THESIS
ADULT ASPERGER’S SYNDROME

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Thesis
Adult Asperger’s Syndrome
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My thesis topic is the Adult Asperger’s Syndrome. The starting point for my thesis is the fact that many persons affected by the syndrome do lead independent adult life, with jobs, careers, long-term relationships and many have also children. Nevertheless the syndrome, which nowadays is diagnostically placed within Autistic Spectrum Disorders, does have implications for the persons affected and their families. In some cases the ramifications are more severe for the people around than the person himself/herself. The research literature studied during the thesis work were mostly concerning the coping and the well-being of the persons with the Asperger syndrome, but also the spouses and close family members. Nevertheless this view that the persons around the AS person could be in need to be seen and heard is still new, and requires more research.
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1 INTRODUCTION

The topic of my thesis is the Asperger's Syndrome (AS) in the adults. In my research plan I was aiming to discover practical and doable ways to overcome problems which arise in the family when it is a partner or the parent with the Asperger's Syndrome. In the actual thesis work, I am evaluating the information available in the research literature, in the view of my research questions. These were the recognition of Asperger’s syndrome in adults, as the disorder is often undiagnosed. The research questions also included the recognition of the situation of the family members, and their coping in the situation where the partner or the parent has Asperger’s syndrome. I was posing the research question around what is Asperger’s syndrome in adults, how it presents and how persons live with it. I was also looking these very same questions in the view point of persons living with someone who has Asperger's syndrome.

The purpose for the nursing aspect of this study is to find ways to help nurses to recognize situations where it could be possible that the patient’s or client’s Asperger’s syndrome can have a bearing in the situation. The nursing fields where this ability to recognize the parents’ Asperger’s syndrome are paediatrics, occupational health care, psychiatric nursing, even medical nursing. In the nursing work, it is always important to communicate with patients/clients and their family members, and my thesis work could also be seen as promotion to think about communication in a different way. E.g. for a person with the AS, eye-contact could be uncomfortable, if not impossible, he/she does not mean to be impolite, and in that kind of situation a nurse could use the knowledge of the AS to find alternative ways to communicate.

The Asperger's Syndrome is a neurodevelopmental condition, which affects social and emotional behaviour and relationships throughout person’s lifespan. (Montgomery et al. p.1931, 2016) My aim was to gain a holistic and systematic view on the complex issues of the AS in the adult. Another side of the coin is
the so called Cassandra phenomenon. This refers to the demands and stress and their consequences in families where a member has Asperger’s Syndrome. (Rodman Karen, p.11, 2003). My aim in the nursing field with the choice of this topic was also to raise the awareness of the situation faced by the persons with the AS and their family members. I wanted to find out about the coping mechanisms family members have or develop around the AS person.

There are a lot of research material and literature about the childhood autistic disorders, but not so much research has been concentrated on the similar disorders in the adult population. The idea that it could be the parent affected with the autism is still fairly new. E.g. Edward Ritvo with his co-workers have been writing about this aspect of Asperger’s Syndrome, noting that indeed the children affected do grow up and sometimes have families of their own. (Ritvo, Edward, p.48, 2005). Often the Asperger’s Syndrome is a hidden condition, for many persons affected are also undiagnosed, yet making an impact on person’s lives. This aspect of the Asperger’s syndrome made the research and writing of the thesis work challenging, and for the nursing field the challenges are the same. A hidden condition is difficult to deal with, and more visibility, including writing a thesis about it, could alleviate problems for the AS persons and their families. As well as Edward Ritvo, another researcher in this field, Uta Frith has pointed out the complicated nature of the AS; in her article ‘Confusions and controversies about Asperger syndrome’, she writes that the problems in social communication might not be pinpointed during the childhood, and in the adulthood the problems can be hidden, because the person with the AS has learned to compensate the lack of social communication to some extent. (Frith, Uta, pp. 672-673, 2004)

Asperger’s Syndrome is defined shortly as a neurobiological and medical disorder on the autistic spectrum, it can also be understood as higher functioning autism. (Rodman Karen, p.11, 2003). Diagnostic criteria by Gillberg & Gillberg gives a flavour of problems the persons affected and their nearest and dearest are facing. The criteria according these researchers lists the following traits: 1. Problems with social interactions, 2. Special interests, very narrow and intense. 3. Strict routines, 4. Problems with speech and communication, 5. Problems with non-verbal communication, 6. Problems with
motoric (gross or fine) development. (Gillberg, p.13, 1999). This diagnostic criteria fits the picture, but nowadays the term Asperger’s is about to be replaced by the term Autistic Spectrum Disorder, shortened ASD.

Indeed, there is no shortage of the material about the AS or the ASD in children, but finding the suitable material about the conditions in adults was not so easy. This finding was confirmed in the articles I found to review in my thesis. In Winnie Lau and Candida C. Peterson’s article ‘Adults and children with Asperger syndrome: Exploring adult attachment style, marital satisfaction and satisfaction with parenthood’, the writers comment the fact that adults with the AS do marry and raise the families of their own, but as yet, this phenomenon is not widely researched. (Lau and Peterson, p.392, 2011) Strunz and her co-writers in the article ‘Romantic Relationships and Relationship Satisfaction Among Adults With Asperger Syndrome and High-Functioning Autism’ state that even the topic of their research is important in understanding the experiences of the persons with the AS and HFA and their partners, it is not commonly studied. (Strunz et al. p.113, 2017). Even if not studied widely, the sociological approach with the aims of inclusion and participation points to the direction that the thought of the persons with the AS having an independent life with career, romantic relationship and children is becoming accepted. (Ryan and Räisänen, p. 136, 2009)

2.0 Main Concepts

In the thesis work the key terms used concentrate around the Asperger’s syndrome and the autism spectrum disorder. The Asperger’s syndrome has its’ origins in the work of Hans Asperger, an Austrian paediatrician, was first to describe cases of considerable intellectual abilities and grown-up like speech combined to symptoms which he described as ‘autistic psychopathy’. Hans Asperger did his research in the 1940’s and the coined term reflects the time. Asperger himself draw attention not only of the children in his care with the autistic traits, but also noticed that some of the parents shared similar symptoms. Asperger was also effectively a first campaigner for the rights and equal education for the persons with the autism, he recommended for the more individual approach in the class room for these pupils. He also wrote about the
possibilities of the autistic individuals in their chosen fields of profession and that their high intellect was of value for the larger society. (Frith, Uta, pp. 673-674, 2004)

In the modern research the Asperger’s Syndrome is defined as a neurodevelopmental condition, which affects social and emotional behaviour and relationships throughout person’s lifespan. (Montgomery et al. p.1931, 2016)

American Psychiatric Association describes the ASD (the autism spectrum disorder) also as a neurodevelopmental disorder and explains that it is most visible in ‘persistent deficits in social communication and social interaction’ as well as in ‘restricted, repetitive patterns of behaviour, interests, or activities.’ (American Psychiatric Association, p. 50, 2013)

Asperger Syndrome, AS, is also a part of the autism spectrum disorder. Yet, research done by Roy et al, differentiates between autism and Asperger syndrome in the point that in the AS there is no notable delay in speech and cognitive development in childhood, as is the case of autism. (Roy et al, p. 50, 2015) The idea of the spectrum is explained by other researchers also, and the AS could be seen as the high-functioning part of the aforementioned spectrum. The spectrum allows the thought of large variety of traits in different individuals. (Myhill and Jekel, p.1, 2008)

These definitions explain the some of the nature of the AS and ASD, and in the thesis work I have concentrated in the Asperger syndrome. Nevertheless, the diagnostic process is changing and the AS is placed under the umbrella term of ASD, and thus the definition of ASD in this context also.
2.1 Components of the cognitive psychology

In her book, 'Asperger Syndrome in the family', Lianne Holliday Willey poses a question which of the following is the definition of the Asperger’s Syndrome: 1. Neuro-biological disorder characterized by marked deficiencies in social and communication skills, 2. High-functioning autism, 3. A subclass of non-verbal learning disorders, 4. A pervasive developmental disorder, 5. An excuse for poor behaviour, 6. All of the above. (Willey, Lianne Holiday, 2001, pp. 14-15). As light-hearted this list of traits may look like it has a grain of truth. The theoretical frame work of the thesis builds around the cognitive psychology components of which I have already listed in the introduction but from there I will expand to implications of these in the adult life. With these in mind Willey’s book was a valuable background source material, as behind the diagnostic criteria and the cognitive psychology real people live the Asperger-complicated lives.

In the theoretical framework the cognitive psychology components of the Asperger’s Syndrome will also help to understand the complications of the day-to-day and family life. Gillberg in his book ‘Nörtti, Nero vai Normaali; Aspergerin oireyhymä lapsilla, nuorilla ja aikuisilla’ lists four cognitive functions which do not work effectively in Asperger's Syndrome. These four are; empathy, theory of mind, executive functions, central coherence, automatizing the functions. (Gillberg, 1999, p. 88) These four components are used as a backbone against which the articles are assessed.
2.2 Theory of mind

Theory of mind means that the person has an ability to recognize different mind sets in self and in others and to recognize that they are not the same in self and others. Also the theory of mind contains the idea that the thoughts and beliefs are can be different in self and others. (Baron-Cohen et al. 1985; Premack and Woodruff 1978)

The theory of mind is a necessary thought process to develop empathy. The lack of the developed theory of mind has an impact on the aptitude to receive and to respond to emotions. (Montgomery et al. 1932-1933, 2016; Attwood, p.106, 2007) As well as the difficulties in the social situations, the traits associated with the lack of theory of mind do hinder the close romantic relationships between adults. Different stages of the relationships, from the initial stage of wanting to attract the attention of the potential partner, to established relationship in which the partners need to maintain the relationship, require the skill of being able to see the other’s viewpoints. (Strunz et al. p.113, 2016) Tony Attwood has written in his book ‘The Complete Guide to Asperger’s Syndrome’ how the person with the AS can seemingly be incapable to regret something he/she has done or said and also to apologize and to forgive. These traits are connected to the theory of mind, as a person with the AS finds it difficult to understand the feelings of the others, and Attwood stresses in his writing that this is a central trait in the AS. The implications of this for the romantic relationships are manifold. (Attwood, p. 301, 2007).

In the similar vein the article written based on the Uta Frith's lecture on the controversial nature of the Asperger syndrome paints a picture with the core features of problems in social learning and social awareness. The writer describes of egocentrism which does not have any place for consideration for others. This does not work the same as in the normal person who has selfish motives. The normal person would change the behaviour and the means to get one’s goals achieved according to the situation and the context. Whereas the person with the AS cannot see the context and would rigidly act on the egocentric drive without the thought whether that was on one’s best interests or
not. Also it seems that this behaviour is unintentional. This kind of behaviour presents a big stumbling block to the long-term relationships and can leave partners and family members frustrated and hurt. The reciprocity of the emotional exchange can be completely lacking, even when the person with AS is highly intelligent. (Frith, p.679, 2004) The missing reciprocity in the relationships is strongly linked to the undeveloped theory of mind, and other writers in their articles are also commenting that.

An article by Myhill and Jekel on the Asperger marriages also gives an overview of the features of the AS; the diminished social interaction and rigid behavioural patterns are the most harming for the daily functioning. Communicating in a way that is intuitive for non-AS persons is another problem area making life complicated for both the sufferer and his or her family. This article also confirms that these problems are present even when the person with AS has a normal or high intelligence. Many can only deduct some of what others may feel or think using the intellect, but it does not come intuitively, and some cannot do that at all. (Myhill and Jekel, p. 1, 2008) This deducting and intuitive communications are essential parts of theory of mind. According to Tony Attwood, the neurotypical children notice and process the social tips and hints, which point to the thoughts and feelings of others very clearly. It seems that their minds process these social tips and hints first, before any other stimuli coming to their consciousness, and that they have an inner ability to respond to the social stimuli. (Attwood, p. 106, 2007) Yet with the intellectual capacity and the ability to develop the interests, many person with AS are capable to compensate and manage independently. (Myhill and Jekel, p.1, 2008)

The same article by Myhill and Jekel proceeds to further map out how the living in the relationship with an AS individual affects the partner. The main issues seem to be the isolation, lack of emotional support, anger and depression. The writers also point out that many persons with the AS depend on their non-AS spouses on social, practical and emotional needs, but are unaware of the needs of the others’, and also are unaware of their own behaviours and their consequences. In the case of the non-AS spouse raising a subject concerning this kind of issue, the response from the AS spouse might be an outright denial, stonewalling, or even physical or verbal attack. (Myhill and Jekel, pp.4-5, 2003)
Other researchers have also discussed the relationships and the implications of the AS. In the article written by Sandra Strunz and her collaborators, the deficits of the ASD in mind, the writers do present the thought that the romantic relationships are hard to understand for the persons with the AS. Furthermore the difficulties in making informed choices, rigidity of thinking, self-centredness, lack of emotional maturity and sensory problems complicate the AS persons possibilities to have and to maintain close relationships. Nevertheless the writers do present the view that the relationships are part of the life quality for all people, and taking part in social life in the form of relationship is a considerable aspect of well-being. (Strunz et al, p.114, 2017)

The article by Ryan and Räisänen follows the sociological thinking while also concentrating on the issues of the AS tied to the social sphere. The article was called “Like you are just a spectator in this thing”: Experiencing the social life the ‘aspie’ way”. The writers stress their thought that the AS could be dealt better with the thought of difference rather than a disability. The sociological approach of this article combined with the thought of difference rather than a disability. (Ryan and Räisänen, p.135-136, 2009) This article also gives a definition of the AS within the framework of the wider autistic spectrum. The diminished social interaction, communication problems and the mind blindness being the core issues according to the writers. Nevertheless the writers argue that some issues, especially troubles with communication and interactions could be partly caused by the wider society’s lack of knowledge and understanding of the AS. (Ryan and Räisänen, p.136, 2009)

The interviews of the Ryan and Räisänen article also show how the participants doubt the intuitively used rationale by which the persons without the AS see and interpret the daily happenings and interactions between people. E.g. A man remembers the childhood games he did not understand, he simply could not bring himself to play cops and robbers, because he only saw a group of school kids running about pretending to be something they were not. Even now, as a young man, he did not understand the meaning of children playing. According to the writers this could be seen as an example of lacking the theory of mind in a sense of deficit, whereas the writers want to see this as different way of thinking. (Ryan and Räisänen, p. 137, 2009)
Connected to the theory of mind is the self-awareness. The article written by Uta Frith takes on a sensitive view point with the thought that many people with AS have the intellectual powers to process the world around them and that some find the insight into themselves and to their condition in the adult life. Yet, even with this insight, they seem to lack interest of the experiences of others. Often persons with AS think of themselves as having a different ‘wiring’ and thus different needs, just like Ryan and Räisänen were pointing out to a different way to think in their article. (Ryan and Räisänen, p. 137, 2009) Many persons with AS don’t perceive this difference as a clinical condition, and many tend to emphasize the difference by calling the people who do not have Asperger’s syndrome as neurotypicals or ‘NTs’. (Frith, p. 684, 2004)
2.3. Theory of mind and the diagnostic process

Diagnosis process is also within some dimensions connected to the problematic of the theory of mind. The AS has not been in the diagnostic manuals that long, but there is also a problem of the individuals with the AS not willing to seek the professional opinion. This unwillingness is tied to the social deficits of not being able to see the own behaviour and its’ consequences and also a certain lack of awareness. (Myhill and Jekel, pp. 2-3, 2008)

The articles discussed the diagnosis process from different points of view, but often the lack of theory of mind was mentioned as a factor making the diagnosis process harder, and sometimes preventing it altogether. Uta Frith commented of the diagnosis process also from the point of view that a child with a good progress in the language, who has interests and hobbies, even if the interests might be intense and particular, and a good memory, does not necessary make parents worry, at least not initially.

Even when the child does not develop the usual relationships with other children, the parents might not be overly concerned as the child’s other skills might compensate so effectively. This might lead a much later diagnosis than in other cases on the autistic spectrum, but it might lead to a situation in which the AS is not diagnosed at all. The AS is often referred as a hidden condition, due to this, and also because of the compensation skills and mechanisms. (Frith, p.678, 2004)

Caroline Sandell, Anette Kjellberg and Renee R. Taylor have in their article studied the diagnostic process. The article is called ‘Participating in diagnostic experience: Adults with neuropsychiatric disorders’. The article explains the ASD as an umbrella for several conditions which include autistic syndrome, Asperger’s syndrome, atypical autism, and pervasive developmental disorder, not otherwise specified. This reflects the changing diagnostic trend, in which the Asperger syndrome is not an independent, separate diagnosis anymore. The ASD symptoms are presented in the framework of problems in the executive functioning, cognitive processes and social interactions. The persons with the
ASD are reported likely to be misunderstood and misunderstanding others, and likely to go through social isolation and loneliness. (Sandell et al, p.136, 2013)

The writers have described the reactions of the adults receiving a neuropsychiatric diagnosis, including the ASD. The actual nature of the ASD makes the diagnosis process and then the consequent reactions complicated. This finding has been mentioned in other articles also, and it seems that for adult Asperger syndrome that is a defining characteristic which makes it such a problematic condition. As Sandell et al point out, the person with the ASD is born that way, but lacks the self-awareness of the condition. The ASD is not likely to be progressive and the symptoms are idiosyncratic, thus a long-term forecast of how the condition evolves over time is not easy to present. Some individuals find the diagnosis labelling and unhelpful. Yet, the diagnosis can offer new insight and opportunities for support and acceptance. (Sandell et al, p.137, 2013)

Laura Lewis Foran has studied the self-diagnosis of the ASD in her article, which is called ‘Exploring the Experience of Self-Diagnosis of Autism Spectrum Disorders in Adults’. According to her research also when the ASD symptoms are in place, without the intellectual disabilities many persons with the ASD go through the childhood without getting the formal diagnosis. In adulthood these people are able to function independently, but often have difficulties in some areas of their lives due the symptoms, and often suffer from depression, anxiety and risk of suicide. The undiagnosed persons with the ASD often lack insight to their own behaviour and that of the others and this is likely to make depression or anxiety more pronounced. All these findings support the results of what happens when the theory of mind does not work, and are mentioned in other articles as well. (Lewis, p.575, 2016)

Lewis also refers to writings of Philip Wylie, who has had a diagnosis of the ASD as an adult. Wylie comments in his model about the diagnosis process that the self-identification and self-awareness are important steps that happen before the diagnosis. Also, the development of the self-awareness might be even more constructive process for an individual with the ASD than a diagnosis. (Wylie, 2014, Lewis, pp. 576-582, 2016)
2.4. Executive functions

Executive functions involve the ability to organise and plan, working memory, ability to manage their reactions and manage the impulsivity, self-regulation, managing time and putting things in the order of importance, prioritize, understanding complicated and abstract concepts and using new strategies. Finding the alternative ways to solve problems might be very difficult and flexible thinking might be very limited in a person with the AS. In the practical terms, the person with the AS might struggle in a situation where he\she needs to change his\her way to do any given thing. They might only have one way to do something, and it is difficult to change that, even when seeing that it is not working. (Attwood, pp. 226-227, 2007)

The problems with the executive functions are reflected in the adult relationships also. The partner of the person with AS may feel like they were only domestic staff, accountant and a parenting figure, as Tony Attwood mentions. (Attwood, p.302, 2007)

The article by Uta Frith also maps the cognitive components of the AS. The writer points out that often the persons with AS have very good grasp of non-social parts of their lives. It is noted that an uneven profile of skills and cognitive functions is typical of AS and also other forms of autism. (Frith, p. 677, 2004).

In the article by Sandell et al, as already mentioned, the ASD symptoms are presented in the framework of problems in the executive functioning, cognitive processes and social interactions. (Sandell et al, p.136, 2013) Sandell and her co-workers also discuss the diagnosis process in the view of the weak executive functions. The diagnosis with strong emphasis on the individual participation helped the study group to come to self-acceptance. The problems they might have had all their lives were given names also helped them to take responsibility for their own choices. That the diagnostic process has a strong emphasis on the practical solutions and own responsibility allowed the use of practical support to compensate the areas which cause difficulties. The practical
support comes in different forms, for one it was cleaning help at home, for another a hand-held device to help with time management at work. (Sandell et al, p.139, 2013)

Roy and her team of researchers have been studying and writing about the comorbidities of the ASD. They presented the connection of the central coherence, the ASD and the comorbidities as a complicated pattern of many factors. Also it seems that the weak central coherence combined to the lack of theory of mind does wreak havoc in the AS persons lives, and also in the lives around them. The demands and frustrations which may seem overwhelming in social and working lives may explain some cases of the substance abuse. The occurrence of the OCD is linked with the repetitive behavioural patterns often reported with the autism. (Roy et al, p.56, 2015)

Tony Attwood also writes about the repetitive behavioural patterns and strict routines. Some of the repetitive patterns and routines can be explained by the weak central coherence, the person with the AS finds it very difficult to develop a clear picture of the day-to-day life. The new things in life, any kind of confusion or disorganization, or uncertainty cause anxiety and frustration for an AS person, and the routines and repetitive behaviour are in place to prevent anything from changing, and thus the AS person does not need to change the concepts of his/her preordained world view. (Attwood pp. 235-236, 2007)

Strunz et al ponder the reasons for some of the participants in their study who did not have a relationship history had for this. Some reasons were stated as the demands of the relationship were too much, or that not being able to meet the expectations of the partner. Another dimension of these reasons for not having relationships is the lack of flexibility, the own routines cannot always be followed with other person, and in the relationship the partner’s needs do also need responding to. The authors do concede that the partners without autistic traits might experience these relationships differently, that the partner with the ASD is often satisfied with a relationship, but the reality for the partner is very different. (Strunz et al, p.122, 2017)

The results of Roy et al study showed that even the participants were on the high-function end of the spectrum with many of them with university degrees,
this did not translate in the professional success. The writers’ thoughts on this finding were centred simply on the demands of the adult life; the requirements for fluidity, independence, and interactivity manifolds after school and further studies. On the family-and marital life the pattern seemed that the persons with the AS do want to have a relationship, but their feeling toward the relationship is controversial; the need for own space and the special interests do come first before the partner or the needs of the family. Some persons with the AS do manage to have successful relationships according to the authors, yet the article concludes with the thoughts that the AS, even the milder cases, has severe consequences for the adults, and these make the likelihood of the comorbidities more pronounced, and the comorbidities also become more severe. (Roy et al, pp. 57-58, 2015)

The study by Pollmann et al found that the autistic traits affect the duration of the relationship in a positive manner. The possibility of the divorce in these relationships is not extensively studied though, but the finding according to their study, is that the men with autistic traits are less likely to be satisfied with their relationships would cause a higher incidence of the divorce. Nevertheless it does not seem to be that way, and it has been suggested that the unwillingness to face changes in life for the autistic persons could be a driving force for the long duration of these marriages. (Pollmann et al, p.478, 2010)
2.5. The central coherence

The weak central coherence means that many people with the AS concentrate on the details, but cannot process big entities. The small details might seem very relevant, but the important, ‘big picture’, is not visible for someone with the AS. The need for the strict routines in the everyday life is likely to be connected with the weak central coherence, the routines make it easier to make sense of the unpredictable life. (Attwood, pp. 234-235, 2007)

Attwood mentions another name for the weak central coherence, that of the monotropism. This means that the person with the person with AS may concentrate on things, whatever they may be, with curious reasons, and he or she cognitively does not register large areas of potentially relevant information. The reality which is based on this method of information gathering is splintered. Also, the AS person learns separate facts, but the analysis based on the larger entities might not be possible for him or her. (Attwood, p. 234, 2007)

Uta Frith has also discussed the weak central coherence in her article, her view on that was that the weak central coherence in a way ‘forces’ an individual with AS to concentrate on details, as the so-called ‘big picture’ simply is not visible to an individual, and this also explains the narrow interests. Another leading researcher on the AS, Simon Baron-Cohen has brought forward an idea that a person with AS makes sense of the world by collecting vast amounts of facts in a systematic way, ‘systemising’. According to his research, this is part of the weak central coherence. (Baron-Cohen, 2002, Frith, p.684, 2004) These findings do resonate with the writings of Tony Attwood.

The interviews completed for the study of Ryan and Räisänen do confirm the thoughts suggested already about the central coherence. The writers comment that the participants were reluctant to answer questions which were general by nature, and wanted clear questions which could be answered in a precise way.
The interviews show how the participants doubt the intuitively used rationale by which the persons without the AS see and interpret the daily happenings and interactions between people. (Ryan and Räisänen, p. 136, 2006)

In the interviews conducted by Ryan and Räisänen, the use of the computer for the communication is widely discussed. The computer takes away the need to be able to discern the facial expression or the body language, and the precise way the computer works the misunderstandings were lessened. This precision required for the communication and the whole life, as the discussion about home space, illustrates the weak central coherence. The home was seen as place were other peoples’ presence, opinions and unpredictability is minimised. This was not the case if a person was living with someone else. As already mentioned, some interviewed persons with the AS had made the conscious decision not to share their lives with significant others, the same can be seen here as discussing the living arrangements. The interviews show also unconventional ways to overcome difficulties when people do live with others, e.g. family members’ communication through text messaging at home and creating small separate areas within the home to cater the needs of the AS persons. (Ryan and Räisänen, p.141, 2009)

According to Strunz et al, often the persons with the ASD would like to pair with a partner who is neurotypical, because of the benefits someone with the social, emotional, and practical skills will bring into the relationship. (Strunz et al, p. 114, 2017) This statement refers to both weak executive functions and weak central coherence, as well as the theory of mind. Myhill and Jekel also point out that many persons with the AS depend on their non-AS spouses on social, practical and emotional needs, but are unaware of the needs of the others’, and also are unaware of their own behaviours and their consequences. (Myhill and Jekel, pp.4-5, 2003)

Myhill and Jekel’s take on the issue of the weak central coherence as well as the weak executive functions is tied to the strict routines. An area in the relationships which might cause difficulty for the couples is the rigid structure and routine required by the AS partner. The non-AS partner will occasionally crave spontaneity, and at least flexibility. For the couple it can be difficult
situation to grasp, that what looks like a behavioural issue, has actually a neurological root, and thus, understanding, negotiating, compromising and ultimately a change, are hard to achieve. This situation often causes disappointment, depression and anger according to the writers. (Myhill and Jekel, p.3, 2008)

2.6. Automatizing the functions

Automatizing the functions means in the context of the Asperger’s syndrome the inability to take the learned information to the next level, the information does not seem to stick, or it seems that the person with the AS does not learn from the mistakes. In the normal learning process the learnt things become sooner or later automatic, but with the AS this process is limited. This problem is often very visible in the daily living, and combined with the tendency to get ‘stuck’ in the details, the people closest to the person with the AS are very aware of this side of the AS. (Gilbert, pp.94-95, 1999)

In the interviews conducted by Ryan and Räisänen, one man talks about his realisation that he understood the demands of the close relationship including the sexual side of it, but could not share his life in the way a partner would expect. The AS persons interviewed in the study with long-term partners reveal having problems in their relationships because emotionally they are not able to share their feelings, or give an experience of closeness to their partners. Similarly the interviewees tell of struggles in communication which is not purposefully exchanging information. They see the communication which is emotional, or for the social interaction without a clearly defined goal as pointless. (Ryan and Räisänen, p.139, 2009) These findings are connected to the automatizing the functions and the lacking of theory of mind. The person with the AS might have been asked repeatedly by his or her significant others about the emotional feedback, and they might have been told how to demonstrate that, but that skill does not take root. (Myhill and Jekel, p. 3, 2008)

In the article written by Lau and Peterson, the Asperger syndrome was presented as a pervasive condition with a neurological and developmental origins. The AS has at its’ core problems with social interactions, intellectual inflexibility and restricted communication. The language skills might be very well
developed in adults, but these skills are combined with the lack of social interaction and the mind-blindness. The writers also bring forth the thought that even with the same diagnosis, the individual variation is high within the outcomes in life. (Lau and Peterson, p. 392, 2011)

3. Literary review as a method

A literary review is defined in the research and academic writing guides as an “account of what has been published on a topic by accredited scholars and researchers”. (http://advice.writing.utoronto.ca/types of writing/) The same academic writing guide gives as purpose of a literary review the conveying readers what knowledge and thoughts have been amassed on a given topic, and also what the strengths and weaknesses are in the research literary of that topic. (http://advice.writing.utoronto.ca/types of writing/)

I chose the articles according to the theme and topic, choosing the articles which dealt with the AS and the ASD with an approach rooted to the realities of the adult life. Admittedly I had a pre-conceived opinion in my research that the persons with these conditions do lead independent adult life. Unfortunately my thesis topic is not widely researched, so the inclusion was almost guaranteed to any article written in the 2000’s concerning the adult with the AS. I also consciously chose articles which had their research question rooted in the relationships and daily life, as I wanted to study the topic on basis of lived experience. I also used some book sources, the most influential of these was Tony Attwood’s ‘Aspergerin Oireyhtymä lapsuudesta aikuisuuteen’. The literature used was concentrating on the adult persons with the AS, the themes of the different sources concentrated on the relationships, daily life, and problems connected or caused by the AS. In this point I have to stress how much more research is conducted on the children with autism spectrum disorder. Finding suitable articles concerning adults was challenging. In the following table I have presented the articles I used in the thesis, in the table the publication year and the theme of the articles are presented.
<table>
<thead>
<tr>
<th>Article</th>
<th>Writers</th>
<th>Publication</th>
<th>Year</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emanuel Miller lecture: Confusions and controversies about Asperger syndrome</td>
<td>Uta Frith</td>
<td>Journal of Child Psychology and Psychiatry</td>
<td>2004</td>
<td>General overview of Asperger syndrome on both children and adults</td>
</tr>
<tr>
<td>Asperger Marriage: Viewing Partnership thru a Different Lens</td>
<td>Grace Myhill and Dania Jekel</td>
<td>Focus Homestudy Course, NASW</td>
<td>2008</td>
<td>Relationships</td>
</tr>
<tr>
<td>‘It’s like you are just a spectator in this thing’: Experiencing social life the ‘aspie’ way</td>
<td>Sara Ryan and Ulla Räisänen</td>
<td>Emotion, Space and Society</td>
<td>2009</td>
<td>Sociological approach to Asperger syndrome on adults, social encounters</td>
</tr>
<tr>
<td>Mediators of the Link Between Autistic Traits and Relationship Satisfaction</td>
<td>Monique M. H. Pollmann, Catrin Finkenauer and Sandee Begeer</td>
<td>Journal of Autism and Developmental Disorders</td>
<td>2010</td>
<td>Relationships</td>
</tr>
<tr>
<td>Participating in diagnostic experience: Adults with neuropsychiatric disorders</td>
<td>Caroline Sandell, Anette Kjellberg and Renee R. Taylor</td>
<td>Scandinavian Journal of Occupational Therapy</td>
<td>2013</td>
<td>Adults, Diagnostic process</td>
</tr>
<tr>
<td>Beyond childhood: Psychiatric comorbidities and social background</td>
<td>Mandy Roy, Vanessa Prox-Vagedes, Martin D. Ohlmeier and Psychiatria Danubina</td>
<td></td>
<td>2015</td>
<td>Adults, psychiatric problems associated with</td>
</tr>
</tbody>
</table>
The thesis work as a literary review shaped up at the end as a narrative and qualitative review. Qualitative in a sense that it was concerning the human experience, which cannot be put in numbers or tables as such. Narrative literary review came in the play as the articles used had a common thread of adult AS, but the approaches were wide, concerning relationships, diagnostic process etc. Narrative literary review is explained as a tool used when connecting studies on differing topics with the view for reinterpreting or interconnecting. Narrative literary review can be used to build theories of variety of topics, and also to help formulating a hypothesis on any given subject. (Baumeister and Leary, p. 312, 1997) In my thesis work I see the narrative literary review technique in work not only as linking the variety of view points in the articles, but also in the building method of my theory that the persons with AS lead independent adult life with successes in some areas and difficulties in others. My theory, and the hypothesis for future study of this subject could be formulated that many persons with AS are content and capable in their own lives, but the lives of the family members and spouses are sometimes hard and made complicated by the needs of the AS person.

The analysing the content of the material used in the thesis was conducted in phases which followed the drafts written in the course of the thesis work. The earlier drafts were more of an essay and presenting the articles in form of the summaries. This method familiarized me with the material, but did not offer any synthesized text at that point. The analysing was based on the cognitive psychology components affected by the Asperger syndrome. I was shifting
through the articles in the view of how these psychology components affect the persons with AS in different areas of life and in different life situations. Also I kept in mind how they present and how they affect the family members and spouses who live in close contact with the AS person. As already mentioned this could be a research question for future study.

The literary review as a research method was used to evaluate the existing information and the approaches on the adult Asperger syndrome in the view of the components of cognitive psychology. The process of comparing, synthesising and writing into a thesis required several drafts, and also of trial and error. The scientific research literature written on the adult Asperger syndrome is still quite narrow on scope, many articles used in the thesis did mention the same trend. I ended in the decision to write a literary review as a useful tool to both find out about the existing research and to study and present the topic of adult Asperger syndrome itself. Maybe all in all I have not achieved these goals entirely successfully.

4. Conclusions

For any adult, a mutually satisfying romantic relationship is a big part of life. This thought has been in one of the central themes of the articles in the thesis process. Pollmann et al put that idea succinctly as the satisfaction in the relationship is dependent on the specific behaviours within that said relationship; responsiveness toward the partner, understanding, validation, and caring are all these behaviours needed in the close relationship. Also disclosing of intimate knowledge about self for the partner and sharing feelings and thoughts are desired behaviours in the relationship. The writers allow here the thought the ASD is characterized by the lack of these behaviours; poor understanding of others’ emotions and limited communication are all hallmarks of the ASD. The relationship can develop only if the couple finds feelings of closeness and trust, and these are the main building blocks for a happy and working romantic relationship. (Pollmann et al, p.471, 2010)
Other hallmarks of adult life are family life, as already mentioned life partner, but also as a parent, and the working life. All these spheres are affected in the ASD, but often it is the family and the partner who bear the brunt of the consequences of the ASD symptoms. In some research, the cognitive psychology components; theory of mind, executive functions and central coherence are mentioned as the big three, which are affecting deeply both the person with ASD and the family.

Myhill and Jekel write about this, as a problematic time for the relationships affected by the AS is the birth of the first baby. The same, already mentioned traits of the AS do complicate the family life, which is now not only the couple themselves, but a small child needing a lot of care and responding in an intuitive manner. (Myhill and Jekel, p.3, 2003)

The same writers also do state in their article that the marriages to persons with the AS are full of challenges, and the consequences of these challenges can be considerable. The psychological well-being of the family-members can be affected. This statement is given, according to the writers, with the hope that clinical staff could be able to understand and support individuals with the AS and their partners and families. (Myhill and Jekel, pp. 1-2, 2008)

The theoretical framework of the research plan also contained the different terminology. As the diagnostic criteria have changed, the name of the condition has also changed from Asperger’s Syndrome to ASD (Autistic Spectrum Disorder), or Autism Spectrum Conditions, ASC. Montgomery and her collegues in their paper, give a picture of unifying and shared set of problems across the spectrum; namely the difficulties in the social, emotional and behavioural fields, and it is only the severity of the problems which places the individuals on the different places on the continuum, which is thought as the spectrum. (Montgomery et al, p. 1931, 2016)

The theory behind the Cassandra phenomenon was mentioned in the research plan. The effects of having a family member with Asperger’s Syndrome can cause development of chronic stress, depression and medical and psychological disorders consequently. (Rodman, Karen, 2003, p.14)
5. Discussion

The articles I used in my work had a variety of viewpoints concerning the ASD or the AS in adults. Nevertheless, it was not an easy task to find suitable articles, as the research is still very much concentrated on children with these conditions. For the search of the suitable articles the Ebsco and the Google Scholar were used. In addition, especially in the early stages of the work book sources were used. All in all 9 articles were chosen. The articles, even with a variety of viewpoints, gave similar results concerning the ASD and the AS. The uneven profile of skills and abilities was one of the characteristics of the AS mentioned by almost all the articles. Another occurrence reported was the relatively poor outcome in life considering the subjects’ often considerable intelligence. The common features of the AS mentioned by all the articles were the difficulties in the verbal- and non-verbal communication. Even with the considerable intelligence and verbal skills, the actual communication might be very limited for a person with the AS. This is linked with the lack of spontaneous sharing of thoughts and experiences, and also linked to the mind-blindness. How to share and communicate, when not having the understanding that the others don’t know something if not told, and how to have empathy when not understanding how others feel and think, that their feelings and thoughts might be completely different from own. The articles presented the core symptoms of the AS such as the above mentioned ones, but also inflexibility, restricted interests, limited social skills, limited social imagination, self-centredness, emotional immaturity and sensory issues. All of these can hamper close relationships severely, yet the majority of the articles gave an optimistic view of the ASD in the relationships.

The book sources read in the planning phase of the thesis work gave slightly different view. One source from that reading used in this part of the thesis
project, writing by Tony Attwood, describes the emotional exhaustion and neglect experienced by the partners of the AS persons. Certainly in the future research it would be interesting and useful to study the situation of many partners of the AS persons, as that side was so rarely touched in the articles I found for the thesis.

The individual variation within the diagnostic criteria is pronounced, as is the wide variety of outcomes with the fairly similar presentation of the symptoms. Yet the core problems and symptoms are very alike, and often the positive characteristics are not enough to shield the individual and the closest to him\her from the consequences of the less positive characteristics. The positives mentioned in the articles are centred on the high intelligence and the good grasp of the non-social spheres. Other positive characteristics mentioned in the sources were loyalty, gentleness, the special interests often mean a large body of information. Some persons with the AS have made the special interest into a career. The positive characteristics seem superficial in many ways, the loyalty itself can be suffocating in a relationship which is lacking the emotional connection and the partner who displays many symptoms of the ASD can wear the non-ASD partner down. The longevity of the relationships mentioned in the articles was referring to this. The resistance to the change, even when it costs the happiness and the well-being of the one, if not both partners, is a common feature in these unions. The longevity was referred as a positive feature, but that does not tell anything about the quality of the relationship. That though brings forth another characteristic damaging the relationships, namely the lack of self-awareness.

The self-awareness is also connected to the ability to empathize and to see things from other points also. For a person with the ASD this is a very difficult concept, and the lack of self-awareness means also that it is difficult to take responsibility of own actions, and to see how own actions and words affect others. The thought that the developing of the self-awareness would be even more important than the actual diagnosis was mentioned in the articles.

The diagnosis could bring acceptance and maybe some peace of mind for both partners in a relationship. But in a way, the diagnosis is only that, without it
bringing some changes and insights, it is only lettering in a document, a diagnosis number in a manual. The articles dealing with the diagnosis process was touching this paradox. Also the diagnosis was seen as complicated issue, as a large number of adults with the ASD are without the diagnosis, the ASD, especially the Asperger syndrome is a hidden condition. Many did not get the diagnosis as children due to the lack of suitable diagnosis at the time, and because the high intelligence and verbal skills covered the lack of social skills. The lack of the social ability and the lack of emotional reciprocity do come apparent in the adult life at some point for almost all persons with the ASD. Even the so-called high-functioning individuals are struggling in some areas of their lives.

The situation is complicated by the acquired coping mechanisms, which often include denial, strict routines, inflexible scripts used in the social situations, including the romantic encounters. Many of the chosen articles concentrated on the needs and wishes of the persons with the ASD, and it was understandable within the context of the subject. Nevertheless, the articles about the ASD in the context of the relationships and the family life could have a more wide and balanced view. Only one of the articles discussed the difficulties caused by the AS with the view point of the partners and family members. The consequences for the health and well-being for the family members could be discussed more openly, and often it is the family, especially the spouse who might need more support and help than the ASD person in the family. The future research could address this imbalance, with the sensitive view to both persons with the AS and their family members. When the family members’ situation is taken into account and their coping and well-being is also considered, they are better able to take care and support the AS person in their life. This dilemma could be my next research project, should I return to this topic in the future.

The numbers how common the syndrome is, varies according to the researcher, but Edward Ritvo’s estimate is 30 to 40 of every 10 000 people. Ritvo also estimates that it is four to five times more common in males than in females. (Ritvo, Edward, 2005, p.26). The articles studied for the thesis project gave variable numbers, but the crunch here is that it is estimated that half the cases go undiagnosed. This means that there are a vast number of people
affected by the syndrome, not only as individuals having it, but their families also.

By the nature of the topic my research was following the methods of the qualitative study. A literary review seemed like the most realistic way to achieve the research goals at the time. The topic is very sensitive, as probing into anyone’s family lives could be seen intrusive, and with the aspect of adults with Asperger Syndrome in the family this intrusiveness could be sensed heightened. The sensitivity of the topic could affect the credibility of the study. I strongly believed at the starting point of the thesis work that I get the best results with a literary review using the source material from the Ebsco and Ebrary. The weakness in the material was that it was quite narrow, only 9 articles and the bibliographical sources. It was nevertheless a problem which was admitted in the research articles themselves; this topic is not widely studied yet and a wider scope of viewpoints is needed to ensure well-being of both the ASD persons and their families.
RESOURCE EVALUATION

My resources by far have been almost solely in the English language. It seems that there is very little material Finnish about the Asperger’s Syndrome in the family, with the starting point that it is a parent with the syndrome and not the child. The Finnish material I have found by far concentrates on the children or is very cautious with the idea of the person with the Asperger’s Syndrome having a family.

The resources in Ebrary mostly come from the same publisher, Jessica Kingsley Publishers, and I readily admit that it is weakness in the resources.

As it stands at the moment, the adults’ Asperger’s Syndrome in the family is not a widely researched topic.

TIMING OF THE STUDY

A realistic time frame for my thesis work was about a year. I did do large amounts of reading and I tried to find quite a lot source material, and I was planning to accomplish this during the spring and the summer 2016.

In the autumn 2016 I was planning to move to the actual writing process of my thesis.

In the spring 2017 the thesis work should have been complete. The actual completion was in the spring 2018 while working already as a RN.
In the timing I had to take on the account the fact that I worked as a substitute practical nurse, and then as substitute RN, sometimes a lot of hours, sometimes less and these hours are out of my control. I am most of all mum to my girls.

REFERENCES


http://advice.writing.utoronto.ca/types of writing/ sourced 20.3.2018


Lewis Foran, Laura; ‘Exploring the Experience of Self-Diagnosis of Autism Spectrum Disorders in Adults’, Archives in Psychiatric Nursing, volume 30, issue 5, October 2016, pp. 575-580

Myhill, Grace and Jekel, Dania; ‘Asperger Marriage: Viewing Partnership thru a Different Lens’, Focus Homestudy Course, NASW, December 2008, pp. 1-8

Pollmann, Monique M.H., Finkenauer, Catrin, Begeer, Sander; ‘Mediators of the Link Between Autistic Traits and Relationship Satisfaction in a Non-Clinical Sample’, Journal of Autism and Developmental Disorders, April 2010, volume 40, issue 4, pp. 470-478
Roy, Mandy, Prox-Vagedes, Vanessa, Ohlmeier, Martin D., Dillo, Wolfgang; ‘Beyond Childhood: Psychiatric Comorbidities and Social Background of Adults with Asperger Syndrome’, Psychiatria Danubina, volume 27, no 1, 2015, pp. 50-59

Ryan, Sara, Räisänen, Ulla; “like you are just a spectators in this thing”: Experiencing social life the ‘aspie’ way’, Emotion, Space and Society, 1, 2008, pp. 135-143


Strunz, Sandra, Schermuck, Constanze, Ballerstein, Sarah, Ahlers, Christoph, J., Dziobek, Isabel, Roepke, Stefan; ‘Romantic Relationships and Relationship Satisfaction Among Adults With Asperger Syndrome and High-Functioning Autism’, Journal of Clinical Psychology, volume 73, 2016, pp. 113-125

Bibliographical Sources:


Attwood, Tony, 2007: Aspergerin Oireyhtymä lapsuudesta aikuisuuteen, Oppimateriaalikeskus Opike, Helsinki

Gillberg, Christopher, 1999: Nörtti, Nero vai Normaali? Aspergerin oireyhtymä lapsilla, nuorilla ja aikuisilla, Atena Kustannus, Jyväskylä


Appendix 1

The American Psychiatric Association’s Diagnostic and Statistical Manual, Fifth Edition (DSM-5) provides standardized criteria to help diagnose ASD.

Diagnostic Criteria for 299.00 Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:
Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social
communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder)

(Coding note: Use additional code 293.89 catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

References