and comorbid condition had negative effects to maternal mental health.



Promoting Positive Mental Health of Families with Children with Autism Spectrum Disorder - A literature review

Nea Nykopp, Katariina Partanen

The purpose of this thesis was to describe the methods on how to promote positive mental health of families with children with autism spectrum disorder (ASD). The aim was to use the acquired knowledge to promote positive mental health of families with children with ASD. This thesis answers the questions: 'what are the factors related to positive mental health in families with children with ASD' and 'what type of methods are available in order to promote the positive mental health among families with children with ASD'.

Parental stress and other psychological issues caused by a child's autism, were some of the key findings in this literature review. The stress experienced by parents was visible in most of the articles used. The potential of various coping methods should be further studied, as not all of the methods suit all families.

Factors related to positive mental health

- Parental stress
- Psychological problems
- Resources
- Family relationships

Methods available in order to promote positive mental health

- Social support
- Professional guidance
- Therapeutic methods
- Religion and spirituality