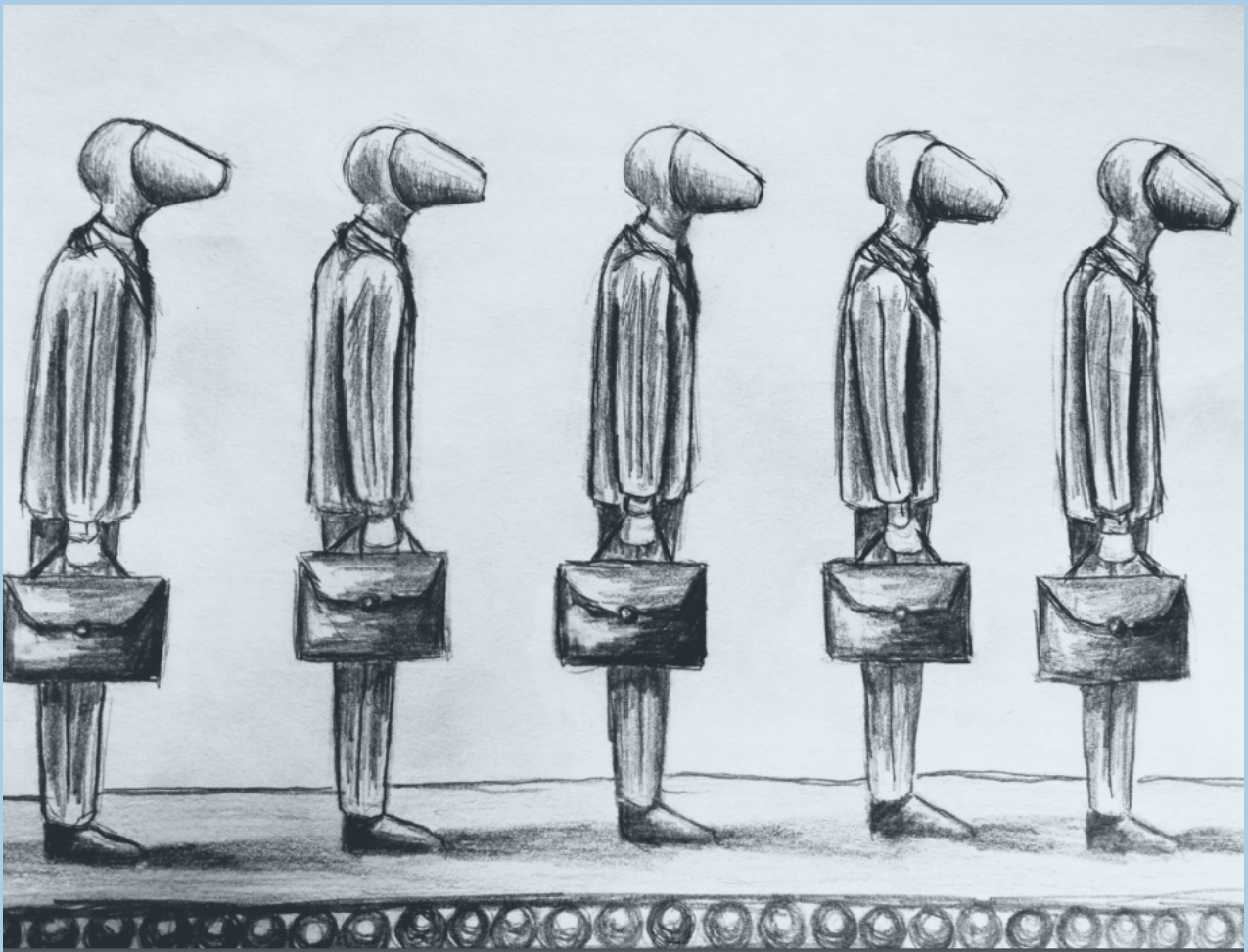


Autism and eating disorders

– a study focusing on autistic women with
anorexia nervosa or atypical eating disorders



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Illustration:

"The Daily Humdrum" by Nicoline Stieper

The study has received funding from the Central Denmark Region funds for developing the social area. The data were collected in the period 2016-2018.

We thank all participants - interviewees and colleagues alike who helped us along the way. And we thank our autistic collaborators for helping us develop the interview guides and the description of the study.

The study may be freely quoted with due source reference. This, however, is not the case with the illustration.

We present the most important results of the study: 'Autism and eating disorders – a study focusing on autistic women with anorexia nervosa or atypical eating disorders', which was carried out by Specialist Area Autism, Central Denmark Region.

There is a well-known and significant overlap between autism and eating disorders. There is also evidence that the treatment prognosis is worse when both diagnoses are present.

In Specialist Area Autism, we see many rigid processes where an eating disorder becomes chronic, long-lasting or particularly severe. The aim of the study has been to create more knowledge and hopefully contribute to improving conditions for the target group.

Method

An exploratory qualitative approach has been taken. 31 interviews were conducted with a total of 42 people in the period 2016-2018. The data for the study is thus:

- Eleven interviews with autistic women with eating disorders
- Nine interviews with parents of autistic girls and women with eating disorders
- Four interviews with professionals who have special knowledge about the combination of autism and eating disorders
- Four interviews with a representative from regional centers / units for eating disorders (respectively two senior doctors and two nurses)
- A focus group interview with representatives of a regional center for eating disorders (chief physician, nurse and psychologist) and a specialized residential home (head of department and two pedagogues)
- A focus group interview at a specialized residential home for adults with eating disorders (a professional coordinator and two educational staff)

The main findings in the report

In this report, we move from a preventive focus using a previous diagnosis of autism, to an understanding focus using possible causes and functions of the eating disorder, to a focus on treatment. Below follow the most important findings within these three focus areas. These areas of attention should be examined in greater detail in larger studies before they can act as definitive recommendations for e.g. treatment.

Prevention

One of the most well-substantiated findings in this qualitative study is a hypothesis that earlier diagnosis of autism can help prevent the development of eating disorders in autistic women. In order to succeed with earlier diagnosis, it is recommended to be aware that:

- some autism symptoms appear less clearly, and it is important to be aware that autism can appear more subtly in, for example, women. As a professional, you must be able to adapt your assessment to this, by focusing on examining the person-first perspective as well as the quality and character of the social communication thoroughly.
- parents or other caregivers can compensate for a person's challenges, so that they appear even less visible. In addition, the person's own ability to camouflage or compensate may mean that daycare centers or schools do not experience a different behavior or unhappiness that causes concern, whereas they experience great challenges and unhappiness at home. It is important, in these situations, that the concerns of the close relatives are taken seriously and not automatically attributed to conditions at home.
- there is a need for more knowledge about autism within Adult Psychiatry to ensure better access to diagnosis, also in adulthood. Some autistic people manage to camouflage their difficulties and only make contact with the psychiatric services when the burden has become too great. The greater the competences of Adult Psychiatry in relation to autism investigation, the earlier autism can be detected, which can probably prevent further stress reactions or worsening of these, including in relation to eating disorders.

Understanding

Another fundamental finding is that it is crucial to gain an understanding of the background of the eating disorder, in order to ensure the right treatment and efforts as well as reducing the amount of 'symptom treatment' and feeling of powerlessness for all parties involved.

It is important that this is examined and understood individually. In this study, however, we found four overarching themes that can be used as background knowledge when, as a professional, you seek to investigate and understand the background of an eating disorder in an autistic person.

The four themes that you can pay attention to are:

- A feeling of being different or wrong can be a trigger for the development of an eating disorder, where there are clear rules for when you are ok and doing well.
- The eating disorder can be an effective defense against social demands when the complexity of social interaction increases during adolescence and it becomes more difficult to camouflage basic difficulties inconspicuously,
- Transitions and unpredictability are particularly challenging for autistic people. For some, an eating disorder can help to create control and in turn act as an unconscious defense against the new demands.
- Some autistic people, and people with eating disorders, have difficulty understanding and managing emotions (despite a rich and varied emotional life). An eating disorder can soothe the frustration that can be associated with this.

Treatment

A final fundamental finding is that the treatment should be adapted to the autistic prerequisites. For this to be possible, it is crucial to know about any undiagnosed autism in people with eating disorders. It is therefore essential that professionals within eating disorder treatment are aware of the significant overlap between autism and eating disorders and are aware of

distinguishing between the two conditions, for example by focusing on thorough anamnesis recordings, investigating whether social contact improves in line with weight gain, and whether there are some sensory challenges, for example in relation to eating.

When there is a known autism diagnosis, these point of attentions can be considered in the treatment of an eating disorder:

- Let the treatment be based on an in-depth knowledge of autism and ensure that there is also knowledge of eating disorders. Coordinate collaboration across sectors if the skills are not present simultaneously.
- Support the autistic person's autonomy and, if necessary, show a little more patience in relation to weight gain.
- Make reasonable, concrete agreements and consider negotiating.
- Offer psychoeducation both in relation to autism, the eating disorder and the combination of the two. Support the person in building a positive self-image with realistic expectations of themselves. If possible, involve the patients network in this.
- Avoid an approach where you answer rigidity with more rigidity and focus too much on weight.
- Consider carefully whether group therapy is a good idea and involve the autistic person in the decision.
- Be aware that there must be something positive to return to after an eating disorder – for example, help with expanding the network, finding the right school or education or engage in interests.
- Work with the autistic person to find the person's non-eating disordered "normal" in relation to food and eating. Recognize that different or "autism-friendly eating habits" are ok and support in such a way that the person herself recognizes and accepts this.