UiT The Arctic University of Norway

Institute of Psychology

Parenting an Adolescent with Severe Emotional Difficulties

A Qualitative Study of Family Experiences with DBT-A

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Abstract

Parenting an adolescent with severe emotional difficulties is challenging, and research show that when parents do not receive adequate support it can have adverse consequences for the parents, the adolescents, and their siblings. Dialectical behavioral therapy for adolescents (DBT-A) is a treatment method that has an increased focus on parental support, and by including parents to treatment DBT-A attempts to empower parents and families. The aim of this study was to explore the experience of parenting an adolescent with severe emotional difficulties, and how parents' needs are accommodated by health care services in general, and DBT-A in particular. It is a qualitative study with a phenomenological approach utilizing a descriptive design. Semi-structured interviews were supplemented by graphic elicitation and conducted with participants individually (N=10). Data was analyzed following a thematic approach. Participants experience of parenthood was dominated by fear, unpredictability, and pressure. They described having to take on tasks far above what they are capable of, which had direct consequences for their health and families. Parents express a need for support and assistance, but describe a system with no systematic structure to include and help them. DBT-A seems to accommodate for parents needs and facilitate for positive experiences more efficiently than other methods, and parents with DBT-A express a greater sense of control and optimism than those without. These findings show that parents who receive information, support, and guidance are more resilient to stress and have a higher sense of self-efficacy, which contributes to positive experiences and makes them less reliant on the health care system.

Keywords: adolescents, dialectical behavioral therapy, parental involvement, parental support, severe emotional difficulties, qualitative research methods, mental health services

Sammendrag

Foreldrene til ungdommer med alvorlige emosjonelle utfordringer har et utfordrende ansvar, og forskning viser at når foreldre ikke får tilstrekkelig støtte, kan det få uheldige konsekvenser for foreldrene, ungdommene og deres søsken. Dialektisk atferdsterapi for ungdommer (DBT-A) er en behandlingsmetode som har økt fokus på foreldrestøtte, og ved å inkludere foreldre i behandlingen forsøker DBT-A å styrke foreldre og familier. Målet med denne studien var å utforske foreldrenes erfaringer med å ha en ungdom som har alvorlige emosjonelle utfordringer og hvordan foreldrenes behov imøtekommes av helsetjenester generelt, og av DBT-A spesielt. Dette er en kvalitativ studie som tar en fenomenologisk tilnærming med et beskrivende design. Semistrukturerte intervjuer ble supplert med grafisk fremkalling og gjennomført med deltakerne individuelt (N = 10). Data ble analysert etter en tematisk tilnærming. Deltakernes opplevelse av foreldrerollen var dominert av frykt, uforutsigbarhet, og press. De beskrev å måtte påta seg oppgaver langt over hva de er i stand til, noe som hadde direkte konsekvenser for helsen og familien. Foreldre uttrykker et behov for støtte og hjelp, men beskriver et system uten en systematisk struktur for å inkludere og hjelpe dem. DBT-A ser ut til å imøtekomme foreldrenes behov og legge til rette for positive opplevelser mer effektivt enn andre metoder, og foreldre med DBT-A uttrykker en større følelse av kontroll og optimisme enn de uten. Disse funnene viser at foreldre som mottar informasjon, støtte, og veiledning er mer motstandsdyktige mot stress og har en høyere følelse av selveffektivitet, noe som bidrar til positive opplevelser og gjør dem mindre avhengige av helsevesenet.

Nøkkelord: ungdom, dialektisk atferdsterapi, foreldreinvolvering, foreldrestøtte, alvorlige emosjonelle utfordringer, kvalitativ forskningsmetode

Preface

The idea for this study is based on an interest in Dialectical behavioral therapy (DBT) as a treatment program. I have always found the systemic processes behind and around illness more interesting than illness in itself, and because DBT is a treatment method that takes a systemic approach I was instantly intrigued when I heard about the possibility of working with a DBT team. The specific focus and research questions for this study were developed throughout conversations with my supervisor Geir Lorem and meetings with the DBT-team. Parents are important stakeholders when children struggle with illness, but their sacrifices are often taken for granted. My goal was therefore to provide insight on parent's experiences, and by that hopefully contribute with knowledge on how a system can be constructed in order to not only care for those who are ill, but also limit the consequences of illness.

I would never have been able to complete this project on my own, and there are several people that must be recognized. The first person I want to thank is Geir Lorem. Thank you for giving me complete ownership of this project and for always being available to motivate, guide, and provide valuable feedback. This has been a very educational and interesting process and I appreciate everything you have done for me and this project.

The locations for data collection have been anonymized in order to respect the confidentiality of participants, but I want to give a special thanks to the entire DBT team for making room in their schedules, talking to me about their experiences with the treatment program, and for assisting me in the recruitment process. I also want to thank *Pårørendesenteret* for helping me recruit participants by publishing information about this project in their newsletter. And thank you too all participants for their openness and letting me interview them about some of their most personal experiences, feelings, and thoughts. This project would not have been possible without anyone of you, and I hope you all find this project and my findings to be valuable.

Finally, I want to thank Tove I. Dahl, Mikolaj Hernik, the Mastercommittee, and the entire The Department of Psychology at UiT – The Arctic University of Tromsø for creating a master program unlike anyone else in Norway. Thank you for giving us the opportunity to focus on our interest, construct our own degrees, and doing whatever you can to help us reach our goals.

Christina Rolandsen (student) and Geir Lorem (supervisor) had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. The concept and design of the study were developed in collaboration between the two researchers. Christina Rolandsen scheduled and conducted the interviews with parents, drafted the manuscript and critically revised them for important intellectual content, and was responsible for the writing of the thesis, all under guidance from Geir Lorem.

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Parenting an Adolescent with Severe Emotional Difficulties – A Qualitative Study of Family Experiences with DBT-A

Adolescents who have severe emotional difficulties experience significant distress; they often struggle in relation to others, have unstable relationships, a disturbed self-image, and are at an increased risk for self-harm and suicide. Adolescence is also an important developmental phase in life, which makes the presence of these problems all the more concerning (Fossati, 2014; Linehan, 1993; Linehan et al., 1991; Mehlum et al., 2014; Miller & Glinski, 2000; Rathus & Miller, 2002). These are teenagers who have lost control over their impulses and tend to push boundaries and engage in self-destructive behaviors, which makes them highly dependent upon others for stability, care, and control. This responsibility will generally fall on parents, whose capacity for involvement becomes crucial for the overall outcome.

Parental involvement is important anytime children struggle with illness or disabilities, but the instability and urgency related to adolescents with severe emotional difficulties makes this a particularly demanding situation; these parents do not only have to provide support, but they also have to protect the adolescents from themselves, a responsibility found to be traumatic (Raphael et al., 2006). Previous research show that the chronic stress associated with these circumstances puts parents at an increased risk for exhaustion and other stress-related health problems, which if not adequately supported can end up exacerbating the consequences for the adolescents, the parents, and the family as a whole (Wilks et al., 2017).

We know that parental support and involvement is key to a good prognosis, and that the activation of networks benefits adolescents and young adults (Calandri et al., 2019; Cavaleri et al., 2011; Gregory et al., 2020; Mikolajczak et al., 2019; Rathus & Miller, 2002), but what do we know about the networks that are activated? What are parents' experiences, what do they need, and are these needs fulfilled?

My systematic review of literature show that when it comes to parents of adolescents with severe emotional difficulties, the majority of research concentrates on dysfunctional parenting styles and pathology, not on the value of parents, the implications this has for them, and methods for empowering them (Chanen & Thompson, 2014; Conway et al., 2017; Courtney-Seidler et al., 2013; Gill et al., 2018; Koster et al., 2018; Linehan et al., 1991; Miller & Glinski, 2000; Rolland, 2019; Swales et al., 2017). Parental involvement is consistently portrayed in a negative light and problematized, and research that can support their importance and positive contributions to treatment is missing. This is also reflected through treatment practices, where the majority of programs focus on the adolescents and do not systematically include the network around them (Biskin, 2013; Stoffers et al., 2012).

A treatment method that is different from others, that includes and gives parents a constructive and important role in adolescents treatment, is the adolescent adaptation of dialectical behavior therapy (DBT-A). Instead of protecting against parents, DBT-A includes them, which in itself seems accommodating. The dilemma is however that parents are still described in terms of maladaptive parenting and pathology (Fleischhaker et al., 2011; Groves et al., 2012; Linehan, 1993; Linehan et al., 1991; MacPherson et al., 2013; McCauley et al., 2018; Mehlum et al., 2014; Rathus & Miller, 2002; Wilks et al., 2017). So, although parents are included in DBT-A, the question remains whether parents are actually seen in themselves, or if they are regarded as a vulnerable element that must be assisted to benefit the adolescent's treatment.

Adolescents with Severe Emotional Difficulties

It is estimated that about 16 % of adolescents struggle with severe emotional difficulties and engage in self-harming behaviors. This prevalence is consistent between countries and has been stable for the past decades (Franklin et al., 2017; Muehlenkamp et al., 2012). Having emotional difficulties is not regarded as a mental illness in itself, but it is often associated with diagnoses such as anxiety, depression, bipolar disorder, or borderline personality disorder (BPD), a population that has a suicide rate 50 times that of the general population (Pompili et al., 2005). Adolescents with severe emotional difficulties are not necessarily diagnosed with any of these diagnoses, but they show symptoms of them, and are at an increased risk for developing them later in life if they do not get the help they need.

The theory of how emotional difficulties develop is complex and dependent upon many factors. It is thought that some adolescents have a biological vulnerability that predisposes them to have strong emotional reactions and takes them longer to return to an emotional baseline. So, they have strong feelings, and they feel them for longer. When this predisposition meets an environment that is not able to validate or tolerate the adolescents' emotions for as long as they need, problems arise. Under these circumstances, the adolescent never learns how to understand, regulate, or tolerate their emotions in a functional way, but instead that they are unwarranted and to be coped with internally. Not knowing how to manage own emotions causes the adolescent significant distress and results in the use of counterproductive and self-harming strategies (Linehan et al., 1991; Mehlum et al., 2014; Miller & Glinski, 2000).

This theory is supported by several researchers who have shown that self-harm in itself does not necessarily reflect an underlying wish to die (Madge et al., 2008; Mehlum et al., 2014; Williams, 2010; Ystgaard et al., 2009). A study with 30 000 adolescents from 7 European countries found that adolescents mainly engage in self-harm because it gives them relief from a terrible state of mind (Madge et al., 2008). There will always be a relationship component between self-harm and suicide and wanting to die remained the second most common reason adolescents gave for harming themselves (Madge et al., 2008). Suicide was the second most common cause of death among 15–29-year-olds globally in 2016 (Burton, 2019), which illustrates that emotional difficulties is a major public health problem.

Self-harm tends to be a coping mechanism, whereas suicide is more concerned with ‘giving up’ and to stop living, often because ones coping strategies are not working and they have been unable to get help (Burton et al., 2014). Research show that less than 20% of those who self-harm receive help from health services (Ystgaard et al., 2009), which suggests this is only the tip of the iceberg, and that there is a large “hidden” population of distressed adolescents and impacted families that go through this alone and in silence.

Implications for Parents and the Family

It is well known that parents feel like them and their families are blamed when one of their children develops severe emotional problems, (Byrne et al., 2008; Dunne & Rogers, 2013; Giffin, 2008; Kay et al., 2018; Östman & Kjellin, 2002; Preminger, 2018; Whitlock et al., 2018), and a substantial amount of research points to the role of maladaptive parenting and pathology (Conway et al., 2017; Crowell et al., 2009; Linehan et al., 1991; Miller & Glinski, 2000; Rathus & Miller, 2002; Swales et al., 2017; Wright et al., 2015). Whether this is correct is not something this study will get into. However, I will say that this does not mean that all adolescents who have emotional difficulties have grown up in malfunctioning home environments, and even if some families are more vulnerable than others, it only intensifies the parent’s need for support and assistance and makes helping them along the way all the more important.

Regardless of their background, family support and parental involvement are essential for the adolescent’s prognosis (Calandri et al., 2019; Gregory et al., 2020), but being involved is demanding and it is unreasonable to expect parents and families to manage this alone. Research shows that family members of individuals with emotional disorders experience chronic and traumatic stress (Aschbrenner et al., 2009; Dunne & Rogers, 2013; Kay et al., 2018; Lukens et al., 2004; Preminger, 2018; Raphael et al., 2006; Whitlock et al., 2018), and many are exposed to stigma and discrimination regarding their liability, which increases the pressure and distress they already experience (Giffin, 2008; Kirtley et al., 2018; Mikolajczak et al., 2019; Song et al., 2018; Whitlock et al., 2018). Parents are expected by health care personnel to be a resource and an essential part of the adolescent's recovery, which has consequences that goes on the expense of themselves and their families.

User Involvement and Parents Rights in Relation to Health Care Services

The health care system depends on parents to provide the adolescents with all the daily caregiving and support they need, and parents are the ones who are responsible for the majority of the time. Parents are expected to be involved and support the adolescent's treatment, but they are not automatically allowed to participate or be involved in the adolescent's treatment process. We even have laws that prohibit parents' rights for information and involvement, regardless of the parents' role and responsibility as caregivers.

The Norwegian Patient and User Rights Act (2018, § 3, 4) says that if patients are above 18 years old parents have no rights in regard to information about or involvement in their child's treatment. If a patient is under 16 years old parents should generally be informed about decision regarding their child, and they have a right to contribute and be involved in their children's treatment process. If the child is above 12 years old and has a legitimate reason for withholding information from their parents, practitioners should respect them and parents no longer have rights for information or involvement (2018, § 4, 3, § 4, 4). As long as a patient is under 18 years old parents do have a right to be informed about all aspects that is necessary for them to have in order to fulfill their parental responsibilities (2018, § 3, 4). However, the practitioners are the ones making the decision on what is necessary for parents to know, not the parents themselves. And this is problematic. These laws are crucial for protecting the adolescents as patients, but they do not protect parents to the same extent. Based on these laws, it seems like we have a health care system that expects parents to be involved and responsible, without actually having a system that always facilitates for them to do so.

Dialectical Behavioral Therapy for Adolescents (DBT-A) and the Family Perspective

The discrepancy between the expectations parents is held to in terms of supporting the adolescents, and the enablement of them to do so, is an unbalance that Dialectical behavior therapy for adolescents (DBT-A) acknowledge and address. DBT was originally developed to treat suicidal and self-harming adults (Linehan et al., 1991) and has been found to be superior to other treatments in reducing self-harm and suicide attempts, as well as emergency department visits and hospitalizations (Linehan et al., 2006; Perseius et al., 2007). DBT is a highly recognized method and has been adapted to treat adolescents with similar problems (DBT-A) (Miller et al., 1997; Rathus & Miller, 2002). The biggest changes made in the adaptation was reducing the length and complexity of the treatment program, as well as including parents and caregivers in weekly skills training groups (Mehlum et al., 2014; Miller et al., 1997; Rathus & Miller, 2002).

In DBT-A, parents are included in the treatment process; they are educated, they are trained in mindfulness, emotion regulation, interpersonal effectiveness, and distress tolerance, and they are continuously guided (Miller et al., 1997; Rathus & Miller, 2002). Parent’s role is still described as invalidating, unsupportive, and ignorant, but parents are acknowledged as an essential part of the adolescent’s treatment and recovery. Resources are therefore spent on teaching parents about the mechanisms behind the adolescents’ difficulties, training them in ways to support the adolescents, and how to manage difficult situation and personal distress in an efficient way (MacPherson et al., 2013; Rathus & Miller, 2002; Woodberry, 2008).

Purpose and Research Question

My examination of current literature shows that research on the parent role and the type of support parents need when caring for adolescents with severe emotional difficulties is limited, and often paints a negative picture of parents. The aim of this study is therefore to explore parents' experiences and gain an understanding of what this situation is like for them, independent of the adolescents. This study also explores what parents need in order to fulfill the expectations they are held to, as well as how these needs are accommodated by health care services in general, and DBT-A in particular.

My research questions are 1) What are parents experiences with having an adolescent who has severe emotional difficulties? 2) What do these parents need? 3) How have health care services accommodated for these needs? 4) In what ways do DBT-A address parents' role and needs? Answering these questions is important to protect the health of parents and families that are caregivers. It is also important in terms of enforcing the environment adolescents are treated in and assessing how the health care services we have today work in practice.

Method

Design

This is a qualitative study that takes a phenomenological approach with a descriptive design, where semi-structured interviews are supplemented with graphic elicitation. A qualitative method is the most appropriate choice for exploring feelings and experiences of individuals, and by conducting personal interviews I was able to collect rich and individualized information from each participant (Choak, 2011). Because the goal of this study was to describe participants lived world and experiences as precisely and accurately as possible, a phenomenological approach with a descriptive design was chosen. Phenomenology is the description of individuals' immediate experiences, how they make meaning out of it, and the impacts it has on them (Edmonds & Kennedy, 2017). In this method participants descriptions and explanations are approached with openness, and they are recognized as being the expert of their own experiences (Brinkmann & Kvale, 2015). The intention of this study is to describe and present parents' experiences, not examine, evaluate or judge.

A semi-structured interview developed by the researcher was the primary instrument used to gain insight to participants' personal experiences and values. The interview schedule of open-ended questions ensured consistency and kept all interviews focused on relevant themes, at the same time as it opened up for subjective viewpoints and other themes to develop and be explored during the interviews (Brinkmann & Kvale, 2015; Choak, 2011). This allowed me to gather similar information from all participants while acknowledging the differences that exist.

Interviews were supplemented by photo-elicitation, specifically a wellbeing chart. This was a task where participants were asked to draw a timeline of how their wellbeing has developed throughout supporting the adolescents. Utilizing visual instruments like the wellbeing chart in interviews has shown to facilitate rich interview data and draw into focus details that might otherwise have been left unsaid (Drew & Guillemin, 2014), and was included in this study as a means to provide depth to the understanding of parents' experiences.

Participants and Recruitment

This study utilized a purposive sampling strategy in order to recruit parents of adolescents with severe emotional difficulties. A purposive strategy is designed to enhance the understanding of particular individuals' experiences (Devers & Frankel, 2000), and because these are relatively rare circumstances, participants had to be intentionally sought out. Two distinct groups were formed to account for differences in participants experiences, and in the interest of exploring DBT-A as a treatment program.

One group consisted of parents with DBT-A experience. Inclusion criteria included being a parent to an adolescent with severe emotional difficulties, having gone through DBT-

A treatment with the adolescents, and giving informed consent. Participants were excluded if they were not the primary caregiver of the adolescents or if they were involved in active treatment themselves. The other group consisted of parents who did not have DBT-A experience, but who had experience with other treatment methods aimed at the adolescents. Having received treatment ensured a certain level of severity to the adolescents' problems. Otherwise, inclusion and exclusion criteria were identical to the group with DBT-A experience. The consent form for parents with DBT-A is included in appendix A1, and parents without DBT-A in appendix A2.

The study sample consisted of ten parents. There were five participants, four mothers, and one father, in each group. Recruitment of participants was assisted by clinicians on a DBT-A team and *Pårørendesenteret*, which is a support organization for parents and others who are affected by a loved one's illness.

Recruitment Through the DBT-A- team

Four participants were recruited with help from clinicians on a DBT-A-team. All of these parents had experience with DBT-A treatment and were placed in the DBT-A group. Clinicians informed parents in treatment about the project towards the end of their program and distributed a consent form that included more detailed information about the project, as well as the researchers' contact information. Parents that were interested contacted the researcher directly to schedule a time and place for the interview. Having interested parents contact the researcher directly protected parents' anonymity and ensured that I did not take advantage of any dependencies present between the clinicians and their patients.

All parents in this group had daughters between the ages of 14 and 18 who currently lived at home. Three of the participants were single parents, where one was a foster parent. The fourth participant lived in an extended family, which included a stepparent. All parents had adolescents who struggled severely with self-harming behaviors and had experience with suicide attempts and hospitalization. All participants had more than one child and have taken time off from work to support their adolescents. Participants also had experience with a variety of other treatment methods before DBT-A, which the discussion regarding parents' experiences with health care services in general includes.

Recruitment Through Pårørendesenteret

The recruitment process assisted by *Pårørendesenteret* was similar to the one used with the DBT-A team. *Pårørendesenteret* published information about the project and the consent form in their newsletter and on their website. Interested participants contacted the researcher to schedule the interview. This protected participants' anonymity and ensured that we did not take advantage of any dependencies present between the organization and their members.

Six participants were recruited through *Pårørendesenteret*, one whom had experience with DBT-A treatment. This participant was placed in the group with the other DBT-A parents. The remaining five had experience with a variety of mental health services, including the local unit for child and adolescent psychiatry (BUP), assertive community teams, youth consultants, educational-psychological services (PPT), child protective services, and foster care, as well as other staffed living arrangements for the adolescents. Some of the adolescents had moved out of the home or over to units for adult psychiatry, but the focus of this project remains their adolescent years when they lived at home with their parents.

Due to a larger variety in the type of treatments the adolescents had received and a broader parent pool, the participants in this group varied substantially more than the parents who were recruited through the DBT-A team. Parent's description of their adolescent's difficulties includes depressive symptoms, obsessive-compulsive behaviors, and substance abuse. All participants have adolescents with severe emotional difficulties and experience with self-harm, suicide attempts, and hospitalization. For some of the adolescents their problems manifested in the teenage years, but others showed symptoms already in early childhood. All participants had children who were between 15 and 22 years old. Two out of the six were single parents, and the others had a traditional family with their co-parent. Two participants came from the same family. Four of the participants had daughters, and two had sons. All participants had more than one child.

Parents Motivation for Participation

All participants were polite, engaged, and motivated. When participants were asked about their reason for participating, common answers included wanting to be heard and getting the opportunity to tell their story from their perspective. Many also wanted to contribute to research and hope increased insight to their situation can contribute to things being done differently in the future.

Data Collection - Interviews and Graphic Elicitation

Data was collected using a semi-structured interview supplemented by graphic elicitation (i.e., wellbeing charts). Appointments were scheduled with participants individually, and all interviews were conducted in a private place convenient to the parents. One interview was conducted with two parents from the same family. This interview was longer than the individual interviews, and these parents are regarded as two participants despite being from the same family. The interviews lasted between 45- and 90 minutes and was conducted by the researcher between September 2020 and December 2020.

Interview Guide

The interview guide was developed by the researcher in collaboration with the project supervisor. The schedule consisted of open-ended questions regarding participants' experiences with their role as parents and meeting with health care services. It was constructed with the goal to facilitate an honest, open, and reflected conversation. Participants were encouraged to be nuanced and objective by talking about positive and negative experiences equally.

As a means of receiving a range of responses, the questions began broad and then narrowed into specifics as the interviewee was explaining. Key questions included “talk about how you have experienced being a parent and support system to an adolescent with severe emotional difficulties”, “what are your needs in a situation like this”, and “talk about your experiences with health care services”.

Parents with DBT-A experience were asked additional questions such as “tell me about your experiences with DBT-A treatment” and “was there something that worked particularly well, or not so well.” The parents who did not have DBT-A experience were instead asked questions such as “can you tell me about your situation”, “what type of help have you received”, and “is there anything you have been particularly satisfied, or unsatisfied with.” See appendix B1 for the complete interview guide used with parents who had DBT-A, and appendix B2 for the one used with parents who did not have DBT-A.

Graphic Elicitation

A series of questions were also directed at participants’ wellbeing and the interview was supplemented with graphic elicitation, specifically a wellbeing chart. Having to draw a timeline of their own wellbeing is an uncommon and advanced task that parents might be uncomfortable to do. The task was therefore voluntary, parents were informed about it beforehand, and it was saved to the end of the section regarding parent’s experiences with parenthood. This gave participants time to decide whether they wanted to participate or not and assured that the task did not interrupt the interview. The wellbeing chart and pencils was brought to the interview by the researcher.

Seven parents participated in the visual task. Following their drawings, parents were asked to explain different aspects of what they have drawn. The parents who did not want to draw a timeline were instead asked questions such as “tell me about how your wellbeing has been through this” and “do you have any thought on what influences this”. Asking similar questions independent of the task also ensured that the topic was discussed with all participants.

The Course of The Interviews

The interview process went according to the plan. All interviews began by going over the consent form with the participants and assuring them that this interview is about them, not the adolescents. If there were any questions participants did not feel comfortable answering they could just say so, and we would move on. The researcher brought tissues to all interviews in case the topics became too emotional.

The interview schedules worked well and did not have to be adjusted throughout the process. Some participants were more open than others, but this was managed by asking more formal questions in the beginning and asking about personal experiences towards the end. If questions were misunderstood or unclear to the participant, they were modified and asked somewhat differently later on. If participants consistently answered avoidantly, it was taken as a sign that it was something the participant did not want to discuss. I did not want to overstep any boundaries regarding what the parents were comfortable discussing, but this never became a problem.

The interview material consists of rich data; in the sense that participants seemed authentic, and gave reflected, coherent, and nuanced descriptions of their experiences and perspectives. All participants talked about having both good and bad experiences. The difference between participants was particularly noticeable between parents who had gotten DBT-A treatment and those who had not.

Data Analysis

The interviews were audio-recorded, and subsequently transcribed verbatim. Data were analyzed according to a thematic approach following Brinkman and Kvale (2015). The analysis was focused on meaning, data were categorized, and themes identified. This approach allowed us to move beyond what was explicitly stated by the participants and identify both implicit and explicit ideas within their explanations (Greg et al., 2012). Doing so required more involvement and interpretation but gave a privileged access to and deeper assessment of participants experiences (Brinkmann & Kvale, 2015).

There were six steps to the analysis; First, data was transcribed line by line. The transcription was checked twice for accuracy as well as during the analysis by the researcher. The data from each interview was then coded. This was done by identifying interesting aspects of what was said and their categories. All codes identified were placed in overarching themes. Themes were critically evaluated; if they were considered problematic or inappropriate in any way, measures were taken to correct them. Themes were then named in ways that captured their essence and complied with their content. The last step of the analysis was writing the report. Citations that reflected the themes and the point the rapport was trying to make were pulled out in their original form and translated from Norwegian to English. Themes and categories were further elaborated on and implications discussed (Brinkmann & Kvale, 2015).

The visual data was analyzed in the context of the conversation they generated and along the same lines as the general interview. The primary interpretation process is based on the verbatim analysis, and a direct content analysis of the wellbeing charts was based on participants' explanations. This is presented as a unified analysis, and wellbeing charts are included in the report to illustrate how certain situations affect parents and provide depth to the understanding of the general report (Drew & Guillemin, 2014). The software used was NVivo 12.

Research Ethics

The project was approved by the Norwegian Centre for Research Data (NSD) 01.04.2020. After having trouble recruiting parents with DBT-A experience, I reapplied to broaden the sampling pool the 24.09.2020. this application was approved by NSD 25.09.2020, and the change meant that I could move beyond recruiting through the specified DBT-A team and reach out to other parental support associations in order to recruit parents. Because the purpose of this study was to portray parents' experiences with their role and health services, not generate new information about health, illness, or disabilities, the purpose fell outside of the Health Research Act (2008, §4, 10). It did therefore not require approval from the Regional Committee for Medical and Health Research (REC).

These parents represent a vulnerable population, but this study was dependent upon their participation, and there was no way to accomplish this without talking to them. The knowledge this project generates will also serve to their advantage. This can be demanding topics for parents to discuss, but I was sensitive to it in the interview setting and did not push boundaries on topics parents did not want to discuss. This is a challenging situation for parents, but they were informed about this in the consent form, and I considered the parents to be best capable of evaluating their own vulnerability.

Because the interviews concentrated on the parent's experiences, not the adolescent's problems, consent from the adolescent was not needed. However, the interviews will indirectly include the adolescents as a third person. Parents were therefore encouraged to discuss participation with their children before the interview. I assume that if the adolescents had not wanted their parents to participate, consent would not have been given. There was no indication that this was a problem to any of the interviewees, and because their job is to protect the adolescents, I was comfortable leaving this decision up to them and consider them capable of consenting on behalf of them both. No questions were asked about the adolescents directly; they all concentrated on the participants experiences as parents, so the information received about the adolescents' and their problems was information that the parents discussed on their initiative.

To not harm and avoid disturbing ongoing therapy, parents recruited via *Pårørendesenteret* could not be involved in active treatment at the time of the interview, and the clinicians on the DBT-A team distributed information about the project towards the end of their treatment program. Eight participants were not in treatment at the time of the interview, and two participants who were recruited through the DBT-A teams was at the end of their program. This was an evaluation made by the DBT-A clinicians, and I trusted the clinician's evaluation of parents' vulnerability. This was also done in this way to accommodate for parents who did not live close by and make logistics easier.

No compensation was given to participants and help with the recruitment process was based on voluntariness from *Pårørendesenteret* and the DBT-A team. I emphasized that this project should not have any consequences for the DBT-A team, *Pårørendesenteret*, participants, nor their relation to health care services, parents, or adolescents.

Results

Three major themes emerged from the thematic analysis of participants' transcripts; participants described their experiences with parenthood, their experiences with health care services in general, and their experiences with DBT-A treatment in particular. Although participants were separated into two groups upon analysis, the samples did not significantly differ and will be presented as one. An important difference between the samples was found regarding participants' needs and experiences with health care services, where participants without DBT-A expressed additional needs and more negative experiences with health care services than participants with DBT-A, which will be elaborated on. The section concerning participants' experiences with DBT-A treatment will only include the parents who have been through the DBT-A treatment program.

Direct quotations from participants have been translated from Norwegian to English and are provided to support the content. Examples of participants' wellbeing charts are included to provide depth and give an illustration of the effects this has on parents. Themes and findings are presented in table 1.

Table 1.

Overview of themes and findings.

Theme	Findings
Parents experiences with parenthood	• **The experience of the parent role** was characterized by a fear for suicide, self-harm, and the adolescent's future development. The situation was unpredictable, and parents felt like they have lost control over their child's development and safety. This has consequences for parents' health and wellbeing, but they prioritized the adolescents needs. • **Implications and challenges for the family.** This situation changes the dynamic of the entire family. Parents describe both advantages and disadvantages of partnership and explain that siblings continuously receive less attention. • **Implications for school and ability to work** • **Implications for parents' social circle** • **Parents need** assistance and relief, as well as practical advice and guidance. They also want to be more involved in the adolescent's treatment and speak with someone who understands their situation. **Additional needs of parents without DBT-A treatment** include help to understand and process the situation, tool and coaching, as well as help to set boundaries and hospitalization of the adolescents.
Parents experiences with health care services in general	• Positive experiences and gratefulness • Negative experiences and the implications of them • Lack of services, time, and capacity • Imbalance between physical and mental health problems • Lack of recognition, respect, and information • The system as uncoordinated and hard to navigate within

	Additional experiences of parents without DBT-A treatment include being devalued, dismissed, treated as a problem. Parents also explain that the family is rarely worked with as a system.
Parents experiences with DBT-A treatment in particular	• Inclusive method that teaches valuable information, tools, and techniques • Inactive group structure and complex concepts that are difficult to follow • Not comfortable sharing openly in a group setting with the adolescents • Parents remained uninvolved in the adolescent's treatment process • Complexity of family structures were not taken into account • Improved self-efficacy, resilience and optimism

Participants Experiences with Parenthood

When participants discussed their experiences with parenthood, they described their experiences with their role as parents. They described the implications this situation has for the family. Implications for the adolescent's school progress and the parent's ability to work, as well as the social circle they are able to maintain. Participants also described what they need to withstand the demand that is put upon them, where participants without DBT-A described a set of additional needs that parents with DBT-A did not.

The Experience of The Parent Role

A significant level of fear characterized participants description of the parent role; they constantly worry about the adolescents' self-destructive behaviors, the danger they pose to themselves, and what this may do to their future development. The adolescents' state is unpredictable, and participants explain that they are unable to manage and protect them as much as they want to. The parents always have to be available, and they have had to put their own life and needs aside to support the adolescents, which has consequences for their health and wellbeing.

Parents Fear Suicide, Self-harm, and The Adolescent's Future Development.

Adolescents with emotional difficulties tend to engage in self-harming behaviors and are at an increased risk of suicide. The fear parents have for what the adolescents may do to themselves is substantial.

> *"The self-harm for example…it is terrifying when you notice that your daughter is cutting herself, and you immediately worry about an artery being next." (Mother without DBT-A)*

Self-harm and suicide are parent's biggest fears, but it is not their only concern. These problems are also happening in an important formative phase of the adolescents' lives and may have damaging repercussions for their development. These adolescents' interpersonal characteristics and behavioral patterns are known to be challenging, and they often struggle in relation to others. Participants describe that in addition to fearing for the adolescents' lives, they also worry about their future development and how the networks they find themselves in will impact them:

> *"And there was this outsider-group that he became a part of... the-smokers («røykerne»). So, he began smoking, began drinking, got experience with marijuana, and dropped out of school. The next year he applied to another school and was well taken care of, but he had now established those friendships". (Mother without DBT-A)*

The parents constantly worry about what the adolescents are doing and how big of an impact it will have. Participants explain that from the moment they wake up in the morning to the moment they fall asleep at night, their child's wellbeing is on their mind. There are high levels of uncertainty connected to this situation and parents' fear for the adolescents' is a constant stress source.

> *"You constantly have to watch what you are saying and what you are doing, you constantly have to worry about whether she has taken her medications, did she hide them, did she buy new ones. Where is she, how long had she been alone." (Mother with DBT-A)*

> *"I took a mattress and slept right outside her room. Which made me sleep better because I knew that if something happened, I would wake up, but if I slept far away, I would have to set a timer and go check on her regularly". (Mother without DBT-A)*

Losing Control Over Their Child's Development and Safety. Parents are scared, but they can't control the adolescents, their state, or their actions. They have to let the adolescents live their lives and trust that they will be ok, which is challenging with the stakes being as high as they are. Participants describe having lost control of their own children's development, and to some extent their safety. This is a loss of control that goes beyond what is generally expected when children become teenagers; all parents will at some point lose control over their children, but not all parents will have to worry about the consequences being life-ending.

> *"I am scared that she will spiral into dark thoughts; she has after all been there before. And she has been able to handle it, but you never know." (Mother with DBT-A)*

> *"I've sat there many times tripping of anxiety, wondering if it was going to be the police or the priest knocking on my door." (Mother with DBT-A)*

Participants explain that the unpredictability of the adolescents' state combined with the potential for disastrous consequences makes them desperate and increasingly protective. They see potential danger everywhere and will go to far lengths to protect the adolescents. Parents describe that they have to be prepared for anything, and they fear everything:

> *"We took down everything that was possible to tie something to high up, we took away all ropes, we hid all the medications and chemicals we had in our house... anything that one could think of. But you do those things because you don't know any better… you have no idea what you are supposed to be doing." (Father without DBT-A)*

Participants acknowledge the importance of the role they have; their child's life and development are endangered, and the parents do whatever they can to protect them. Participants explain that their constant safeguarding has stopped several suicide attempts and is the reason their child is alive today, but this is an overwhelming, stressful, and traumatic responsibility to have.

> *"I had nights where I lied under the kitchen table to watch if he left his room. Once I laid down on our red couch with a red blanket over me and the light off, and he didn't notice me. And that night I stopped another suicide attempt. He had found the belt to his robe…" (Mother without DBT-A)*

The quote above illustrates the importance of parental involvement and support. But participants describe constantly pushing their own limits, they are exhausted and not giving up is sometimes very difficult.

Consequences of Fluctuating States and Unpredictable Circumstances. The adolescents' condition varies substantially over time and in unpredictable ways. Participants describe that changes in the adolescent's state could happen in the split of a second and anything could be a trigger. This implies unpredictability, which means the parents always have to be available, and they make large sacrifices do so:

> *"You never knew when it was going to be difficult and the big challenges was coming, so someone had to be there all the time, and act immediately. Because things happened very quickly." (Mother without DBT-A)*

> *"She could go outside, but I had to be at home, because it was safest for her and nothing could happen if I was here. So, it was sort of like a prison I was in for several years." (Mother with DBT-A)*

Participants describe that all incidences with the adolescents directly affect them; when the adolescent's condition worsens, the parents perceived wellbeing follows, and vice versa. In the wellbeing chart that follows we can see how the adolescents state fluctuates, and how this directly influences parents. One participant drew several turning points. Point (1) and (3) depicts what happens to the participants' wellbeing when there is a relapse or severe situation with the adolescents. At point (2) and (4) the participant shows us the effect (Figure 1).

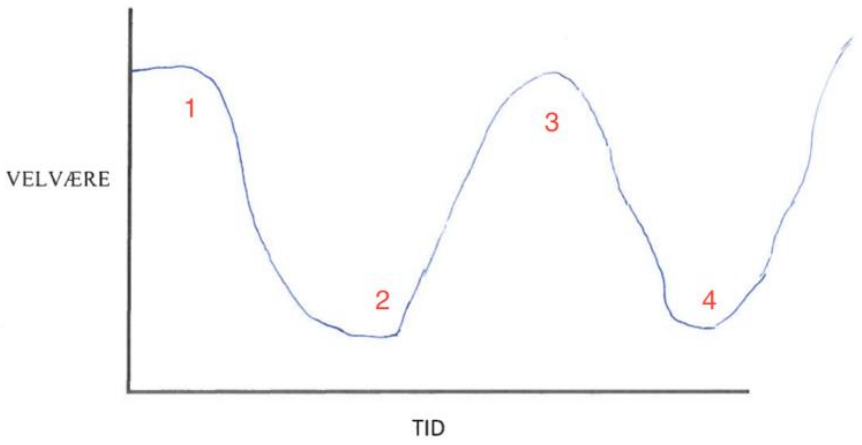

Figure 1. The impact of unpredictable and fluctuating circumstances. *(Mother with DBT-A)*

Prioritizing the Adolescent's Needs. Always having to be available means that parents have to put their own lives aside to support the adolescents. Participants describe an immense loss of freedom associated with their role, and this has impacted their lives beyond what they could have imagined.

> *"It's difficult going anywhere or doing anything. I love hiking for example, and I still go, but only on short trips so that I can be back within a certain time. I can't go on longer trips or camping with my partner because I can't leave her alone. I haven't had alcohol in almost two years, and it is not like I drank that much before, but I need to stay sober because something can always happen." (Mother with DBT-A)*

Participants describe that they are in a situation where they have to prioritize the adolescents' need above anything else. They always have to be there for the adolescents and there is little time for them to care for themselves, which combined with the stress and pressure parents experience, exacerbates the consequences this has for parents.

Parents Lose Control Over their Health and Wellbeing. The connection between the adolescents' state and the parents' wellbeing is obvious. Participants describe having lost control of their health and explain that their wellbeing has become completely dependent upon the adolescents.

> *"I don't have a life separate from him. I don't have any thoughts or feelings that are not 100% influenced by him and how he is doing." (Mother without DBT-A)*

The influence of the adolescents' state is also clearly depicted in figure 2. As this chart illustrates, the adolescent triggers every move the parents make in terms of own wellbeing, which is a trend that is recognizable in all wellbeing charts.

Point (1) shows us what happened to this participants wellbeing when she found out about her adolescent self-harming. This period is followed by negative experiences with treatment, until point (2) where they found something that worked. After this the adolescents shape stabilizes and the participants wellbeing improved. At point (3) her daughter had her first suicide attempt, and this drastically impacted this participant. At point (4) she moved and started treatment in a new place, which lead to improvements for the mom's wellbeing:

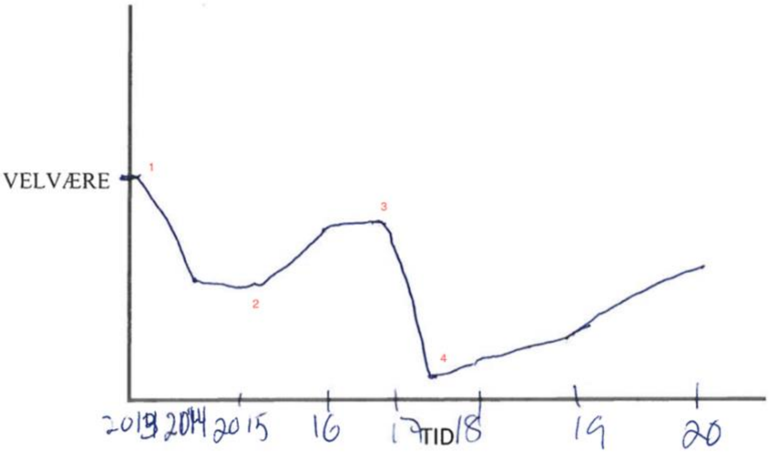

Figure 2. Parents wellbeing as dependent upon the adolescents. *(Mother without DBT-A)*

In addition to the distress directly connected to the adolescents and their challenges, participants describe struggling with their own self-esteem and belief in parental abilities.

This is illustrated by the quote below where one participant describes the added burden of self-blame:

> *"There is a lot about psychiatry that is taboo. And I often worry about others seeing me as a bad mother, that I must have done something wrong. (...) You start thinking that I have not been a good enough mother, that I haven't been able to protect her enough, or that there is something I have done that has been wrong." (Mother without DBT-A)*

The fear, worry, and stress connected to their role has consequences for the parents in more ways than one; Participants describe deteriorating health outcomes, and that their entire body is hurting. Many have problems with concentration and memory, and all participants describe being sleep deprived because they are too scared to sleep and cannot stop worrying about what the adolescents might do.

> *"Eventually you get so exhausted that you have nothing more to give. Everything becomes challenging. You get stuck in a bad place for too long and it starts eating at your confidence, it was like that for me at least. You start thinking that you are not handling this at all right now, that I am a terrible mother, I can't even serve dinner without seeming irritated. It tears down your energy. You are so tired that you put an edge to everything you are saying, or you are moody because you haven't slept at all, and your entire body hurts from the strain of the situation. So, the less time and opportunity you have to recharge the more difficult it becomes. Doing this is basically torture, and for weeks, and months and years. You might never get time to fully restore yourself." (Mother with DBT-A)*

Parents are exhausted and it is painful for them to have to watch their own children be as ill and function as poorly as they periodically do. There are feelings of helplessness, sorrow, and frustration that they carry with them every day:

> *"There is a lot of emotions. It is sadness. It is courage. This is kind of a journey we have been through. A journey that I don't wish on anyone else for that matter".*
> *(Mother with DBT-A)*

Challenges and Implications for the Family

Participants describe how their families have changed, advantages and disadvantages with partnership, and that the urgency connected to the adolescents continuously leads to lack of attention to their other children.

Change of Family Dynamic. Participants explain that everything in their lives is now about psychiatry and the needs of the adolescents always have to be prioritized. The unpredictability of the adolescents' problems makes it hard to plan anything or travel anywhere, and vacations are particularly demanding. Everyone is affected, at the same time as everyone contributes.

> *"This has affected many things in our family. It has affected our professional accomplishments. It has affected how well we have been able to take care of his sibling. It has affected those fun and exciting things we wanted to do as a family, traveling to exciting and interesting places and develop as a family. His sibling's entire upbringing has been defined by the fact that we must first take into account what [NAME] is able to be a part of, and how we can arrange things in relation to him so that it is possible to do." (Father without DBT-A)*

Advantages and Disadvantages of Partnership. Parents in this study have various family structures, and participants describe advantages and challenges with all of them. Participants in nuclear families and extended families explain that having a co-parent or partner is supportive and gives them opportunities for relief that they would not have had if they were single parents. However, they describe that the relationship's dynamic has changed into more of a working alliance, and it is difficult for them find time to spend together.

> *"The big problem is time, having time… My husband and I have not had much time together since she's been sick. One of us is always available. But the benefit is that one of us can get some time off, while the other is on standby." (Mother without DBT-A)*

But, having and maintain a partnership is challenging; it requires time and dedication, something not all parents have the capacity to prioritize. There are also more grounds for conflict, led by differing opinions and high stress levels.

The Down-prioritization of Siblings. Siblings are the other major stakeholder in the family, and parents explain that this affects their entire upbringing. Sibling's experience many of the same situations as their parents, and they are exposed to more stress at home, at the same time as they are given less time and attention. Participants explain that due to the urgency with the adolescents, all other children are continuously down prioritized. Parents acknowledge that this is not ideal, but they have no other option:

> *"Our other children tell us that we only think about her, and not them. And they are probably right, because we live in that constant fear." (Mother without DBT-A)*

> *"When you are standing in the midst of everything, especially when you are a single parent, the situation with my one child steals all the attention. And I can't understand how it will result in something other than neglect of the other, who takes care of my other child?" (Mother with DBT-A)*

Implications for School and Parents' Ability to Work

Many adolescents who have emotional difficulties are not in a state of mind where they are able to prioritize schoolwork; going to school is demanding, and it might be hard for them to deal with so many people and deadlines all at once. Hospitalization or other interferences might also make it impossible for them to attend:

> *"We have had some contact with her school now, but the entire last year fell to illness and that made school impossible for her. (...) Which is probably problematic for a lot of people in situations like this, because not being able to go to school increases the demand at home, given you don't find another solution..." (Mother with DBT-A)*

When the adolescents are not able to go to school, the demand at home will increase. Participants explain that they are not comfortable leaving the adolescents home alone for too long, so when they are not going to school, the parents will also have to stay home and stay available to them.

> *"I haven't worked in almost four months. I've tried to slowly go back to work, but then stuff happens at home. Which means that I can't go, or that it is best to stay at home." (Mother with DBT-A)*

All participants talk about how their accomplishments at work have suffered, and many have had to quit their job to be a full-time parent and guardian. But even when parents are able to go to work, they worry about the adolescents, and participants explain that this gets in their way of concentrating on their professional tasks:

> *"I have been very tired and stressed at work. I was constantly calling home, and if she didn't answer, and she wasn't as school, I start worrying about what she is doing." (Mother without DBT-A)*

Not being able to work will also have financial consequences for the family. There is a loss of income and expenses are not reduced, and several of the parents explain that they have had to take up loans or get social aid to make ends meet.

Implications for Parents' Social Circle

Participants explain that the adolescents are their most important concern, and all their time is spent on them. This has implications for their own lives, it has implications for their families, and it has implications for the social circle they choose and can maintain. Participants describe not being able to devote much time to their friendships and that their situation is so extreme that relating to others and finding things to bond over is challenging, which contributes to making this a lonely experience.

> *"It has affected who we are friends with. We are only friends with people who are able to handle us, and who have children that are able to handle us. And even the ones closest to us, and that has been with us this entire time, has been impossible for us to meet for longer periods of time." (Mother without DBT-A)*

> *"It makes it hard to maintain close friendships because you constantly feel like you are in a different place than everyone else. (...) It is hard to relate because you don't have the same life and the same challenges as they do." (Mother with DBT-A)*

Parent's needs: How to Empower Them and Enhance Their Ability to Remain Involved and Responsible.

Participants have concrete needs and several suggestions for how parent participation and involvement can be facilitated. Parent's exhaustion and the health implications they describe can be seen as a direct consequence of having responsibilities and task that are too demanding for them to manage alone. Participants describe being pushed beyond their limits and express a need for assistance and relief. They want to be included in the treatment and decision-making process, and to collaborate with treatment personnel. Parents also express a need for guidance and talking to someone that can understand what they are going through.

Need for Assistance and Relief. Participants describe working and worrying around the clock. They need help in order to live up to the expectations they are held to, and withstand the demand put upon them.

> *"What I really needed was for someone to say, "you know what, you can't live like that", and then actually do something about it. Not someone who says, "you can't live like that, it hurts you, it hurts your children, and your entire family will suffer if that continues", and then do nothing..." (Mother without DBT-A)*

Participants describe being exhausted; they are stressed, scared, and overworked. Participants explain that getting help, even if it is only a few hours a week, makes a big difference:

> *"For a while, we had someone who came and took care of the kids one night a week so that we could have one night off. So right after work we would go eat dinner at a restaurant, go to the movies, the theater, an art show, or just something we wanted to do, even if it was just skiing in the woods. And then we would come home around eight or nine to take over again, which gave us the space and time we needed to breath." (Father without DBT-A)*

The benefit of receiving assistance is also illustrated by figure 3. At point (1) the participant describes becoming aware that something is wrong. At point (2) the participant describes negative experiences with treatment and treatment personnel and illustrates how this affected him. At point (3) the adolescents respond to treatment and begins to function better in school and the social sphere. This is also a time where they received weekly assistance, and as we can see, there is a steady increase in this dad's wellbeing. At point (4) the participant explains that the adolescent has a severe relapse. The adolescent starts using harder substances and gets in a bad state. At point (5) the adolescent is able get clean and his condition starts improving, which has a significant impact on the participant.

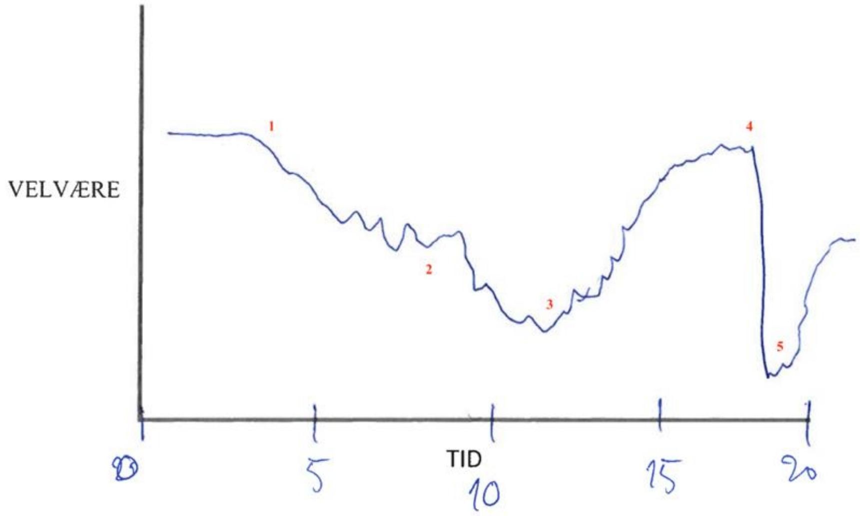

Figure 3. The benefit of receiving assistance. *(Father without DBT-A)*

Need for Practical Guidance and Advice. Parents also talk about needing concrete and practical advice. This situation is unfamiliar and unexpected, and many have no prior education or preparation. Participants describe needing guidance, and they need help figuring out concrete and specific ways to best protect their adolescent:

> *"That they actually know what the situation is like at home, so that they can be sure that we are going to be able to take care of her when she is suicidal or if she needs to be hospitalized. To have a concrete dialog about the setting at home, how far away are the bedrooms, where do you sleep in relation to her. Just practical and concrete." (Mother without DBT-A)*

> *"I handled a lot of things right, but there is also a lot of things that I did not handle as well, so just having some direct guidance on how to best support her and be there for her." (Mother without DBT-A)*

User Involvement, Participation, and Collaboration. Parents expressed a need to be included and heard by the treatment personnel. The parents are with the adolescents every day and they know them well. Participants explain that listening to their experiences could be beneficial and will give the clinicians more ground to build on in their planning of the adolescent's treatment.

> *"I think could have been smart for the clinicians who are in charge of the treatment to include the adults, or the parents, to a larger degree. I know from experience that when she goes into these therapy sessions, she gives her sincere opinion about her experiences and overall situation, but then again, I also have experiences with her and*

> *the ways in which she reacts, as well as how she is really functioning in her daily life, which I could have contributed with." (Father with DBT-A)*

Having a good relationship with the clinicians is important to the parents and they want to be allowed to participate. When parents feel valued it builds the relation between parents and clinicians, and the trust parents have to them. Parents explain that they do not mean that they want to decide the treatment of the adolescents, but they want to be heard, they want to be respected, and they want to be explained the reasoning behind decisions that are made for their children.

> *"To be heard when we have an opinion regarding something we read for example, and not just disregarded with "oh no, they googled again" right. Because I've heard that one. And we have had many good clinicians who were willing to have that discussion with us, and many times we even feel like we have actually contributed with something" (Father without DBT-A)*

> *"Not that we should decide anything, but we want to know why things are done, and we want to be able to come with our opinions and thoughts, and then be explained why, or why not." (Mother without DBT-A)*

Social Support. This can be a lonely and isolating situation for parents. Participants explain that friends have been valuable and supportive, but that they need to talk to someone in similar situations and that can understand what they are going through. Not necessarily to talk about the adolescents, but that there is a comfort in knowing that they understand, and that you are not alone. In this context, support groups are mentioned as a good alternative, and something several parents have positive experiences with. However, parents also explain that it is difficult to find, and not offered everywhere.

> *"It would be very helpful to hear from other parents about their situation and their experiences, because I have often felt like we are the only ones in the world who has it like this." (Mother with DBT-A)*

> *"We don't have to talk about it, but we know. There is something about the understanding and having something in common that is supportive." (Mother without DBT-A)*

Additional Needs of Parents Without DBT-A Experience

Parents without DBT-A experience expressed some additional needs that the DBT-A parents did not discuss, which suggests that families have certain needs, but that families in DBT-A get them covered by the treatment program. These additional needs include help to process and understand the situation, tools and guidance, as well as help to set boundaries and hospitalization. This section only includes parents without DBT-A experience.

Help to Understand and Process the Situation. Parents describe feeling confused and helpless. They do not understand what is going on with their adolescents, and they need help to process this situation. This information has not been given to them, and it has not been easy for them to find.

> *"With something as challenging as self-harm, to get information, professional and academic information. That will make us better. (...) Gaining that information and*

> *knowledge is something I've had to do myself, that it is about regulating own emotions. There could have been some sort of schooling." (Mother without DBT-A)*

> *"As parents we have also wanted help with processing the situation. Getting therapy directed at us. But that has been incredibly hard to find, and the waiting lists are so long…" (Father without DBT-A)*

Tools and Coaching. Parents also talked about needing tools to help them handle situations and the adolescent's behavior more efficiently. They need someone to teach them specific techniques and tools they can use when difficulties arise. Not knowing what to do makes many feels unprepared and powerless.

> *"I am not able to stop her when she is like this, I don't have any tools. The only thing I can do is call someone or run away, so you feel completely powerless." (Mother without DBT-A)*

> *"Someone who saw us, not just me as a person, and not just her as a person, but us together, and that could help me make things better. Because I had no idea what to do when she had one of her outbursts… I had no idea what to do…" (Mother without DBT-A)*

Parents also need help managing the demand and stress that is put upon them. Parents explain that they are often told about how important it is that they are able to take care of themselves, but they are never really given any concrete advice on how to do that.

> *"I wish someone would have said, "stop for a moment, we have to do something about this", but what am I supposed to do? Because several people told me that I had to remember to take care of myself, but how am I supposed to do that? What does that even look like? I never understood that because I couldn't just leave. I would watch the news and think that this is probably what they meant by taking time to myself… but I never understood what they meant." (Mother without DBT-A)*

The Need for Boundaries and Relevance of Hospitalization. The situation sometimes descends into what parents describe as out of control, and to a place where they need someone to come in and set boundaries for them, and for what they should have to accept and be responsible for.

> *"In these deep valleys it is not manageable. It is far from what is acceptable in any way. If it is God, the police, child protective services, or the prime minister, someone should have interfered and said that this can't go on." (Mother without DBT-A)*

Participants describe that as they become increasingly exhausted, these needs for boundaries only grow stronger, and hospitalization comes into the picture. Participants explain that when they feel like the situation is getting out of control, they become insecure, more reliant on health care providers, and in need for someone to step in and take over.

> *"As the problems with my child escalated, I would constantly call them, and that doesn't really work… What I needed was for her to be hospitalized." (Mother without DBT-A)*

We can also see how hospitalization of adolescents can be directly connected to parents' health, wellbeing, and exhaustion, at point 4 in in figure 4. At point (1) our participant describe that the problems are beginning. Point (2) marks the birth of her other child, which was followed by a temporary increase in wellbeing. Point (3) demonstrates school start. The participant explains that school went well in the beginning, but then her adolescents started having problems there as well.

Point (4) marks the aftermath of having negative experiences with treatment and treatment personnel, and where the adolescent's condition is severe, and the mom is exhausted. This results in hospitalization and medicalization, which the adolescent responds well to and leads to an increase in the mom's wellbeing. At point (5) the problems with the adolescent are exacerbated. At point (6) the adolescent regains control and moves out of the house, which relieves the parents for the daily caregiving and improves their wellbeing.

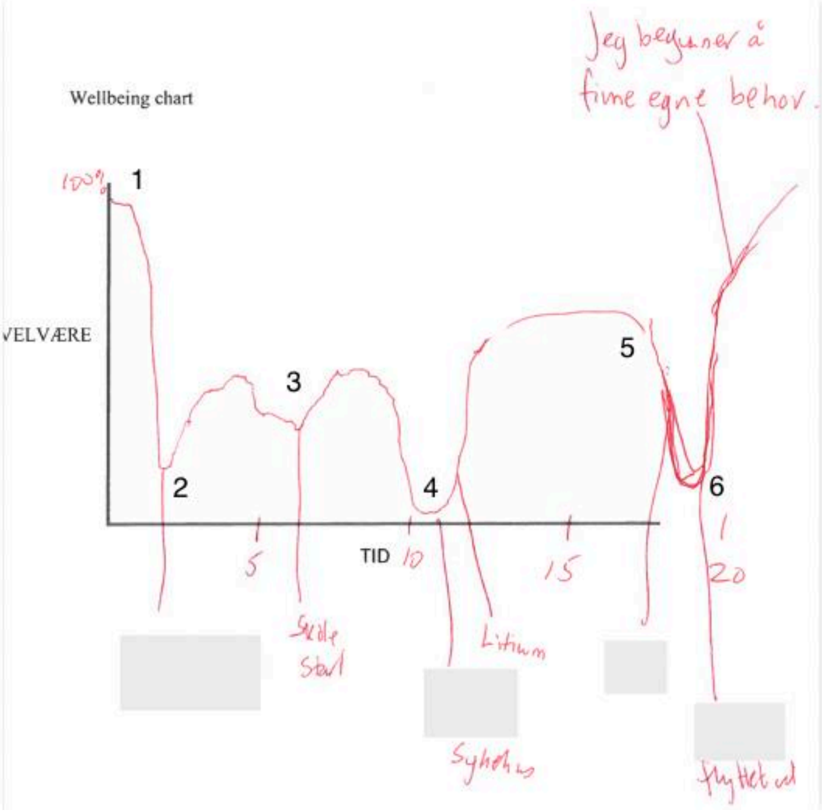

Figure 4. Parental exhaustion and hospitalization of the adolescents. *(Mother without DBT-A)*

As we can see; the adolescent being hospitalized is followed by increased wellbeing, which can be due to both the adolescent seeing progress, and the parent having the opportunity to relax and care for themselves.

Parents Experiences with Health Care Services

The second major theme participants discussed were their experiences with health care services. Although all parents talk of positive experiences and gratefulness, it had been a struggle for them to get the help they needed, and they experience regularly being treated with a lack of care and concern. Participants describe being overlooked and disrespected by health care providers, and that the health care system is uncoordinated and hard to navigate.

Positive Experiences and Gratefulness

Participants describe being grateful for the help they have received from the health care system and practitioners, and many have had positive experiences where they were well taken care of, included, answered, and given the information they felt they need:

> *"After coming to BUP I've been very impressed by the way they have approached her, taken her seriously, and helped her, as well as the way they included me before DBT-A started. So, I have been very impressed, and I am incredibly grateful." (Father with DBT-A)*

> *"We have been very lucky. I have a lot of positive things to say about the health care system, what they do, and how they have respected us, with only a few exceptions." (Father without DBT-A)*

Negative Experiences and Implications of Them

Although parents describe being grateful for the help and services they have received, it does not seem to happen consistently and is not sufficient. Participants are not satisfied with how they have been treated by some practitioners, the services available to them as parents, and the way their needs are prioritized in the system. This is something all participants describe, which suggests that it is not rooted in individual practitioners or meeting someone on a bad day, but rather that the system is flawed and unable to give parents what they need.

Participant's descriptions of their negative experiences including everything from bad effects of treatment, personnel who acted in unacceptable ways, rejection, and blame. When this happens, parents describe being hesitant to disagree with clinicians and speak up for themselves because they know it is important that their adolescent remains in treatment, and they have to trust that the professionals know best:

> *"We were critical, but everyone we knew told us how important it was that we supported the practitioners and their methods in front of our son. (...) And that year we were standing in a real tension, because we disagreed completely with what they were doing to him. We saw that it had a bad effect, and he got worse than he had ever been before. And at the same time, we were supposed to be on their side and convince him that they knew what they were doing, which was horrifying." (Mother without DBT-A)*

It is important to recognize that there is a power dynamic in place between clinicians and parents, where clinicians are the professionals, the ones with power, and whom parents are seeking help from. With this in mind, parents describe being perceived as dangerous and blamed for the adolescents' difficulties, which has been as a terrible and traumatizing experience:

> *"In the beginning you are a suspect too, what is happening at home with that person? What has triggered this behavior? What is this person doing wrong? And in the beginning, I felt like they took my child away from me, that I had to be protected from, and that was terrible." (Mother with DBT-A)*

> *"One clinician told me that I am incompetent and that I am not fit to be this child's mother. But I was fit to be my other child's mother, to the one that could handle life. And even though I know that this is untrue it has stuck with me and damaged my confidence as a mother and our relation." (Mother without DBT-A)*

Lack of Services, Time and Capacity

Participants describe that it has been difficult for them to get the help they need; it was a struggle to get into the system in the first place, the waiting lists are long, and helping parents is not a priority. They explain that there is lack of services, and that the services that do exist are limited in both time and capacity:

> *"It is a fight for health care services. There are not enough resources, it is a battle between professions, it is a battle between diagnoses, and there is far from enough psychologists." (Father without DBT-A)*

> *"When she was like that she should have been hospitalized, but nothing was available. (...) Our social worker did her best, but she did not have that much time." (Mother without DBT-A)*

There are not enough mental health resources or services to cover everyone who needs them, and even fewer are aimed at parents and support systems. The vast majority of services are directed at helping the adolescents, not at supporting and helping the ones around them. Participants explain that it does not feel like there is a system or network in place to care for parents when something like this happens.

> *"Treatment personnel would always tell me that I am no help if I am completely exhausted, but how is it possible not to end up there when there are no other services for parents? (...) As long as the adolescent is living at home, the parents are responsible 24 hours a day, every day, every week, every weekend. There is nothing... unless it is child neglect there are no services." (Mother with DBT-A)*

Participants describe being overworked by a health care system that pushes much of the responsibility onto them; that they are a resource that can be used, rather than a person in a difficult situation who also needs help. Participants feel abandoned, and many are pushed far beyond their limits.

> *"It seems like everything is always postponed until the situation is so bad that us as parents are completely burned out. That it has to get to the point where you actually can't handle it anymore, or that the situation is so bad that you are too scared to have the responsibility." (Mother with DBT-A)*

Parents being pushed beyond their limit is also illustrated in figure 5, which shows how low this mom's wellbeing got before getting help. Point (1) is when the adolescents' problems became severe, and the mom's wellbeing starts decreasing. The rapid descend in the mom's wellbeing between point 1 and point 2 also illustrates what happened to her when they were waitlisted for treatment. At point (2) they get into treatment, but the adolescent is not getting better. This results in the mom becoming completely exhausted. When this happens, at point (3), she seeks out help from child protective services, which gives her relief and someone to talk to. In the time following the adolescent is improving, which continues the increase in her wellbeing.

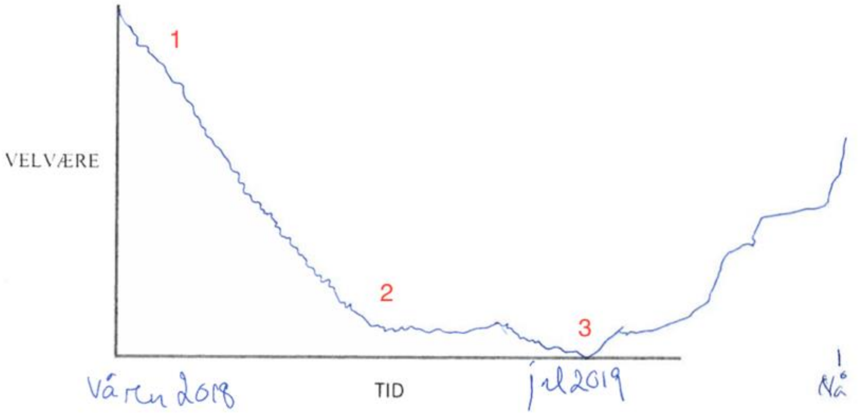

Figure 5. When parents do not receive help. *(Mother without DBT-A)*

Imbalance Between Physical Health and Mental Health Problems

What makes the situation even more frustrating for parents is the imbalance they have observed between the support and care available to parents when they have an adolescent with physical health problems compared to mental health problems. It can be argued that there are clear differences between the pathology of physical health and mental health problems, but this is nevertheless a distinction that participants make:

> *"If my kid had gotten cancer, we would probably have gotten some sort of follow-up, if my kid was paralyzed and ended up in a wheelchair, a system for helping parents would probably had been activated automatically. But I've never even heard of that when it comes to psychiatry and mental health." (Mother without DBT-A)*

> *"When it comes to physically disabled adolescents for example, there is a system of getting an assistant, a taxi to school, or some sort of help. Don't get me wrong, it is not given to you there either. There is an entire process around applications, but there is a system that can help you without it meaning that you lose custody of your child, which seems to be the more natural way when it comes to mental health. The choices you have here is either hospitalization, child protective services, or its you… and then of course I choose me." (Mother with DBT-A)*

Lack of Recognition, Respect, and Inclusion to Scheduling

Parents are relied on extensively when it comes to supporting the adolescents. However, participants explain that they do not always feel like the importance of their involvement is recognized by the health care system. They describe being taken for granted and regularly overlooked. The parents see the adolescents every day and they are with them in their daily lives. This means that they have experiences and insight to the adolescent that clinicians do not have, yet they are not included to the adolescent's treatment process and they do not feel as if clinicians are interested in getting their input.

> *"I choose to believe that everyone wants to do what is best by her and have good intentions, but because some people have refused to listen to us and our experiences it has had serious consequences for her and her problems." (Mother with DBT-A)*

> *"They should listen to us too. Because we observe everything, and even though we might not know the explanations to and processes behind the behaviors, we can see that it is happening. So, there is a lot of things that could have been made more efficient when it comes to her treatment process." (Mother without DBT-A)*

Parents do not have a say in what happens and are not included in the treatment process, but they are expected to have all the responsibility at home. This imbalance made it increasingly difficult for parents to play their part, at the same time as it makes them feel unimportant and disregarded.

> *"Sometimes when they are hospitalized you don't hear anything and are not included at all. They take away all your responsibility and you are kept on the outside, at the same time as you are supposed to take 100% of the responsibility when she is at home." (Mother with DBT-A)*

Parents are also expected to make their schedule fit with whatever works for the clinicians. The parent's daily tasks and appointments are not taken into consideration, and they are rarely included when it comes to the when and where of things.

> *"What I have missed is the understanding of how much energy and time it takes to coordinate everything. They can just change appointments, and sometimes they don't even tell me about it, they just give my daughter a new appointment and assume that I'm available to take her there. Which is a problem because everything doesn't always work for me, and I'm not always included in the scheduling and planning of appointments and treatment." (Mother with DBT-A)*

Lack of Information

Parents talk about not being heard and included in the treatment process, and how they have not been given adequate information about services or how to find them. Basic information such as services directed at parents is not discussed with them. Parents describe that some of the general information that could make things much easier for them is not prioritized nor given.

> *"It is very important that my daughter can trust her clinicians. If there's anything she does not want us to know, everyone should respect that. But that doesn't mean that they can't give us general information on how the system works, a pamphlet or something. Fundamental information like that is missing." (Mother without DBT-A)*

The Mental Health Care System is Uncoordinated and Hard to Navigate

Understanding how the system works has been a big challenge for the parents and figuring it out has not been easy. Parents describe the health care system as both uncoordinated, messy, and confusing:

> *"Coordinating the whole thing is often the hardest. There are so many people involved. There is everyone from the youth psychiatric center, there is the entire DBT-A team. Then there are some doctors, and there are different doctors. And then you are also supposed to be responsible for her medication, and then another doctor at the hospital puts her on another medication, which you are not told about, and then you are suddenly standing there with a bunch of medications…" (Mother with DBT-A)*

The system is difficult for parents to navigate. It is not intuitive, and participants explain that you have to be more than competent to understand how the system works, what you are supposed to do, and where you are supposed to go.

> *"It is very difficult. You are completely dependent upon meeting someone who knows the system and how to navigate it because it is impossible to understand it on your own. You can't rely on local and national websites to understand how everything works. And I feel sorry for everyone who are not able to understand what people are saying, or able to express what they need. Because it is so important, it does not happen by itself, and often you are more hindered than helped." (Father without DBT-A)*

Additional Experiences of Parents without DBT-A Experience

The parents who had not been through the DBT-A program described additional experiences that participants with DBT-A did not. This section only includes parents without DBT-A experience. Participants describe regularly being devalued, dismissed and treated as a burden by treatment personnel, and they explain that the services they have received help from have not worked with the family as one interdependent system.

Experiences of Being Devalued, Dismissed, and a Burden. Participants describe being more hindered than helped and have regularly experienced being treated with a lack of care and compassion by treatment personnel, which has been anything but helpful.

> *"It is scary. I think fear is a word that describes the experience when a system refuses to listen to you. You are devalued and what you say is dismissed, which makes you feel violated." (Mother without DBT-A)*

Participants explain that they want to participate and be involved in the adolescent's treatment process, something not all practitioners leave room for. Parents want to contribute and are trying to help, but they often end up feeling more like a burden and a problem to the clinicians when they attempt to do so. The following quotes illustrate parents' experiences with devaluation and dismissal, and the consequences this has for them.

> *"It has worked well with the clinicians who has been willing to cooperate with us as parents and who were confident on the ground they stand. But those who didn't probably saw us as the parents from hell who had too many opinions and asked too many hard questions." (Father without DBT-A)*

> *"If they treat us with an attitude where parents are not supposed to be seen or heard, it makes us feel unsafe, and it makes us question the ways they treat our daughter." (Mother without DBT-A)*

Family is Rarely Acknowledged as an Interdependent System. Participants explain that many practitioners do not treat the family as an interdependent system; they concentrate on the adolescents and do not recognize parent's importance and knowledge. Parents describe that they often feel excluded and unimportant, which becomes another source of stress and worry.

> *"It is important that there is room for the family as well. Which means that they should work more with the entire family as a system, and maybe even single sessions with everyone involved. We didn't get that, and we weren't really followed up on." (Mother without DBT-A)*

Parent's Evaluation of Dialectical Behavior Therapy (DBT-A)

The last theme concerns participants' experiences with DBT-A treatment and will only include parents with DBT-A experience. All participants had positive experiences with the treatment method and found it helpful, but they also had suggestions for how the program can be improved. When parents talk about the DBT-A they emphasize that it was an inclusive method that taught them valuable information, tools, and techniques. However, the group structure is described as inactive and at times difficult to follow. Parents did not always feel comfortable sharing everything in front of the adolescents but had good experiences with group separation. Participants also explained that they would have wanted to be more included in the actual treatment process, and a lacking recognition of complex family structures. Overall, the treatment had a good effect, and parents' express optimism for the future.

An Inclusive Method that Teaches Valuable Information, Tools and Techniques

DBT-A is a treatment method that includes parents to a much larger extent than other methods. The parents were now in a situation where they got to participate in the skills training group with the adolescents, they could have sessions with their own therapist, and receive phone guidance when necessary. Participants describe feeling valued and treated as an important element in the adolescent's recovery.

> *"The most beneficial thing about it was we were together. I think it is important that this is a common thing, the parents and the adolescents are supposed to do this together, that it is a common project." (Mother with DBT-A)*

It was also beneficial for the adolescents that the parents participated in the skills training group; as the stressful and unfamiliar situation it was, parents could be there to keep the group active and engaging.

> *"Even the parents were reluctant to raise their hand in the beginning. But I have thought that it's part of my job to actually raise my hand, come with examples, and help get things going." (Mother with DBT-A)*

Parents highlighted that there was a concrete focus to each session. They came into the sessions and got concrete tasks that they were supposed to work on together. This made the concepts more tangible, and it easier for them to continue the work at home.

> *"When we were in DBT-A we came in every week and there was a concrete focus and we got concrete tasks that we worked on together. It was a nice way to includes us as parents more than what other methods does. In her regular therapy she is the only one who talks, and she tells us about it, but it is not like we are leaving with a common task." (Mother with DBT-A)*

Parents were grateful they were allowed to participate in skills training. They got to learn more about the adolescent's distress. They were also trained in parenting techniques, how to support the adolescents efficiently, and what to do in difficult situations, which was valuable for them moving forward.

> *"It is about being prepared. Knowing what to do when difficult situations arise and how to manage them. So, it has been very valuable to have a set of tools that you can rely on." (Mother with DBT-A)*

Inactive Group Structure, Complex Concepts, and Importance of Time.

Parents were glad that they got to do this with the adolescents, but they also have suggestions for how the program can be improved. Participants describe the skills training as too theoretical; there was too much teaching and not enough time to do, try, and engage. They explain that for the majority of the skills training sessions the parents were quiet, and the practitioner who led the group did all the talking:

> *"There should have been more of a dialog than monologue in the skills training group. Because it can be too much talking, so more practical training in the subjects we are actually talking about, that we are supposed to do something in the sessions we have." (Father with DBT-A)*

Participants describe that the lecture format and inactivity made it challenging for both the parents and the adolescents to keep focused and follow everything that was said. The concepts discussed and the terms used are complex, and sometimes difficult to understand. Parents describe how the program should have been simplified and translated to fit the participant's abilities and language better.

> *"DBT-A is based on American empirical science, which the entire program shows signs of. What I mean by that it can be hard for the adolescents to grasp and understand everything (...) They use some very difficult words, and there are some concepts that the adolescents don't understand. In terms of my girl, she would look at me after skills training and say, "I don't understand what they are talking about."" (...) "These are very complex and hard things to grasp. Reaction patterns, feelings, strategies to make changes, it is very difficult." (Father with DBT-A)*

Participants emphasize that these are complex problems that take time to understand and treat. The DBT-A skills training is also a new and stressful situation, so it can take some time for the parents and adolescents to get comfortable, and for everything to assimilate. Although the program was demanding and took a lot of time and dedication, participants only described benefits of having more time:

> *"I think a lot of the adolescents had an even harder time than us adults to keep up with everything. There is a lot of stress, it was like that for us at least. I don't remember much from the first rounds either, you enter a state of shock, so it is very important that you have enough time." (Mother with DBT-A)*

> *"I think it was just the top of the iceberg really. You could benefit even more from it if you in an ideal world have had more time." (Mother with DBT-A)*

Not Feeling Comfortable Sharing Openly in the Group Setting and Positive Experiences with Group Separation

The skills training group is not intended to be a support group. However, parents are often asked to share experiences and talk about their challenges, something participants experienced as quickly becoming subjective or shallow. Parents only felt comfortable sharing from the surface and about their minor challenges, not the deep issues they are having. This was seen as problematic to parents because they might have benefited even more if they brought those significant challenges to the surface.

> *"What we have felt is that the most difficult things are not addressed in a group like that. The adults end up talking about the difficulties at work or managing stress, and*

> *the adolescents talk about struggling with school or homework." (Mother with DBT-A)*

Participants explain that one of the reasons they did not feel comfortable sharing their most personal problems was the presence of the adolescents, which is why they found it very valuable to be separated from them and getting the opportunity to work and discuss with only other parents. Only having parents in one group also facilitates for a different kind of conversation, which they felt strengthened the bond between the parents.

> *"When we are in one group most of us probably only share the things that are not too bad, I know I do. I am not going to sit there in front of my daughter and tell everyone how miserable I am." (Mother with DBT-A)*

Parents Remained Uninvolved in the Adolescent's Treatment Process

Parents explained that they thought they would be more involved in the treatment process of the adolescents. They got to participate in the skills training, and they were taken care of, but they were not included or asked when it came to the treatment of the adolescents. Parents explain that they have a lot of insight and experiences that could benefit the clinicians, which should have been utilized more.

> *"I think it would have been positive for DBT-A to have a closer contact with parents. (...) I think everyone would benefit from it. I could have gotten the opportunity to talk about what was on my mind more, and it is something about just expressing it that makes you feel lighter. But I also think I could have contributed more to my adolescent's development by giving her clinician more insight and more ground to base her approach on." (Father with DBT-A)*

Parent Participation Requires that the Complexity of Family Structures is Taken into Account.

The presence of secondary caregivers, or stepparents, was not considered when the DBT-A-team included parents. Participants explain that as they enter the treatment program, the role of the other biological parents and primary caregiver is discussed. However, those that have another partner did not have the same discussion regarding secondary caregivers and their involvement.

> *"But nobody… My partner for example, has never talked to anyone. He is not her biological father, so he is completely excluded. He just has to watch, sort of like a bystander to everything that is going on, but this affects him too." (Mother with DBT-A)*

Biological parents will not always be the primary caregiver, at least in practice. Some families have a secondary caregiver that is more directly involved with the adolescent on a daily basis, which would be beneficial to consider.

Improved Self-efficacy, Resilience, and Optimism Following the DBT-A Program

When parents talk about their lives after DBT-A everyone describes progress. Parents talk about an increased ability to face the challenges to come, an increased awareness of their patterns of interaction, and a closer relationship to the adolescents. Parents explain that they understand more of the processes at play, which, combined with the techniques they have been trained in, has made it easier for both of them to face new challenges.

> *"It is better. It has become easier for me to calm her down and remind her to remember what we talked about, "this is a strong feeling, lets breath and take some time before we act". Which affects our entire dynamic." (Mother with DBT-A)*

> *"Our experience is in large positive in terms of the subjects that are focused on and the tools we have been taught. It has given us a deeper understanding, which makes it easier for us as parents to face the challenges that are coming our way." (Mother with DBT-A)*

Participants explain that the DBT-A program has increased their awareness of the patterns of interaction between them and their adolescents. They know more about what to do, what not to do, and when to do it. They have developed as parents and learned more about how to best support the adolescents. Participants explain that the program has taught them and the adolescent better ways of communicating, which has brought them closer together and enabled them to tackle difficulties.

> *"The communication at home has gotten much better. And I think the relation between us has gotten better too because we were able to validate each other more." (Mother with DBT-A)*

This has also become a common project for the adolescents and their parents. For this to work they have to meet in the middle and work together towards the best solution, which have contributed to a strengthened bond between the two.

Parents are in no doubt that this is a treatment method that they will benefit from. The program in itself was demanding, and the days were long, but it was worth it. Parents also emphasize that this is not the end. The treatment may have had a positive effect, but it will not make everything ok. There is still much work to be done, but this program has made them more prepared and able to do it.

> *"It is a step in the right direction. it won't make everything ok, but you are one step further down that road." (Mother with DBT-A)*

Discussion

This study shows several challenges parents of children with severe emotional difficulties face. Participants' experience of parenthood is dominated by fear, unpredictability and pressure, and they describe a continuously traumatic situation where they are expected to take on tasks far above what they are capable of. This is too demanding for parents to manage alone, but participants have diverging experiences with mental health services and describe a system with no systematic structure for supporting or including them. These findings show that parents' need for help and assistance are not fulfilled, and they describe being met with a lack of care and compassion from the system and practitioners. Participants explain that they are exhausted and not being given the support they need, has direct consequences for their health, their families, and their ability support the adolescents.

DBT-A recognizes the importance of parental involvement; the program engages and attempts to include parents into the adolescent's treatment program, and by that help them as caregivers. Something participants have responded well to. DBT-A seems to accommodate for parents needs and facilitate for positive experiences more efficiently than other methods, and parents with DBT-A express a greater sense of control and optimism than those without, which suggests that aspects of this method empower parents to a greater extent than other methods do. However, participants still have constructive suggestions for how the method can be further improved, specifically when it comes to the structure of the skills training program, the recognition of complex family structures, and the inclusion of parents as collaborators, not just participants.

DBT is considered to be the gold standard treatment for suicidal and self-injurious patients, and its effectiveness is well documented among both adults and adolescents (Biskin, 2013; Fleischhaker et al., 2011; Groves et al., 2012; Livesley & Larstone, 2018; MacPherson et al., 2013; McCauley et al., 2018; Mehlum et al., 2014; Rathus & Miller, 2002; Reed, 2017; Woodberry, 2008). The strength of DBT lies in taking a systemic approach and having an increased focus on not only activating, but also helping the social networks that are activated (Linehan, 1993; Linehan et al., 1991; Rathus & Miller, 2002). Something participants have particularly positive experiences with and benefits from. But despite there being a documented advantage of including parents to a child's treatment (Gill et al., 2018; Mehlum et al., 2014; Rolland, 2019), the majority of other methods uphold an individualized focus on patients and do not prioritize family systems or situational contexts to the same extent (Biskin, 2013; Stoffers et al., 2012). In general, parents are not given an active role in the adolescent's treatment process, yet they are expected to have all the responsibility outside of the clinic, which is a problematic discrepancy.

This study shows that participants who are included in treatment, educated, and trained in parenting techniques reflect a greater sense of control and self-efficacy than those who are not. This requires resources, but DBT-A shows us some ways in which this can be done. For example, by including parents in the treatment process, helping them understand the situation, and guiding them along the way. The program can therefore be used as a paradigm for how parents can be included and empowered in other treatment programs, which will be further discussed.

The Importance of Parental Involvement

It is well documented that parental involvement is directly connected to a child's prognosis, and parents' ability to support the adolescents is crucial for their recovery (Calandri et al., 2019; Gregory et al., 2020). Participants acknowledge the responsibility and obligation they have; they express a dedicated attitude towards their role as parents but explain that lack of care and support from health care services makes living up to the expectations they are held to challenging. Participants describe a system where their involvement is not necessarily seen as being positive, and many describe that instead of being guided and assisted, they regularly experience being questioned, blamed, and perceived as a potential threat.

That maladaptive parenting and childhood maltreatment is related to the development of psychological distress and pathology (Crowell et al., 2009; Johnson et al., 2002; Linehan et al., 1991; Swales et al., 2017) does not mean that problematic parenting will always be to blame. It is important to be aware of familial factors that could exacerbate an already vulnerable situation, but this study shows that suspicions and accusations only led to self-doubt, shame, and increased stress levels. This is further supported by past researchers who found that parents are often blamed when their children have psychological distress, and because of this blame, many parents experience profound guilt for having contributed or not been able to prevent their child's disorder (Darmi et al., 2017). Assessing the circumstances around the adolescents is an important step to their treatment process, but practitioners should be careful when they evaluate parents' liability, and they must remember to remain unbiased and open, and not let other factors such as negative misconceptions and previous experiences with parents get in their way of an accurate assessment.

The findings of the current study show that the barriers for parental involvement are not necessarily grounded in parents, their dedication, or their willingness to make changes. It is instead the lack of support received from the system that makes this difficult for them. This is further supported by past research that shows when parents are not supported, their levels of distress and anxiety is exacerbated and they become increasingly vulnerable to exhaustion and other stress-related health problems, which subsequently will impede on their ability to provide for the adolescents (Louis & Kumar, 2016; Raphael et al., 2006; Roskam & Mikolajczak, 2020).

Consequences for Parents' Health and Wellbeing.

This study demonstrates how parents' wellbeing varies with their children's general situation; parents constantly worry about the adolescents, and their wellbeing and self-perceived health becomes completely dependent upon the adolescents. This becomes particularly obvious through the wellbeing charts. The parents are put under a lot of pressure, the stakes are high, and this situation requires all the time and resources they have. Participants describe experiencing chronic distress and deteriorating health outcomes, and a magnitude of other studies have demonstrated that the sacrifices parents have to make goes at the expense of their own physical and mental health (Aschbrenner et al., 2009; Bilgin & Gozum, 2009; Chessick et al., 2009; Lindström et al., 2010; Masoumi et al., 2020).

Participants describe having sleep disturbances, problems concentrating, memory loss, and physical pains. These health implications are consistent with those frequently found among other parents of children with severe mental health problems or other disabilities (Barker et al., 2012; Lindström et al., 2010; Song et al., 2018; Song et al., 2015), which is a clear sign that parents who are caregivers need more help than they are getting, and reflects a clear unbalance between what parents are expected to handle and what they are enabled to handle.

Partners, Relationships, and the Recognition of Complex Family Structures

The current study show that the entire family is affected. They all live under the same circumstances, they witness the same incidents, and they all make sacrifices to accommodate for the adolescents' needs. A partnership is supportive and gives parents opportunities for relief that they would not have had if they were single parents, but they do not get much time together, and the relationship dynamic changes. Past researchers have also found that due to the extra conflicts and ongoing challenges at home, parents who have a child with a disability or chronic illness experience more difficulties in their marriages than comparison parents (Aschbrenner et al., 2009; Kay et al., 2018). This is problematic because parents are already under a lot of pressure, and anything that is stressful complexifies the situation and makes exhaustion all the more likely. The adolescents are also in a vulnerable position and having an unstable or challenging home environment may have damaging consequences for them as well.

Although the current study regards the experiences of parents who are primary caregivers, the participants in this study live in diverse family structures, and it is important to consider the role of secondary caregivers such as stepparents as well. The inclusion of parents to treatment and support given to the family seems to be based on the idea of a traditional family consisting of two biological parents and biological children. It is increasingly common that families are extended and include both stepparents and siblings, but this study shows that treatment personnel often forget to consider them as equal stakeholders. Stepparents do not have the same rights as biological parents, yet in some families they are more involved with supporting the adolescents and assisting the parent, and this affects them too. It is the role the caregiver plays for the adolescents that become important, not necessarily genetics, which more awareness should be directed towards.

DBT-A included parents, but this study suggest that secondary caregivers' role is still overlooked. I cannot conclude that this is the practice everywhere, but I still encourage treatment personnel and researchers to consider the role all family members have when assessing a situation, not only the ones who are presumably closest to the adolescents. In many family's stepparents are significant persons for the adolescents and including them at the same level as primary parents will strengthen the adolescent's network and the support provided to them.

How to Minimize Adverse Consequences for Siblings

All participants had more than one child and they describe continuously down prioritizing their other children. Participants express worry for the implications this had for siblings and their development, but they are not in a situation where they have the capacity to care for everyone equally.

This study did not include siblings and was not able to investigate the consequences of this, but other researchers have found that siblings experiences of increased emotional distress, family conflict, and loss of parental attention significantly impacts their lives and personal development (Lukens et al., 2004; Preminger, 2018). Siblings report feeling invalidated and unimportant to their parents (Preminger, 2018), and they consistently describe experiencing a complex set of negative emotions, including anger, guilt, loss, fear, and anticipated burden (Lukens et al., 2004). Multiple studies have also been conducted with siblings in comparable situations and findings show that siblings of children with disabilities or other chronic illnesses are more likely to have problems with interpersonal relationships, use of leisure time, psychopathological functioning, and functioning at school compared to siblings of typically developing children (Goudie et al., 2013; Louis & Kumar, 2016). Findings such as these are concerning and underlines the importance of recognizing the consequences this has for siblings and supporting them.

Implications for the Adolescent's Prognosis

It is evident that without support the unlimited dedication expected by parents becomes an unrealistic ideal that they exhaust themselves trying to live up to. Failing to incorporate parents and other family members into the bigger process has repercussions that affects them as individuals, which subsequently harms the adolescent in treatment (Calandri et al., 2019; Gregory et al., 2020). Supporting parents and family members who are caregivers is important in all instances, but the interpersonal characteristics and behaviors of adolescents with severe emotional difficulties are particularly demanding and supporting them is challenging (Mehlum et al., 2014; Rathus & Miller, 2002; Wilks et al., 2017). These adolescents are at an increased likelihood of exhausting the network around them, so supporting their parents and family members is very important. Safeguarding around the adolescents is important to make sure that everyone can contribute as much as possible, because it is crucial for them that their parents and families remain involved and supportive.

Mental Health Services

Parents are essential actors in the health care system, and they are relied on to do a lot of the caregiving and surveillance that practitioners do not have the time or capacity to do. They provide care, as well as logistical, emotional, and financial support that no other person or system can, which makes them a particularly powerful asset when it comes to a child's treatment and well-being (Fitzpatrick et al., 2019; Rolland, 2019).

Participants in this study had both positive and negative experiences with mental health services. They describe being grateful for the help they have received, but that it is not sufficient, and as parents they are often excluded and overlooked by support services and treatment personnel. This is consistent with past studies where caregivers report regularly being overlooked, unappreciated, and not receiving adequate information from practitioners (Cleary et al., 2005; Dunne & Rogers, 2013; Goodwin & Happell, 2007b). Supporting parents might not be the primary purpose for adolescent's treatment personnel, but parents are given a lot of responsibility, they remain an essential part of the adolescent's recovery, and they should not be expected to manage this without help. Caring for and supporting parents will require resources, but there are clear advantages of doing so, and by empowering parents, the adolescents and their treatment will benefit (Calandri et al., 2019; Gregory et al., 2020).

The Importance of Information, Support, and Guidance

This study shows that there is a clear discrepancy between the expectations parents are held to and the help they are given. Most parents will not have prior training or education intended to prepare them for this role. Participants explain that a systematic structure for providing this does not exist, and they need help understanding what is going on and where to go from here. This is consistent with several studies that show that carers for young adults who are engaging in self-harming behaviors want more information on what is happening, why it is happening, and what they should do when it happens (Byrne et al., 2008; Cleary et al., 2005; Dunne & Rogers, 2013; Raphael et al., 2006). Their role as parents obligates them to support the adolescents, but it is not a given that all parents will know how to, and participants in this study explain that constantly having to figure everything out on their own is challenging and exhausting.

Psychoeducation, support, and guidance are elements that are documented to be beneficial for parents who are caring for adolescents with severe emotional problems; they improve parents' self-efficacy, relation to services, and their ability to withstand the demand that is put upon them (Cleary et al., 2005; Goodwin & Happell, 2007a; Raphael et al., 2006), yet providing these services to parents is not systematized. There are exceptions, but most treatment regimens do not have a specific focus on or structure that accommodates for this (Biskin, 2013; Stoffers et al., 2012). These are elements that parents are asking for, and that is proven to be of benefit to them, so systematizing these services is a factor that can help make the entire situation more sustainable and beneficial for everyone involved.

Parental Exhaustion and the Need for Hospitalization of the Adolescents

Parents' need for hospitalization of the adolescents is a good example of what can happen when they do not receive the assistance and support needed. Hospitalization is necessary for practitioners to resort to when responding to acute situations, but it does also entail relief for parents and will automatically allow them to take a step back. The question becomes if it is possible that adolescents are in some instances hospitalized not because they need to be, but because their parents are exhausted and need relief?

This study did not specifically investigate the relationship between parental exhaustion and the need for hospitalization. However, participants tell stories that implies this tendency, and mentions hospitalization in the context of their own exhaustion and fear of what would happen if they remained responsible. This interpretation is supported by past research that shows that exhaustion of social networks increases the likelihood of hospitalization to occur (Bonsack & Borgeat, 2005), which is concerning. Suppose adolescents are hospitalized due to parental reasons. In that case, it is also more likely to be involuntary, and regardless the emergency of the situation, coercion is a serious intervention on the adolescent's freedom and something they is described as a traumatic experience of losing control (Riley et al., 2014).

Using involuntary hospitalization in the adolescent's treatment should always be used with caution and as a last resort. If parents' need for hospitalization represents an unfulfilled need for support and assistance, other more advantageous solutions exist. For example, by helping them earlier on. It is plausible that if more systematic structures for providing parental support and assistance existed, it can be possible to reduce the number of times adolescents are hospitalized due to parental exhaustion, and by that we can save the adolescents for trauma and society for resources. However, this is only speculations and something future research will have to take a closer look at.

Parent's Role in Mental Health Care Compared to Physical Health Care

Participants also observe a discrepancy between the way they are treated compared to how parents of children with other physical disabilities or illnesses are treated. When a child struggles with physical problems there is a system that automatically qualifies them for receiving support and other services such as daily assistance and help getting to school, but this is not as straightforward when it comes to children with psychological problems. The law says explicitly that children must have a disability, or a temporary injury or disease, that prevents them from getting to school to get a taxi (The Education Act, 2016, § 7, 3). Although psychological problems can be argued to be a disability, it is not automatically recognized as one, and by using this term the system puts up an immediate barrier.

The paradox is that if emotional problems had been classified as a disability instead of a psychological problem a system for providing the adolescents and their families support would be have been activated. This indicates that psychological difficulties are not acknowledged as equally legitimate, disabling, or demanding as other types of illnesses or disabilities a child can have, and reflects structural discrimination of mental health problems. The adolescents' difficulties define parents' rights, and as long as caring for someone with psychological problems is not recognized as equally challenging as caring for someone with a physical one, we will have an imbalance between the service parents get.

The law says that parents with demanding caregiver responsibilities have the right to get assistance, information, and guidance (The Health and Care Services Act, 2011, § 3, 6). The problem is that this is not automated, and in order to acquire these services parents have to continuously prove to others how demanding their situation is and justify why they should get them. For parents to receive assistance, they have to prove that they deserve it, which participants describe as an unnecessary burden and major limitation to the current system.

DBT-A as a Paradigm for How Parents Can be Supported and Empowered

DBT-A distinguishes itself from other treatment programs by giving parents an active role in the adolescent's treatment. The program is able to help the adolescents at the same time as it includes, educates, and trains parents (Rathus & Miller, 2002). All participants had stories regarding blame, lack of support, and being overlooked by services and personnel, but these were far more extensive for participants who had not been through the DBT-A program. This study also shows that participants without DBT-A experience have more immediate needs than parents with DBT-A experience. The additional needs parents without DBT-A discussed were getting help to process and understand the situation, guidance on how to manage the adolescent's emotions and behaviors, as well as help to set boundaries and hospitalization of the adolescents. What makes this finding particularly interesting is that DBT-A targets all of these needs in one way or another.

Participants Evaluation of Strengths and Weaknesses of the DBT-A Program

As a program, DBT-A specifically concentrates on providing parents psychoeducation and training them in techniques that can help them manage challenging situations (Linehan et al., 1991; Rathus & Miller, 2002). Participants describe that receiving educative information and skills training made it easier for them to manage difficult situations and increases their resilience to stress. This is consistent with past research that shows reliable improvements to parents' objective burden, subjective burden, grief, and parental stress following a DBT-A program (Flynn et al., 2020). Participants in this study also emphasized that the skills component of DBT-A had been particularly useful helping them meeting their own needs, at the same time as they support their child's needs (Flynn et al., 2020).

Under the circumstances where parental exhaustion contributes to adolescent's hospitalization, it is not unlikely that parents with DBT-A's increased self-efficacy, made them less reliant on health care services. Perhaps their situation never got to this extent; DBT-A taught the parents how to manage themselves and the adolescents more efficiently, which made them more prepared for difficult situations, more empowered, and more resilient.

DBT-A is considered an effective treatment for adolescents with severe emotional difficulties, but participants' evaluation of the program also show that it has potential and can be improved. The limitations and future potential of DBT-A are not widely studied. The program has been adapted to fit different purposes, but the general program is rarely critically evaluated. Criticizing something that works may seem unnecessary, but it is important to be dynamic and keep looking for ways to enhance the program. This will help parents, help the adolescents, and increase the confidence we can have in DBT-A.

The Advantage of Parental Inclusion and Support by Treatment Practices

Participants' experience with DBT-A treatment suggests that there is an advantage of including parents as a natural part of an adolescent's treatment and that it is beneficial for everyone to give parents the guidance and information they are asking for. One barrier for DBT-A to be implemented more widely is the number of resources the program requires. However, past studies have shown that it is not necessary to complete the entire program in order for parents and families to benefit. Providing parents and adolescents with only the skills training program while the adolescents continue in his or her individual therapy is shown to be beneficial, and significantly reduced family members' ratings of caregiver strain, difficulties regulating emotions, perceived stress, and interpersonal problems, as well as lead to improvements in family attitudes (Gill et al., 2018; Wilks et al., 2017). Research also shows that parents and their families have benefited from so much as a one-time workshop in these skills and recommends providing this quickly to families who are waitlisted to receive treatment (Flannery, 2018).

These findings demonstrate that there are advantages of providing the DBT-A skills training sessions independent from the rest of the program and illustrates the potential in psychoeducation and guidance. It can also be used to safeguard around parents and as a temporary solution while parents and adolescents wait for treatment because the system is limited, and many families are waitlisted before they get into treatment.

Strengths and Limitations to this Study.

The first limitation of this study regards the possibility of a construct bias and that the parents' satisfaction with DBT-A is grounded in it being new for them, and a recently developed treatment method. Even if parents were unaware of this, they could have been influenced by clinician's enthusiasm. However, this is unlikely; the parents are satisfied because DBT-A accommodates many of their needs for familial and parental support, not because they are getting something that is new. Parents come across as balanced, reflected, and nuanced; they point out weaknesses equally to strengths, which is unlikely that they would have done if they were satisfied simply by it being new and the clinicians were enthusiastic.

The second limitation regards our method of recruitment and the possibility of a selection bias. Parents had to respond to a proposal, which creates a possibility for attracting a biased sample of parents with an agenda and particularly positive or negative experiences. It was not possible to control for this in the process of recruiting participants, but the consequences of it is controlled for in the collection and analyzation of data. The interview-schedule and the process of analysis were structured in a way that intended to bring forward nuanced and balanced perspectives. All participants described positive and negative experiences, and they were able to make objective considerations about the situation, which makes us confident in this material. Without access to any journals or external sources, I had no way of controlling for participants' truthfulness, but there is no reason for this to be second-guessed nor for them to lie.

It is possible that participants could have misunderstood questions, but when this happened questions were asked again in a slightly different and clarifying manner. And if participants wanted to withhold information, it is their information to withhold. Participants' stories were coherent and detailed, and the similarities seen between parents' experiences in this study, and between other studies, further support their reliability. Two researchers were involved in the analysis and interpretation of parents' stories and the data material. All data has been carefully assessed, discussed, and reviewed, and within these boundaries, we believe that participants will see this as an accurate description of their experiences, and that other parents who have been in similar situations will be able to recognize what they are going through.

Conclusion

Lack of support and assistance to parents who have adolescents with severe emotional difficulties is a barrier for parental involvement and creates an unsustainable situation characterized by parental exhaustion and reduced health outcomes for the entire family. The principle of parental involvement has led to some systematization of parental empowerment strategies, but this is not widely implemented and a systematic structure for this does not exist in the health care system. Failure to recognize the complexity of family structures may also result in that individuals, who in practice are primary caregivers (i.e., stepparents), are overlooked and do not receive the support and attention they need.

These findings show that parents who receive information, support, and guidance are more resilient to stress and have a higher sense of self-efficacy than those who do not, which contributes to positive experiences and make parents less reliant on the health care system.

The way DBT-A includes and guides parents in the treatment of adolescents can therefore serve as one model for how parental involvement can be facilitated, and for how these elements can be provided, which would be beneficial to consider implementing on a more general basis in clinical practice.

Current research has a considerably negative portrayal of parents and their liability when children struggle with emotional difficulties. This research needs to be supplemented with studies that concentrate on the empowerment of them and their families, and how to help them. Future research should also critically examine the health policy around support and assistance given to parents who have children with psychological problems, because there are clear elements that makes it more difficult than it has to be for parents to get the help they need.

The finding of the current study is relevant for everyone who works with mental health care for children and adolescents, or in other contexts where a child’s illness or distress can have major implications for parents and families.

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Appendix A1

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

ROLLEN SOM PRIMÆRSTØTTE FOR UNGDOMMER MED EMOSJONELLE UTFORDRINGER.

Dette er en forespørsel til deg om å delta i et forskningsprosjekt til en masteroppgave i psykologi ved Universitetet i Tromsø. Prosjektets formål er å utforske opplevelsen av å være en del av primærstøtten til ungdommer med emosjonelle utfordringer. Gjennom dette prosjektet vil vi utforske hvordan det er å være mor eller far i en slik situasjon, hva typiske problemstillinger er for dere som familie, hvilke behov dere har personlig, og hvorvidt dere får disse behovene møtt. Prosjektet vil også utforske hvordan det er å være en del av det ansvarlige behandlingsteamet til disse ungdommene, og hva som er klinikernes motivasjon for å jobbe med denne gruppen.

Vi er interessert å utforske hvilke perspektiver du har som primærstøtte, og du blir forespurt om å delta på denne studien på grunn av din rolle som foreldre til en ungdom som har gått til DBT behandling. Du er blitt identifisert og kontaktet gjennom felles kontakter ved behandlingsteamet i dialektisk atferdsterapi ved barne- og ungdomspsykiatrisk avdeling på Universitetssykehuset Nord-Norge.

HVA INNEBÆRER PROSJEKTET?

Dette prosjektet vil bestå av et intervju som vil ta en time. Intervjuet vil bli tatt opp, men ingen personopplysninger vil registreres utenom opptaket.

Intervjuet vil foregå på et lukket sted for å ivareta at deltager opplysninger og intervju-innhold forblir private. Sted bestemmes av deltager hvis ønskelig, gjerne på deltagers område for å gjøre det enklest mulig for deltager. Hvis ikke kan intervjuet også foregå ved Universitetet i Tromsø, eller så kan prosjektansvarlig finne et sted som ligger nærmere deltakers lokasjon.

De eneste personopplysningene som vil bli etterspurt er navn og alder. Andre personopplysninger som vil bli registrert avhenger av hva du selv velger å dele; du vil bli spurt om å dele dine personlige perspektiver, men disse vil bli anonymisert og slettet etter prosjektslutt. Du vil ikke bli spurt om å dele noe angående ditt barns utfordringer, men heller dine opplevelser som primærstøtte.

MULIGE FORDELER OG ULEMPER

Fordeler ved deltagelse i dette forskningsprosjektet inkluderer at du, gjennom dine beskrivelser av dine erfaringer med å være mor eller far til en ungdom med emosjonelle utfordringer, bidrar til å øke forståelsen av hva det betyr å være foreldre i slike situasjoner, både med tanke på hvilke utfordringer du og dere som familie møter, hvilke personlige behov du, og hvorvidt du klarer å tilfredsstille dem.

Gjennom samtale har også intervjuet potensialet til å rette deltageres oppmerksomhet mer mot hvordan det å inneha en slik støtterolle kan påvirke deg og hvilke behov du har, noe som ofte kan bli sekundært i et slik rolle hvor hovedfokuset ligger på å hjelpe noen andre. Potensielle ulemper ved deltagelse inkluderer at en slik deling av personlige perspektiver kan være ubehagelig, men du velger selv hva du ønsker å dele.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan trekke ditt samtykke når som helst og du trenger ikke å oppgi grunn. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede data og opplysninger, med mindre disse allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte **Christina Rolandsen** på **40485704**, eller **cro055@post.uit.no**

HVA SKJER MED OPPLYSNINGENE OM DEG?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. Du har rett til innsyn i hvilke opplysninger som er registrert om deg, og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende informasjon. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun **Christina Rolandsen** og prosjektleder, **Geir Lorem,** som vil ha tilgang til denne listen.

Opplysningene om deg vil bli anonymisert og lagret uten noen personopplysninger etter masteroppgavens prosjektslutt, Mai 2021. Du kan trekke deg fra deltakelse når som helst, og da vil også all informasjon bli slettet og ikke brukt i oppgaven, med mindre data allerede har inngått i analyser.

GODKJENNING

Etter ny personopplysningslov har Universitetet i Tromsø og **Christina Rolandsen** et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6 nr. 1a og artikkel 9 nr. 2a og ditt samtykke.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet kan du ta kontakt med **Christina Rolandsen**, **40485704**, **cro055@post.uit.no**.

Personvernombud ved institusjonen kontaktes på personvernombud@uit.no

JEG SAMTYKKER TIL Å DELTA I PROSJEKTET OG TIL AT MINE PERSONOPPLYSNINGER BRUKES SLIK DET ER BESKREVET

Sted og dato   Deltagers signatur

Deltagers navn med trykte bokstaver

Appendix A2

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

ROLLEN SOM PÅRØRENDE TIL UNGDOMMER MED EMOSJONELLE UTFORDRINGER.

Dette er en forespørsel til deg om å delta i et forskningsprosjekt til en masteroppgave i psykologi ved Universitetet i Tromsø. Prosjektets formål er å utforske opplevelsen av å være pårørende til ungdommer med emosjonelle utfordringer. Gjennom dette prosjektet vil vi utforske hvordan det er å være mor eller far i en slik situasjon, hva som er typiske problemstillinger er for dere som familie, hvilke behov dere har som foreldre, og hvorvidt dere får disse behovene møtt.

Prosjektet vil også utforske hvordan det er å være en del av et ansvarlig behandlingsteam for disse ungdommene, og hva som er klinikernes motivasjon for å jobbe med denne gruppen.

Jeg er interessert i din erfaring som som pårørende, og du blir forespurt om å delta på denne studien på grunn av din rolle som foreldre til en ungdom som har emosjonelle utfordringer.

HVA INNEBÆRER PROSJEKTET?

Dette prosjektet vil bestå av et intervju som vil ta en time. Intervjuet vil bli tatt opp, men ingen personopplysninger vil registreres utenom opptaket.

Intervjuet vil foregå på et lukket sted for å ivareta at deltager opplysninger og intervju-innhold forblir private. Sted bestemmes av deltager hvis ønskelig, gjerne på deltagers område for å gjøre det enklest mulig for deltager. Prosjektansvarlig kan også finne et sted som ligger nærmere deltakers lokasjon.

De eneste personopplysningene som vil bli etterspurt er navn og telefon nr eller e-post, men det er kun prosjektleder som ser dette. Andre personopplysninger som vil bli registrert avhenger av hva du selv velger å dele; du vil bli spurt om å dele dine personlige perspektiver, men disse vil bli anonymisert og slettet etter prosjektslutt. Du vil ikke bli spurt om å dele noe angående ditt barns utfordringer, men heller dine opplevelser som foreldre og pårørende.

MULIGE FORDELER OG ULEMPER

Fordeler ved deltagelse i dette forskningsprosjektet inkluderer at du, gjennom dine beskrivelser av dine erfaringer med å være mor eller far til en ungdom med emosjonelle utfordringer, bidrar til å øke forståelsen av hva det betyr å være foreldre i slike situasjoner, både med tanke på hvilke utfordringer du og dere som familie møter, hvilke personlige behov du, og hvorvidt du klarer å tilfredsstille dem.

Gjennom samtale har også intervjuet potensialet til å rette deltageres oppmerksomhet mer mot hvordan det å inneha en slik støtterolle kan påvirke deg og hvilke behov du har, noe som ofte kan bli sekundært i et slik rolle hvor hovedfokuset ligger på å hjelpe noen andre. Potensielle ulemper ved deltagelse inkluderer at en slik deling av personlige perspektiver kan være ubehagelig, men du velger selv hva du ønsker å dele.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan trekke ditt samtykke når som helst og du trenger ikke å oppgi grunn. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede data og opplysninger, med mindre disse allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte **Christina Rolandsen** på **40485704**, eller **cro055@post.uit.no**

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Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. Du har rett til innsyn i hvilke opplysninger som er registrert om deg, og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende informasjon. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun **Christina Rolandsen** og prosjektleder, **Geir Lorem,** som vil ha tilgang til denne listen.

Opplysningene om deg vil bli anonymisert og lagret uten noen personopplysninger etter masteroppgavens prosjektslutt, Mai 2021. Du kan trekke deg fra deltakelse når som helst, og da vil også all informasjon bli slettet og ikke brukt i oppgaven, med mindre data allerede har inngått i analyser.

GODKJENNING

Etter ny personopplysningslov har Universitetet i Tromsø og **Christina Rolandsen** et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6 nr. 1a og artikkel 9 nr. 2a og ditt samtykke.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

KONTAKTOPPLYSNINGER

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Sted og dato Deltagers signatur

Deltagers navn med trykte bokstaver

Appendix B1

Intervju guide – Foreldre

Formål: Intervjuet dreier seg om hvordan det er å være foreldre og en del av primærstøtten til ungdom med emosjonelle utfordringer

Fase 1: Rammesetting

- Informasjon om prosjektet
    - Gjennom dette prosjektet vil jeg representere foreldrenes side, og illustrere hvordan det er for dere å være mor eller far i en slik situasjon og med slike problemstillinger, hva du trenger for å fungere optimalt, og hvorvidt du får disse behovene møtt.
    - All informasjon vil bli anonymisert og jeg har taushetsplikt. Det er helt opp til deg hva du velger å dele, du må finne dine egne grenser. Du kan også trekke deg fra prosjektet når som helst, og det uten å oppgi grunn.
- Er noe uklart?
- Skrive under samtykkeerklæring og få samtykke til opptak
    - *Start opptak*

Tema	Mulige spørsmål	Oppfølgingsspørsmål
1. DBT *Fortell om dine erfaringer med dialektisk atferdsterapi?*	- Hvordan opplevde du samarbeidet med klinikerne - Hva tenker du om behandlingsformens struktur - Har DBT endret perspektivet deres på familien? - Føler du at du har lært noe i DBT som du har dratt nytte av?	- Noe som fungerte spesielt bra, eller ikke så bra? - Noe du like spesielt godt eller ikke fant så nyttig? - Har DBT endret dine perspektiver på foreldrerollen? - Har du lagt merke til noen endringer i familien etter DBT? - Er det noe du savnet underveis i DBT behandling eller i etterkant?
2. Rollen som primærstøtte *Fortell om hvordan du opplever din rolle som foreldre og støtte til ungdom med emosjonelle utfordringer?*	- Hva opplever du som utfordrende? - Er det noe du opplever som givende - Hvilke behov føler du på i den rollen du har?	- Hvordan møter og prioriter du egne behov i en slik situasjon? - Hvilke konsekvenser tenker du det kan ha hvis man ikke får sine behov tilfredsstilt

3. Relasjoner og andre konsekvenser *Hvordan har denne rollen påvirket deg, ditt liv, og dine relasjoner?*	- Hvordan påvirker dette ansvaret resten av livet ditt? - Hvordan har det påvirket dine relasjoner til andre? - Hvordan har denne situasjonen påvirket livet til resten av familien? - Hvordan har denne rollen påvirket deg og ditt velvære?	- Er det noe du opplever er spesielt vanskelig? - Hvilke utfordringer møter dere som familie? - Tror du disse endringene vært knyttet til din rolle som primærstøtte?
4. Introduksjon av "wellbeing chart" *Deltakers plassering av sitt velvære i rollen som foreldre og støtte til ungdom med emosjonelle utfordringer* (Se vedlegg)	- Kan du tegne en graf som viser hvordan ditt velvære har vært gjennom denne tiden forløpet? - Fortell meg hva du har tegnet? - Hva symboliserer denne kurven? - Hva vekkes i deg når du ser på grafen?	- Hvorfor plasserte du … der? - Er det noe du savner i denne grafen? - Hvordan var det for deg å tegne denne grafen?
5. Tjeneste tilbud *Hva slags tilbud/ressurser får de/finnes for dere som foreldre?*	- Skulle du ønsket det var flere tilbud rettet mot å støtte dere som foreldre - Hvordan opplever du det er å navigere i helsesystemet? Er det enkelt å finne frem til tjenester?	- Hvilken effekt tenker du slike tilbud kunne hatt? - Hvordan opplever du å bli mottatt av helsetjenester?
6. Avslutning	- Er det noe mer du tenker jeg burde spurt om eller vil fortelle?	- Fortell hvilke følelser dette intervjuet vekket i deg

Takke for deltakelse. Slå av opptak.

Appendix B2

Intervju guide – Pårørende uten DBT-A

Formål: Intervjuet dreier seg om hvordan det er å være foreldre og en del av primærstøtten til ungdom med emosjonelle utfordringer

Fase 1: Rammesetting

- Informasjon om prosjektet
  - Gjennom dette prosjektet vil jeg representere foreldrenes side, og illustrere hvordan det er for dere å være mor eller far i en slik situasjon og med slike problemstillinger, hva du trenger for å fungere optimalt, og hvorvidt du får disse behovene møtt.
  - All informasjon vil bli anonymisert og jeg har taushetsplikt. Det er helt opp til deg hva du velger å dele, du må finne dine egne grenser. Du kan også trekke deg fra prosjektet når som helst, og det uten å oppgi grunn.
- Er noe uklart?
- Skrive under samtykkeerklæring og få samtykke til opptak
  - *Start opptak*

Tema	Mulige spørsmål	Oppfølgingsspørsmål
1. **Den generelle situasjonen** *Kan du si litt om din situasjon?*	- Hvilken type hjelp har dere søkt utenifra? - Hvordan opplevde du denne oppfølgingen? - Noe som fungerte spesielt bra, eller ikke så bra?	- Har du lagt merke til noen endringer i familien etter behandling? - Er det noe du savnet underveis i behandling eller i etterkant?
2. **Rollen som primærstøtte** *Fortell om hvordan du opplever din rolle som foreldre og støtte til ungdom med emosjonelle utfordringer?*	- Hva opplever du som utfordrende? - Er det noe du opplever som givende - Hvilke behov føler du på i den rollen du har?	- Hvordan møter og prioriter du egne behov i en slik situasjon? - Hvilke konsekvenser tenker du det kan ha hvis man ikke får sine behov tilfredsstilt
3. **Relasjoner og andre konsekvenser** *Hvordan har denne rollen påvirket deg, ditt liv, og dine relasjoner?*	- Hvordan påvirker dette ansvaret resten av livet ditt? - Hvordan har det påvirket dine relasjoner til andre? - Hvordan har denne rollen påvirket deg og ditt velvære?	- Er det noe du opplever er spesielt vanskelig? - Hvilke utfordringer møter dere som familie? - Tror du disse endringene vært knyttet til din rolle som primærstøtte?

4. Introduksjon av "wellbeing chart" *Deltakers plassering av sitt velvære i rollen som foreldre og støtte til ungdom med emosjonelle utfordringer* (Se vedlegg)	- Kan du tegne en graf som viser hvordan ditt velvære har vært gjennom denne tiden forløpet? - Fortell meg hva du har tegnet? - Hva symboliserer denne kurven? - Hva vekkes i deg når du ser på grafen?	- Hvorfor plasserte du … der? - Er det noe du savner i denne grafen? - Hvordan var det for deg å tegne denne grafen?
5. Familielivet *Kan du fortelle litt om hvordan dette har påvirket familielivet?*	- Hvordan har det påvirket relasjonene innad i familien? - Hvordan har denne situasjonen påvirket livet til resten av familien? - Får du noe støtte fra partner?	- Ditt forhold til din ungdom - Ditt forhold til dine andre barn - Hva tenker du om det? - Har denne situasjonen endret dine perspektiver på foreldrerollen?
6. Tjeneste tilbud *Hva slags tilbud/ressurser får de/finnes for dere som foreldre?* *Kan du si litt om hvordan du har opplevd å bli møtt av helsevesenet?*	- Skulle du ønsket det var flere tilbud rettet mot å støtte dere som foreldre - Hvordan opplever du det er å navigere i helsesystemet? Er det enkelt å finne frem til tjenester?	- Hva skulle du ønsket mer av? - Hvilken effekt tenker du slike tilbud kunne hatt? - Hvordan var det for deg?
7. Avslutning	- Er det noe mer du tenker jeg burde spurt om eller vil fortelle?	- Fortell hvilke følelser dette intervjuet vekket i deg

Takke for deltakelse. Slå av opptak.