Maastricht University

Eat. treat. repeat

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Valorization addendum

The impact of research findings in the field of eating disorders in children and adolescents with an Avoidant/Restrictive Food Intake Disorder.

The main aim of this dissertation was to assess the use of existing, and tailor-made interventions in the field of cognitive behavioral therapy (CBT), regarding their feasibility (i.e., proof of concept) and effectiveness in (young) children and adolescents with an Avoidant/Restrictive Food Intake Disorder (ARFID). Since ARFID is a relatively new eating disorder - only a decade old - there is still a lack of empirical evidence regarding effective treatment interventions. The results from the present research should provide therapists and scientists in healthcare and treatment practice with more insight and tools in guiding children with serious eating problems, such as ARFID. The first question that was answered was whether and when CBT is necessary. There is still uncertainty among professionals about when and where to refer children with eating problems for (C)BT, or whether milder forms of treatment or even an expectant policy should be pursued, suspecting that complaints will disappear on their own. The question about which children and adolescents are more or less at risk of continuing eating problems if they refrain from (C)BT is therefore also addressed in this study.

It seems of great importance for clinicians that more information about treatment indication and outcomes becomes available for them, so they can more easily decide about referral options. Furthermore, it must be clear what children and parents can expect from this treatment: What are the chances of success in overcoming this disorder? Today, many initiatives are emerging to offer help to these children, with a tendency to indicate treatment or guidance that is the least intrusive or best available in the region. This referral strategy is not always effective, as children and parents remain in the care circuit for a longer period of time, and improvement is often marginal. Ultimately, this is also not cost-efficient. In response to the physical and psychosocial consequences that children and their families are often exposed to for a long time, besides the misunderstanding from their environment, more efficient forms of treatment must be developed, or existing ones must be used more.

Clinicians may experience a lack of knowledge because there is still limited empirical evidence available for certain forms of treatment and on how to offer good, effective treatment to children and adolescents. The contribution of this thesis is to inspire and provide more clinicians with these insights so that they can use, or refer to, the effective interventions. We hope to motivate health organizations, who are still cautious in offering these interventions, because the disorder is not yet sufficiently known, to work

more to provide this group with good care. Waiting lists are currently long and with more supply, children and young people would suffer less from the consequences that ARFID can have on a physical and psychosocial level. The results of this thesis are socially relevant and can contribute to more efficient and cost-saving care in the field of ARFID in children and adolescents. This also means that if appropriate care is provided for ARFID in childhood, fewer adults may be diagnosed with ARFID. The sooner interventions can be conducted in a more efficient manner, the better the prospects for this target group. The results of this thesis are also relevant for children who may not yet have ARFID, or did not yet reach the age of 18, who are unsure whether they should undergo treatment now or wait until they are adults.

Today it is estimated that 3% of the child population is diagnosed with ARFID, and that this occurs in 1% of the adult population. Perhaps these percentages in childhood cannot be reduced quickly because the development of ARFID is bio-psycho-socially determined, which can be hard to prevent, and preventive care is therefore difficult. However, faster and more effective intervention in childhood can reduce the percentage of ARFID in adulthood, especially for the group that had this issue since childhood.

This been said, it can be concluded that the results of the respective studies are especially important for providing positive perspectives to children, young people with ARFID and their parents, but also to clinicians who work with these children, and researchers who are encouraged to conduct more experimental and applied research into maintaining mechanisms of ARFID, which can be applied in practice in the design of new treatment interventions. A good view on effective treatment is more likely to motivate patients to seek treatment. The shame about their children's strange eating habits can be overcome and parents can focus their attention on other areas in their child's development, thereby providing family life with other positive impulses that they are currently unable to do.

It seems of great importance that these results are also shared in the field of research and practice. The advantage of this research is that it was largely conducted in practice at a specialized clinic for children with ARFID. Testing whether these interventions are feasible in practice therefore seems to be an unnecessary step and saves us time. For example, the usual period of time that represents valorization (the time for research findings to be integrated into practically applicable treatment interventions) may be limited. This requires information campaigns and training for fellow practitioners, but also financiers, health care providers and politicians must be convinced to invest in treatment implementation and education for professionals in CBT.

Although the results from this thesis are promising, we are still on the eve of further developing effective treatment interventions for ARFID. For the future, the aim will be to apply the treatments to more target groups. For example, to children of primary school age, adults, or children with complex comorbid problems. In this thesis we also

investigated the effect of CBT on children with autism, children with intellectual disabilities and children with syndrome related disabilities, which was found to be effective. In any case, this suggests that more children will be able to benefit from CBT in the future. A main target should be to design less intensive treatment interventions in the future, while retaining the effect. For now, it seems a bridge too far for many health organizations to take this approach. With these results I hope to be able to convince them and challenge them to think about how we can make these effective interventions suitable for 1st and 2nd line care in the Netherlands. Knowing the encouraging results, which are published and accessible to every healthcare professional because of open access, we hope to encourage healthcare organizations to include these treatment protocols in their care programs, and/or to participate in further practice-based research projects in collaboration with academic centers, hospitals and universities.