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SELF-HARM AMONG ADOLESCENTS: CORRELATES, TREATMENT, AND HEALTHCARE CONSUMPTION

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Self-Harm among Adolescents: Correlates, Treatment, and Healthcare Consumption
THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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"When day comes, we ask ourselves where can we find light in this never-ending shade? The loss we carry, a sea we must wade.
We've braved the belly of the beast.
We've learned that quiet isn't always peace."

A part of Amanda Gorman's poem at the inauguration of President Joe Biden

To the struggling adolescents and families

ABSTRACT

Background: Self-harm is common in adolescence and young adulthood, and it is associated with adverse outcomes, such as general psychopathology and suicide. We need a better understanding of self-harm and its correlates such as perceived invalidation/validation, emotional awareness, and sexual- and gender minority (SGM)-status to inform interventions. Dialectical Behavioral Therapy for adolescents (DBT-A) is currently regarded as a well-established treatment. However, DBT-A is not widely available to all self-harming adolescents, and in some cases, integrated and intensive outreach treatments are needed. Intensive Contextual Therapy (ICT) includes principles and interventions from DBT-A and Functional Family Therapy (FFT) and was initiated in Sweden to prevent long periods of hospitalization and residential treatment for adolescents with self-harm and complex psychosocial symptomatology. Self-harm and suicide generate large expenses for society. Economic evaluations of interventions for self-harm are warranted as it can inform social policy and political decision makers.

Aims: The aims of the present thesis were to examine the relationship between self-harming behavior and emotional awareness, emotion dysregulation, SGM-status, and the experience of invalidation/validation, and to evaluate the novel ICT treatment in terms of feasibility, and preliminary outcome, as well as its cost and related changes in healthcare consumption.

Methods: Study I and II are based on the same cross-sectional sample (aged 15-20) from the general population, responding to an anonymous Web-based survey. In Study I (N = 1910), we investigated the associations between perceived invalidation/validation measured through a novel instrument: Responses to my Emotions, Thoughts, and Action (REMTA) and self-harm as well as emotion dysregulation, and potential mediational pathways. In Study II (N = 6345) we investigated the associations between emotional awareness, assessed by a performance-based measure, and self-harm, as well as the mediational role of emotion dysregulation. In Study III (N = 49) we used a within-group design with repeated measures to evaluate the feasibility and preliminary outcome of ICT. The participants were adolescents with self-harm and/or suicidal behaviors. Study IV was an economic evaluation of ICT and included clinical outcomes and costs from the same participants as in Study III. Data on healthcare consumption (outpatient and inpatient care, pharmacological treatment) were retrospectively collected from medical records for the time points one-year pre-treatment and one-year post-treatment.

Results: Validation/invalidation were associated with self-harm and to a larger extent with emotion dysregulation (Study I). The association between invalidation/validation and self-harm was significantly mediated by emotion dysregulation. Invalidation/validation from family members showed stronger correlations with both self-harm and emotion dysregulation than from non-family members. In Study II, mediation analysis suggested a significant indirect association between emotional awareness and self-harm through the effects of some of the subscales of Difficulties in Emotion Regulation Scale (DERS). SGM youth reported higher frequency of self-harm and emotion dysregulation.The results from Study III suggest that ICT is feasible, with a low attrition rate (0.09%) and generally high satisfaction ratings. The adolescents reported a reduction of self-harm, suicide attempts and general symptomatology. We also found a sigificant reduction of inpatient care from pre- to post-teatment. Parents reported reduced levels of stress and lower levels of criticism after completing the treatment. The results were maintained at six-month follow-up and improved further at the one-year follow-up. The results from Study IV showed that the estimated average cost of ICT per family was €5293, which corresponds to the cost of other treatments of simlar length and intensity. The average cost for residential care is five times the cost of ICT. There were no statistically significant differences pertaining to cost of health care consumtion between one year before ICT and one year after. However there was a non-significant increase in the utilisation of outpatient and primary care and a non-significant reduction of inpatient care.

Conclusions: The association between invalidation/validation and self-harm was mediated by emotion dysregulation. In addition to emotion dysregulation, it could be valuable to examine levels of emotional awareness as it has an indirect association with self-harm via emotion dysregulation and as such can give a more nuanced picture about the pathway. SGM youth reported a higher symptom load. Their health disparities and the potential role of SGM status merits further investigations. ICT seems to be a feasible intervention for adolescents with self-harm and high symptom burden. The preliminary evaluation also suggests that ICT is beneficial at individual, contextual, and family level. ICT might also have the potential to prevent fulltime institutional and inpatient care, although replications are needed. The treatment cost of ICT is comparable to other similar treatment options, but economically favorable compared to full-time residential care. After completion of the ICT the adolescents consumed more outpatient and primary care, and less specialized and inpatient care.

LIST OF SCIENTIFIC PAPERS

I. Wijana, B.M., Ghaderi, A., Enebrink, P., Liljedahl, S.I. Validation, emotion dysregulation and self-harm. Results from an anonymous large-scale Internet-based study of young people. Manuscript

II. Wijana, B.M., Enebrink. P., Liljedahl, S.I., Myrälf, M., Ghaderi, A. Emotional awareness and emotion dysregulation among self-harming adolescents and young adults in relation to gender or sexual identities: Results from an anonymous large-scale Internet-based study. Manuscript

III. Wijana, B.M., Enebrink, P., Liljedahl, S.I., Ghaderi, A. Preliminary evaluation of an intensive integrated individual and family therapy model for self-harming adolescents. BMC Psychiatry. 2018; 18: 371

IV. Wijana, B.M., Feldman, I., Ssegonja, R., Enebrink, P., Ghaderi, A. Impact of an integrated individual and family therapy model for self-harming adolescents on overall healthcare consumption. A pilot study of a Swedish sample. BMC Psychiatry. 2021; 21: 374

CONTENTS

LIST OF ABBREVIATIONS

ACT	Acceptance and commitment therapy
BPD	Borderline personality disorder
CBCL	Child Behavior Checklist
CBT	Cognitive behavioral therapy
CI	Confidence interval
CR	Cognitive reapprisal
DBT	Dialectical behavioral therapy
DERS	Difficulties in Emotion Regulation Scale
DSH	Deliberate self-harm
DSHI	Deliberate Self-Harm Inventory
DSM	Diagnostic and Statistical Manual of Mental Disorders
EE	Expressed emotions
EMA	Ecological momentary assessment
ERGT	Emotion regulation group therapy
ERITA	Emotion regulation individual therapy for adolescents
ERQ	Emotion Regulation Questionnaire
ES	Expressive suppression
EUC	Enhanced usual care
FFT	Functional family therapy
FSS	Family Satisfaction Survey
HADS	Hospital Anxiety and Depression Scale
HPA	Hypothalamic-pituitary adrenocortical
ICT	Intensive contextual therapy
LEAS	Levels of Emotional Awareness Scale
MBT-A	Mentalization-based therapy for adolescents
NICE	National institute for health and care excellence
NSSI	Non-suicidal self-injury
OR	Odds ratio
PSS	Perceived Stress Scale
QAFM	Questions About Family Members
RCI	reliable change index
RCT	Randomized controlled trial
REMTA	Responses to My Emotions, Thoughts, and Actions
SAFETY	Safe alternatives for teens and youth

SASI	Sex as self-injury
SGM	Sexual and gender minority
TAS	Toronto Alexithymia Scale
TAU	Treatment as usual
YSR	Youth Self-Report

1 INTRODUCTION

Self-harm, especially in adolescents, is highly prevalent and associated with great suffering and often adverse outcomes for both the individual, relatives, and society at large. Self-harm also tends to be stigmatized and there are often stereotypical perceptions about the phenomenon. The behavior confounds the medical professionals as it contradicts the effort of the medical practitioners to fix or heal a patient.

I have had the privilege to work with adolescents who self-harm and their families for more than ten years and it has never ceased to engage me, although it sometimes has contributed to sleepless nights. During the years two main issues have particularly caught my interest. First how can we adapt our interventions to suit even the most vulnerable individuals, the ones who are typically stuck in a limbo between social services and psychiatry? Second, how can we dispel the stereotypical picture of a self-harming person and broaden our understanding of functions and correlates of self-harm?

A true clinician at heart, I have nevertheless been given the opportunity to study these topics with support and encouragement from dedicated colleagues and knowledgeable researchers. This thesis describes the process from when we started to collect data in 2012, in order to evaluate the ICT model (Intensive Contextual Therapy) and what I have learned from designing studies and analyzing data from a large cross-sectional Web-based study. I have become more convinced that in order to treat individuals who self-harm we have to consider the complexity and the intricate interplay between individual factors, family factors and contextual factors. It is surely not a homogenic group, even if some of the characteristics and correlates of self-harm have been well documented. Other aspects are less explored such as emotional awareness and sexual- and gender minority status. In our clinic we have also noted a certain shift over the years regarding the characteristics of the adolescents referred. A larger proportion have difficulties related to neurodiversity often on the autism spectrum and many also suffer from gender dysphoria. By simultaneously supporting two of my own teenagers through all the hardship of life, my understanding of the caregiver's situation has also grown, and I find it crucial to consider self-harm from a systemic perspective.

The studies included in the present thesis have their strengths and limitations. It is my hope that they can improve our understanding and skills and serve as a foundation for further research in the area of self-harm among adolescents.

2 BACKGROUND

2.1 THE BIOSOCIAL THEORY

One of the oldest philosophical issues within psychology is the nature versus nurture debate. However, the study of the development of behavioral traits from the perspective of nature-nurture began with the work from Francis Galton, who in the mid-19th century introduced twin research [1]. Nature suggests what we think of as pre-wiring and influenced by biological factors such as genetics or inheritance. Nurture is generally described as the influence of external factors such as childhood experiences, social relationships and the surrounding culture [2]. With the emerging field of behavioral genetics, psychological researchers today are more interested in how nature and nurture interact in a host of qualitatively different ways [1, 3, 4]. Linehan's Biosocial Theory [5] is the etiological model of Borderline Personality Disorder (BPD) in Dialectical Behavior Therapy (DBT), which has influenced both academic and clinical domains of diagnosis, assessment, and treatment of BPD [5, 6]. The Biosocial Theory posits that a core feature of BPD is emotion dysregulation, originating from the transaction of temperamental/physiological vulnerability (sensitivity to emotional arousal) in the presence of an invalidating environment [5]. In the Biosocial Theory the formulation is that there is a transaction over time in which invalidation in the environment elicits and maintains the biological sensitivity of the individual to heightened negative arousal [5, 6]. When an individual is in a state of heightened emotional arousal the ability to accurately describe experiences including feelings, needs, and wishes, decreases. Inaccurate expressions in turn are not easy to validate, and the probability that the individual is met by a response that amplifies high arousal increases (see Figure 1.) The individual then learns to cope in maladaptive ways such as self-harm [5-7].

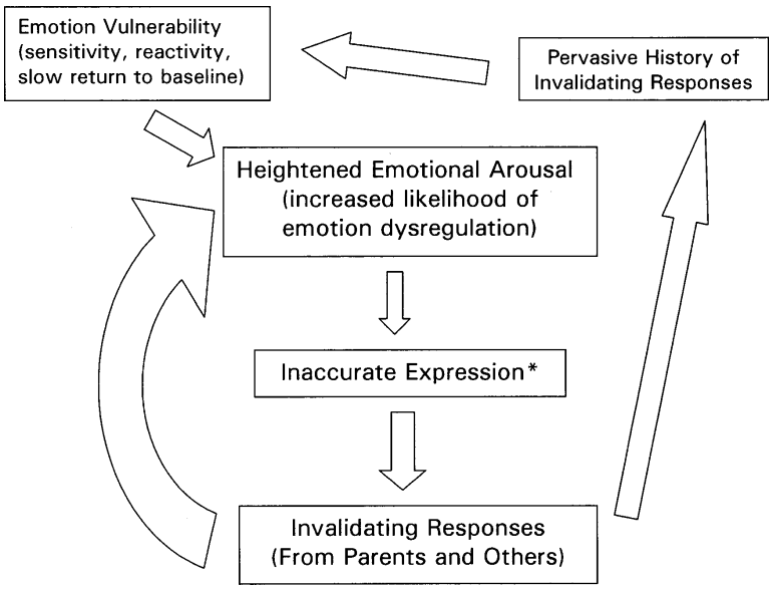

Figure 1. The transactional model: emotion dysregulation an invalidating response cycle; *includes out of control behavior. In: Fruzzetti, A.E., Shenk, C.E., & Hoffman, P. (2005). Family interaction and the development of borderline personality disorder: A transactional model. Development and Psychopathology, 17, 1007-1030. Reprinted with permission from Cambridge University Press.

2.1.1 Emotion vulnerability

The Biosocial Theory states that BPD is characterized by emotion dysregulation across all aspects of emotional functioning which can be divided into three distinctive components [5]. The first is heightened emotional sensitivity, the second is emotional reactivity, an inability to regulate intense emotional responses. The third is a slow return to emotional baseline [5, 6]. Heightened emotional sensitivity is often described as a low threshold for emotional responses, in that it does not take very much emotional stimuli to elicit an emotional response compared to others. Emotional reactivity is a tendency to experience and express strong emotional responses without inhibition. Research suggests that people with BPD tend to show emotional reactivity especially when the trigger is interpersonal or related to social rejection [8, 9]. Individuals with BPD also often have difficulties to return to emotional baseline which makes them chronically vulnerable. Some research point to that there are biological explanations for this. Including a strong physiological stress response system, deviations in the parasympathetic and sympathetic neuro system [10], and brain alterations in areas that are important for emotion regulation [11].

2.1.2 History of invalidating responses

Invalidating responses have been described as having four characteristics: communication of inaccuracy, misattribution, discouraging of negative emotional expression, and over-

simplification [5, 12]. When a person already experiences heightened negative emotional arousal is met with inaccuracy it signals that their private experiences are wrong or unimportant. Examples might be: “You aren’t afraid, you are fine” or “You say you don’t like that, but I know you do”. Misattribution is when someone is labeling vulnerability as a personally undesirable characteristic: “oversensitive, such a baby”. In an invalidating environment negative emotional expression is discouraged and painful emotions are dismissed or ridiculed. Lastly, oversimplification of emotions or thoughts communicates to a person that, for example a positive attitude can overcome any obstacle [5].

When a child or young person who is already prone to strong emotional reactions is met with invalidating responses, they are not taught emotion regulation skills, nor do they learn to trust emotions or the powerful others in the environment. Rather they learn, with ample evidence from the invalidating environment (and their own experience of emotion dysregulation) that something is wrong with them. The child or young person might also learn to use intensified emotions and behaviors in order to be taken more seriously, leading to vicious cycles whit more invalidation form the environment and escalation to out-of-control behavior [6, 13]. Studies have found correlations between experiences of invalidation and self-harm among adolescents [13-15].

2.2 SELF-HARM

2.2.1 History

Self-harm has gained increased scientific as well as media attention during the past decades [16]. Expressions like a new trend, epidemic, a major mental health issue are common. It is easy to get the impression that self-harm is a modern phenomenon, while there are vivid descriptions of self-destructive behaviors throughout the history. Examples are to be found as far back as the old and new testaments of the bible [16, 17]. Often referred to is the gospel of Matthew “And if your eye causes you to sin, gouge it out and throw it away. It is better for you to enter life with one eye than to have two eyes and be thrown into the fire of hell” (Matthew 18:9). The view and interpretation of self-harm has varied over time and the behavior as such has constituted an example about a discourse of what is considered pathological versus normal [18-20]. Our ancestors were omitted to unknown forces. In order to curb fear, spirituality became essential. Religious and pagan activities aimed at avoiding the feeling of being left to random arbitrariness were common. Voluntary castration, for example was widespread during the second and third centuries and was conducted for spiritual, social, and commercial reasons. Middle age flagellants practiced an extreme form

of mortification of their flesh by whipping it with different instruments. It was often conducted in public processions and the purpose was to show religious devotion and redemption for their sins. Bloodletting was a common medical practice, and also used a self-treatment until the late 19th century. It was assumed to prevent or cure illnesses and diseases by restoring the balance of the body fluids "homours" [16]. The desire to be able to influence vital events and conditions is also expressed in some of today's indigenous peoples in what can be described as attempts to stay well with the gods, where self-harming acts are given a sacred meaning [17]. With the emerging secularization and the associated reduction of the explanatory value of religion, a medical/ psychiatric conceptualization of self-harm appeared. Case reports from psychiatry asylums in the second half of the 19th century, contain descriptions of self-harm as a specific category of abnormal individual behavior [16]. Karl Menninger was a pioneer in his attempts to classify self-injury as neurotic, religious or psychotic, as well as self-injury in organic diseases. He also suggested that self-mutilation was an unconscious endeavor for avoiding suicide, by redirecting suicidal impulses and emotional pain to one part of the body [21]. In 1987 Favazza, published "Bodies Under Siege" [22], which has become a landmark and described as the first comprehensive exploration of self-harm. From case studies in clinical psychiatry, he broadened the understanding and awareness of self-harm, presenting it as an effective temporal relive from unbearably painful emotions.

2.2.2 Definition and classification

The research field of self-harm has been subjected to an extensive debate as how to classify and conceptualize the phenomenon [23-26]. The United States Centers for Disease Control and Prevention has recognized that the definitional ambiguity impedes the use of the vast scientific information pertaining to the area [27, 28]. A varied nomenclature illuminates these challenges as self-harm so far has been discussed using terms like partial suicide [21], delicate self-cutting [29] wrist-cutting syndrome [30], self-mutilation [22], parasuicide [31], repeated self-injury [32], self-wounding [33], and deliberate self-harm [34].

When the studies in the present thesis were designed and conducted (2011-2015), the prevailing terminology in Sweden and Europe was Deliberate Self-Harm, DSH or self-harm. The commonly used self-assessment was DSHI-9r, which, by the time was translated into Swedish and had known psychometric properties for adolescents. The field of conceptualizations of self-harm has developed since the outset of the present research. Non-suicidal Self-Injury, NSSI is gaining increasing scientific attention in North America. In the

fifth edition of the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-5) NSSI has been included within Section 3 ("conditions for further study") [35]. NSSI is defined as "deliberately injuring oneself without suicidal intent and for purposes not socially sanctioned". Yet other criteria are that NSSI has occurred on five or more days within the last year and that the individual engaging in the behavior expects obtaining some kind of emotional or cognitive relief, and/or to resolve an interpersonal problem, and/or generate a positive feeling [35]. The definition of NSSI, however highlights some important controversies. First of all, the distinction between suicidal and non-suicidal intent is complex and without consensus [16, 24, 26]. Advocates of NSSI claim that it is divergent from suicidal behavior as it tends to occur also in the absence of suicidal intent and hence requires different approaches when it comes to prevention and treatment [36]. Also, studies that distinguish between individuals who engage in NSSI and individuals who have attempted suicide have noted some noteworthy differences [37]. Among other things, people who have attempted suicide were more likely to have had experienced a traumatic life event [37], and had a more negative view of life [37, 38] when compared to people who engage solely in NSSI. On the contrary those who favor a definition that includes all acts of self-harm, regardless of the intent, argue that suicidal intention is continuously distributed with no obvious cutoff [25, 39]. Individuals who self-harm also report a certain degree of ambivalence with an unclear underlying motivation regarding the act [40]. People hospitalized following a suicide attempt report experiencing self-harm, suicidality and suicide attempts on a complex continuum [41] To make things even more complicated, self-harm has shown to be the strongest risk factor for suicide in children, adolescents, and young adults [37, 42, 43].

In the absence of any consensus regarding appropriate terminology and for the purpose of using a term that corresponds to what is applied in the included studies, self-harm is used in the present thesis. In the UK National Institute for Health and Care Excellence (NICE) guidelines p. 4 self-harm is defined as "any act of self-poisoning or self-injury carried out by an individual irrespective of motivation" [44]. This term, however, excludes some indirect self-injurious behaviors, such as substance use, restricted eating, involvement in abusive relationships and other risky behaviors. There is certainly an overlap between indirect and direct self-harm, however there is some support for separating and distinguishing the two forms [45].

Finally, it is important to note that prior research has focused on self-harm in connection with BPD. Self-harm is one of nine diagnostic criteria of BPD [35]. However, there is evidence

supporting that self-harm often occur in the absence of BPD [46, 47], as a consequence of for example depression or even without definable psychopathology [48, 49].

2.2.3 Prevalence and demography

Notably, it is a complex issue comparing prevalence of self-harm across studies and countries, due to the various nomenclature. It is, however, a major public health concern affecting a substantial amount of young people around the world [36, 50, 51]. To estimate prevalence of self-harm is further complicated by methodological factors such as biased sampling and assessment methods [52, 53]. A recent meta-analysis compiled 172 community-based studies between year1990 and 2015 [52]. The overall lifetime prevalence of adolescent self-harm was 16.9% (95% CI 15.1-18.9). Comparative numbers have been found regarding NSSI, with a pooled lifetime prevalence of adolescent NSSI of approximately 17%, internationally [51]. Yet another meta-analysis looking at the aggregated lifetime and 12-month prevalence, estimated Deliberate Self-harm (DSH) to 13.7% (95% CI: 11.0-17.0%) and 14.2% (95% CI: 10.1-19.5%) respectively [54]. In a large Swedish community-based study 35.6% of adolescents reported at least one episode of NSSI during the past year [55]. Among adolescent clinical samples the rate of self-harm is even higher. Depending on the specific psychiatric disorder, prevalence rates have been estimated to range from 40% to 80% [49, 56].

There are a few major questions that researchers have been particularly interested in: what is the age of onset, what is the gender distribution, are there differences in prevalence between different countries/cultures, and is self-harm increasing? Evidence pointing at that onset of self-harm usually occurs at the age of 12-14 years [57]. However, approximately 20% report onset between the ages of 11 and 13 [58]. Earlier onset of self-harm seems to have connection with higher frequency, multiple methods and self-harm related hospital visits [59]. Regarding the course of self-harm, there are studies suggesting that the behavior peaks in adolescence at around 15 to 17 years and decline in young adulthood [60, 61].

A fairly common misconception is that self-harm solely occurs in women. There is however a variability in findings when comparing prevalence rates in males and females. Some studies have shown that self-harm is slightly more common in adolescent females compared to adolescent males [62-64]. Other studies show no sex differences in prevalence [53, 65]. A recent meta-analysis suggests that while females are overrepresented, the difference is rather small (odds ratio [OR] = 1.5) [66]. Self-destructive behaviors have been conceptualized using an iceberg model. Where the bottom of the iceberg represents non-fatal, community

occurring self-harm, the middle section hospital presenting self-harm, and the tip represents suicides [67]. Findings suggest that there is a higher incidence of suicide in males and a higher proportion of females who self-harm [67].

Studies of self-harm and suicidal behaviors have mainly been conducted with Caucasian samples and in western countries such as United States, Canada, Australia and European countries [68, 69]. Data regarding cultural differences of self-harm are conflicting. A meta-analysis from 2019 found that adolescents from low- and middle-income countries have higher 12-months prevalence of self-harm than adolescents from developed countries, however suicide attempts were more common in western countries [54]. The non-western regions that are represented in most studies of self-harm are China, Japan, Hong-Kong, Taiwan, Indonesia, India, and Turkey [68]. The high 12-months prevalence (32.7%) of self-harm in Hong-Kong for example has been attributed to the discrepancy the young people experience when western values of autonomy and individualism collide with traditional values of a collectivistic culture [70]. Ethnic minority individuals in western countries have been shown to be particularly vulnerable with respect to self-harm, which is often explained by socioeconomic disadvantages [68, 71]. However it is important to note that ethnic identity as well as religious affiliation sometimes are protective factors and negatively correlated to self-harm [68].

Just as data regarding cultural differences of self-harm rates, there is an inconsistency regarding whether rates of self-harm have increased during the past decades [72]. Studies of temporal trends are scarce, however a cross-sectional survey from England found that self-reported rates of NSSI among girls and women (16-24 y) increased from 6.5% in 2000 to 19.7% in 2014 [63]. Another cohort study from UK showed that rates of adolescent self-harm increased from 11.8% in 2005 to 14.4% in 2015 [73]. A cross-sectional school-based survey from Norway revealed that past year prevalence of self-harm increased from 4.1% in 2002 to 16.2% in 2017/2018 [74]. The two aforementioned studies also noted a correlation between increased self-harm and increased depressive symptoms and decreased anti-social behaviors, and substance use [73, 74].

In sum, the stereotypical picture of a Caucasian woman seeking attention for self-destructive behavior should be considered an outdated notion.

2.2.4 Methods, functions, and theoretical models

Different typological characteristics of self-harm have been identified. Methods most often endorsed by adolescents are cutting, preventing wounds from healing, head banging, biting, scratching, self-poisoning, and burning [46, 52, 75, 76]. A recent meta-analysis of community-based samples found that self-cutting was the most common form of self-harm 45 % (95% CI 40-50) [52]. It is common to use several methods [76]. About half of those who reported self-harm in one study had used more than one method and the mean number of methods used was 2.0 (SD = 1.7) [77]. Individuals who self-cut tend to use a variety of body locations, typically concealed. The most common locations are on the forearms, wrists, and thighs [78].

Self-harm usually serves multiple functions for the individuals engaging in these behaviors. The functions can be divided into four broad categories: negatively reinforced intrapersonal (i.e., relief/escape from aversive emotions or thoughts), positively reinforced intrapersonal (i.e., feeling something as opposed to feeling numb), negatively reinforced interpersonal (i.e., relief/escape from social demand), and positively reinforced interpersonal (i.e., get comfort or attention) [79]. The functions of self-harm that are most commonly reported are intrapersonal [80, 81]. A highly influential theoretical framework regarding factors that control and maintain self-harm, is the Experiential Avoidance Model, proposed by Chapman and colleagues [82]. According to the Experiential Avoidance Model self-harm is negatively reinforced through avoidance of unwanted internal experiences, primarily emotional responses. When a stimulus triggers an unwanted emotional response, there is an urge to avoid this experience. Self-harm is assumed to persist in a vicious cycle due to the individual's intense emotional responses, difficulties with distress tolerance, and emotion dysregulation. There is also a paradox of experiential avoidance in the sense that a chronic use of the strategy amplifies the levels of distress and making the individual even more prone to self-harm. Consequently, there is no extinction of aversive emotional responses. Self-harm eventually becomes an automatic escape response through repetition of negative reinforcement [82].

Another theoretical model of self-harm that is often referred to has been put forward by Nock [79]. It is an integrative approach where distal risk factors such as genetic dispositions for emotional reactivity and childhood adversities interact with more proximal factors and self-harm-specific factors such as social learning and self-punishment. The interaction of these

distal and proximal factors makes individuals prone to self-harm in response to stressful life events instead of using more socially adaptive strategies [79].

There are certain types of self-destructive behaviors that are worth mentioning even if they deviate in both characteristics and functions when compared to the more common types of self-harm. First, severe self-mutilation, including extensive body damage such as limb amputation, genital amputation, or auto-enucleation are fortunately very rare. These extreme forms of self-harm are often associated with psychosis or drug-induced states [83]. Second, stereotyped self-harm conducted as a repetitive rhythm is often seen in individuals with intellectual disabilities especially in association with autism spectrum disorder. However, it is important to note that there is preliminary evidence supporting that self-harm in those with autism without an intellectual disability serves similar emotion regulatory functions as in neurotypicals [84]. Third, compulsive self-harm such as nail biting, hair pulling and skin picking are more habitual in nature and are more closely related obsessive-compulsive disorder [85]. Finally, one type of self-destructive behavior that has received more attention during the past years is sex as self-injury (SASI). A Swedish community-based study of high-school student examined similarities and differences in prevalence and function of NSSI, SASI and NSSI + SASI. The study participants reported that they intentionally harmed themselves through sex, and associated pain and NSSI was common. The function of SASI resembled that of NSSI and the most common functions reported were automatic such as to relieve feelings of being numb or empty, to stop negative feelings, and to punish oneself. It was also common for the participants to switch from NSSI to SASI, because the latter is easier to conceal [86].

2.2.5 Correlates

The correlates presented below do not aim to depict a comprehensive picture but should rather be considered a selection relevant to the studies included in this thesis

2.2.5.1 Emotional awareness

An individual's awareness of any given emotion has been proposed by Lane and Schwartz to be distributed across a spectrum ranging from no awareness to complete awareness [87]. The different levels of emotional awareness follow a cognitive-developmental model of emotional experience. Beginning with physical sensation and then with gradually increased complexity: action tendencies, single emotions, blends of emotions, and blends of blends of emotions [87]. Emotional awareness is assumed to be a prerequisite to most forms of

effective emotion regulation [88] and a number of studies have demonstrated higher rates of anxiety and depression symptoms among adolescents who have difficulties in identifying, describing and expressing their emotions [89-91] Furthermore, emotional awareness can be viewed as a transdiagnostic factor as it has been associated with different forms of psychopathology [88]. Importantly, a systematic review revealed that levels of emotional awareness influence psychiatric treatment outcome [92]. A recent systematic review and meta-analysis found a positive relationship with medium effect size between self-harm and difficulties in identifying and describing feelings as well as external oriented thinking [93].

2.2.5.2 Emotion dysregulation

It is a consensus that emotion dysregulation is an important risk factor for self-harm [5, 82, 94, 95]. The different components usually involved in emotion regulation are physical arousal, facial expressions, behavior, cognitive evaluation, motivation, goal orientation, and subjective experiences [96-98]. Different theoretical models have been proposed to conceptualize emotion regulation. Gross and John have defined it as the use of specific strategies aiming at increasing, maintaining, or decreasing emotional responses [96]. Strategies can be applied before an emotional response, antecedent-focused or after, response-focused and may be implicit/automatic or explicit/effortful [99]. There are also researchers that emphasize that successful emotion regulation is not only related to changes in the experiencing of emotion, importantly it also involves acceptance versus devaluing of emotions. Gratz and Romer [100] have synthesized evidence and extracted six dimensions of emotion dysregulation: lack of emotional awareness, deficient emotional clarity, non-acceptance of emotional responses, ineffective emotional regulation strategies, difficulties controlling impulses, and engaging in goal-directed behaviors in the presence of emotional arousal. A systematic review and meta-analysis [81] found a significant association between emotion dysregulation and self-harm with a pooled OR of 3.03 (CI = 2.56 – 3.59). The subscales with the strongest associations were limited access to regulation strategies, non-acceptance of emotional responses, difficulties with impulse control, and in engaging in goal-directed behaviors.

2.2.5.3 Sexual and gender minorities

The rates of self-harm have been found to be significantly higher in sexual and gender minority (SGM) youth than in non-SGM youth [101-103]. Results from the Center of Disease Control and Prevention survey showed that the 12-months prevalence of suicide attempts among gay, lesbian and bisexual youth was 23.0% compared with 5.4% of heterosexual youth

[104]. Further, the 12-month prevalence of suicide attempts was 34.6% among transgender youth as compared to 9.1% in cisgender females and 5.5% in cisgender males [105]. SGM youth also report elevated experiences of stigma, victimization and social isolation [106]. According the Minority Stress Theory social situations do not directly lead to impaired health for minority individuals, rather difficult social situations cause stress that accumulates over time. Distal stressors (i.e., rejection, prejudice, and discrimination) and proximal stressor (i.e., concealment of minority identity, vigilance and anxiety about being rejected or harassed) interact and cause chronically high levels of stress and poor health for minority individuals [106]. It has been suggested that SGM youth encounter both general risk factors for self-harm and specific risk factors being part of a minority group, which together can undermine coping skills and result in emotion dysregulation [103, 107].

2.2.5.4 Diagnostic correlates and comorbidity

Self-harm is sometimes classified as a symptom of other common mental illness, even if some individuals with self-harm do not meet criteria for any psychiatric disorder [108]. However, the majority of individuals who engage in self-harm do fulfill criteria for one or more psychiatric disorders [46, 109, 110] . As previously mentioned, there is an association between self-harm and BPD [47, 111], but self-harm is not in any way exclusive to BPD. Self-harm is also associated with other personality disorders and different Axis I symptomatologies [46, 112]. In a sample of inpatient adolescents with self-harm 87.6% fulfilled criteria for at least one Axis I disorder from DSM-IV. The most common were depression, conduct disorder, and post-traumatic stress disorder [46].

2.2.5.5 Neurobiology

Several neurobiological models have been developed to explain the etiology of suicide and self-harm. The field is relatively new and mostly based on cross-sectional studies, which is important to take into consideration when interpreting the results as it rather represents correlates with self-harm than risk factors [113]. Studies examining the neurobiology related to self-harm usually include structural, functional, and molecular imaging [114]. As self-harm is often associated with adverse or stressful situations it has been regarded relevant to study the hypothalamic-pituitary adrenocortical (HPA) axis. Studies examining the relationship between self-harm and HPA axis show altered patterns of HPA axis regulation [115]. One study measured saliva and hair cortisol in adolescents, with higher awakening cortisol responses found among individuals with self-harm when compared to healthy controls [116]. One of the first studies to demonstrate a distinct neurobiology of self-harm

found altered activation of amygdala, anterior cingulate cortex, and hippocampus, when using functional magnetic resonance imaging [117]. Altered neural processing on emotion eliciting stimuli among adolescent with self-harm compared to controls have also been found [117, 118].

2.2.5.5 Psychosocial factors

There is presumably a plethora of psychosocial factors that covariates with self-harm. The contexts that have the greatest potential to have an impact on youth's mental health are family, friends, and school.

Adverse childhood experiences can be defined as distressing and/or traumatic events occurring during childhood. Exposure to adverse childhood experiences has been associated with a range of negative consequences, for example poor mental health, substance use, relational problems, suicide, and self-harm in later life [119, 120]. Examples of adverse childhood experiences are typically physical or sexual abuse, deprivation, exposure to domestic violence, emotional neglect, parental substance misuse, mental illness, suicide, or imprisonment [120]. A positive association between childhood maltreatment and self-harm was found in a systematic review of 20 cross-sectional studies [121]. Adverse childhood experiences have also consistently been shown to significantly predict self-harm in both community and clinical samples of adolescents [122]. The subtype of adverse childhood experiences that appears to have a particularly large impact on self-harm is neglectful or harsh parenting [123]. Express Emotions (EE) is also a relevant construct with two distinct components: Critical remarks/hostility (dislike and or rejection of a person) and emotional over involvement i.e., amplified or dramatic emotional responses and/or over-protective or intrusive behaviors [124]. Family environments characterized by high levels of parental EE are associated with elevated levels of adolescent depression, hopelessness, and feeling of being trapped, leading to a propensity to self-harm [125]. In a study of adolescents from the community and outpatient mental health clinics, Wedig and Nock [126] examined the association between parental EE and youth psychopathology. They found relations between high parental EE and the presence and frequency of suicidal ideations, suicide attempts, plans and self-harm.

Peer related rejection and victimization are painful experiences for youth [40]. Bullying has repeatedly been shown to be a risk factor for the development of self-harm. In two large longitudinal study samples, experiences from having been bullied by peers in childhood

significantly increased the risk of self-harm in later life, it was even found to be a greater risk factor than parental maltreatment [127]. Similarly, results from a large (N = 12,068) European study found bullying and self-harm to be highly correlated [128].

Adolescents spend a substantial amount of time in school. There is a growing body of research proposing that schools can have an effect on emotional health [129-131]. School-related factors associated with increased risk of self-harm are for example strained relations with peers and teachers, limited involvement in school or school related activities, and poor academic achievements [132-135]. On the other hand, feeling connected to and engaged in school as well as feeling safe in the school environment are associated with a decreased risk of self-harm [136]. As most studies examining school-related risk factors are cross-sectional it is difficult to establish the temporal order of events.

2.3 TREATMENTS OF SELF HARM

Concerns have been raised about the scarcity of evidence-based treatment options for adolescents with self-harming behaviors. Interventions with limited evidence have often been regarded as the best practice [137, 138]. Although interventions specifically designed for reducing self-harm in adolescents are still limited, there have been a mentionable development over the past years [139].

2.3.1 Psychopharmacological treatment

The efficiency of five different drug classes have been studied in relation to self-harm. Selective serotonin reuptake inhibitors, atypical antipsychotics, serotonin and norepinephrine reuptake inhibitors, opioids, and opioid antagonists [140]. However, a Cochrane review concludes that studies regarding efficiency of pharmacological interventions on self-harm in adults are of low quality and small number [141]. Furthermore, yet another Cochrane review examined the pharmacological treatments for self-harm in children and adolescents, and no trials were found that qualified to be included in the meta-analysis [137]. Hence, clinical guidelines do not suggest that psychopharmacological treatments should be the intervention of choice of the direct management of self-harm [142, 143]. However pharmacological treatment can have a significant indirect part in the management of related conditions such as depression, anxiety disorders and psychotic disorders [144].

2.3.2 Psychosocial interventions

A wide variety of interventions have been designed specifically to target adolescents with self-harming behaviors, from community prevention programs [145] to specialized treatments in, for example, emergency departments [144]. However, very few of them have empirical data showing that they are effective. In this part I will mainly cover psychosocial/ psychological interventions for adolescent self-harm, typically offered in an outpatient setting.

A meta-analysis (19 RCT's) on psychotherapeutic interventions for self-harm in adolescents concludes that treatments interventions have a significantly higher reduction of self-harm than control conditions [138]. However, when dividing self-harm as a global category into NSSI and suicide attempts none of the included trials showed superiority to treatment as usual (TAU). The strongest effect sizes though were found for Dialectical Behavioral Therapy for adolescents (DBT-A) [146], Mentalization-Based Therapy for adolescents (MBT-A) [147], and Cognitive Behavioral Therapy (CBT) [148]. A systematic review from 2018 also found support for efficiency of DBT-A, MBT-A, and CBT [149]. A recent evidence update from 2019 on self-injurious thoughts and behaviors in adolescents found 26 RCT's [139]. By applying the *JCCAP* five-level ranking system [150], treatment efficacy was evaluated. Only DBT-A reached the highest level and is now regarded as well-established since there are two RCT's conducted by two independent research groups, with demonstrated effects on DSH and suicide ideations [146, 151]. The authors of the aforementioned studies [138, 139, 149] summarize the efficacious components across the different interventions and conclude that active family therapy or parent training components are crucial. Other common elements which have been shown to be important for the outcomes are emotion regulation skills, communication skills, and problem-solving skills.

There is a shortage of clinical practical guidelines regarding the assessment and management of suicide risk and self-harm in adolescents due to the limited evidence base on which specific recommendations can be drawn [152]. The only high-quality clinical practical guideline on long-term management of self-harm is produced by the National Institute for Health and Care Excellence [152]. In Sweden there is a government-funded National Self-Injury Project[1] with

[1] A national developmental project initiated by the Swedish Ministry of Health and Social Affairs (Socialdepartementet) in collaboration with the Swedish Association of Local Authorities and Regions (Sveriges Kommuner och Landsting). Please visit https://nationellasjalvskadeprojektet.se/english/ for more information.

the aim to gather knowledge about care and treatment related to self-harm. A national quality document for recommended interventions has been created in collaboration between prominent researchers and clinicians [153]. In addition to highlighting the importance of a genuine and empathic approach, proper assessment, and risk management, it underscores that the care provider should offer interventions and treatments that are structured for self-harming behavior including treatment for any comorbidity. It further states that the treatment effect should continuously be systematically evaluated.

A review by Lundh [154] emphasizes four components that appear to be common to treatments that have been shown to have an effect on self-harm. First of all, a clear treatment structure that creates predictability and continuity for the individual. Second, a therapeutic approach that is characterized by an empathic approach in which the individual's experiences are validated. Third, an explicit focus on emotional awareness and improving emotion regulation. Fourth, stated strategies to prevent the iatrogenic effects of care.

2.3.2.1 Individual therapy

DBT-A. DBT is often the treatment of choice for both adults and adolescents with self-harm. Miller, Rathus and Linehan [155] have adapted DBT for suicidal adolescents with Borderline Personality traits. DBT-A is sensitive to developmental and contextual conditions specific to adolescence and has pronounced strategies for keeping patients committed to treatment. In its standard format it is a manualized, 16-week behavioral treatment and it includes parallel individual therapy once a week, family therapy as needed and multifamily skills training group in outpatient settings. DBT-A has generally showed high acceptability and retention rates [138, 149]. The first RCT on DBT-A (19 weeks) was conducted by Mehlum and colleagues [146]. A total of 77 adolescents with recent and repetitive self-harm were randomized and allocated to DBT-A or enhanced usual care (EUC). Over the course of treatment, the DBT-A group reported a significantly higher reduction of DSH and suicide ideations than the EUC group. Treatment effects for DSH also held over a 52-week follow-up [156]. One limitation worth mentioning is that the DBT-A group received a higher dose of treatment than the control group. Furthermore, the EUC was not manualized and hence not monitored for fidelity. In the second RCT, MacCauley and colleagues compared DBT-A (six months) to six months individual and group supportive therapy in a sample of 173 adolescents [151]. The DBT-A group was superior to the individual and group supportive therapy group, with significant reductions of DSH, NSSI, and suicide attempts from pre- to post treatment. The between-group differences were however not significant at 12-months

follow up due to improvement over time in both groups. As these two RCT's are regarded as high quality and were conducted by two independent research groups, DBT-A is considered as a well-established intervention for the reduction of self-harm and suicide ideation in adolescents [139].

MBT-A. Mentalization-Based Therapy (MBT) [157] is a time-limited and integrative form of psychotherapy that was developed from psychodynamic therapy and theory, which also contains aspects of attachment theory and cognitive theory. Unlike psychodynamic therapy in general the aim is not gain insight but to improve mentalization. Mentalization is defined as a process by which inner mental states like needs, wishes, feelings and beliefs are perceived and interpreted. A lack of mentalization causes deficits in the ability to make sense of others and ourselves, implicitly and explicitly [157]. Self-harm in adolescents is assumed to be a consequence of relational stress, when mentalization is impaired and negative self-perception occurs, resulting in the person experiencing an urgent need for distraction and self-destructiveness [147]. MBT-A has showed promising results. In a RCT comparing TAU with 12 months of weekly individual MBT-A and MBT-family therapy once a month, MBT-A had significantly better results regarding reducing self-harm and symptoms of depression. The results were mediated by improvements in, for example, mentalization [147]. Even though the results are promising for MBT-A there is only one RCT, and it is hence classified as probably efficacious for reducing DSH in adolescents [139].

CBT. In general, CBT is short-term and problem-oriented with the aim of helping people to identify and change maladaptive and disturbing thought patterns that influence behaviors and emotions in a negative way [158]. CBT has been applied to a variety of problems. For youth with self-harm, it has been delivered in different settings, packages and in combination with different therapeutic approaches. To reduce self-harm, CBT techniques to enhance emotion regulation, problem solving, and communication skills are used [139]. Pilot studies and smaller RCT's have been implemented, with more or less successful results [139]. One recent RCT is worth mentioning. In an Australian sample of suicidal youths, 50 participants were randomly assigned to either ten weeks Internet-based CBT, (Reframe-IT) plus TAU or TAU only [159]. Over the course of treatment, the Reframe-IT group reported larger reductions of suicide ideations and fewer persons attempted suicide. However, the differences were not significant at follow-up, probably due to a small sample size and variety in TAU.

2.3.2.2 Family therapy

In a broader sense family therapy addresses issues affecting the health and functioning of the entire family, by considering the individuals' problems in the context of the family system, and dynamics of the group [160]. In family therapy, interventions and techniques from cognitive therapy, behavior therapy, interpersonal therapy, and other kinds of individual therapy are employed. In recent years several advances have been made regarding research-informed family therapy methods targeting different adolescent problems from externalizing behavior like conduct disorder and drug misuse to internalizing behavior such as mood and eating disorders [161]. A few of the established family therapies have been evaluated in samples of suicidal youth and their families e.g., Attachment-Based Family Therapy [162] and Multisystemic Therapy [163].

Functional Family Therapy (FFT) is a short-term intervention program of usually 12 to 14 sessions over three to five months [164]. The primarily target groups of FFT are youth referred for behavioral or emotional problems such as delinquency, substance use, and violence. FFT has a strengths-based relational focus and consists of five major phases: engagement, motivation, relational assessment, behavioral change, and generalization. The emphasis in these phases is on decreasing hostility, blame, criticism and overinvolvement, identifying relational functions of behaviors, identifying relational needs and hierarchical patterns, and improving family functioning. The therapist uses techniques like reframing, enactment, meta comments, and communication and skills training. In FFT there is also a pronounced focus on risk and protective factors [164]. A meta-analysis of 14 studies concluded that FFT was superior to control conditions or alternative treatments in reducing conduct problems and rates of recidivism [165]. FFT has also proved effective in treating adolescents with depression [166] and bipolar disorder [167]. FFT has to date not been evaluated specifically for adolescents with self-harm. However, with the focus on strengthening the parent-youth relationship and improving family functioning and communication, FFT could certainly have potential benefits for this group.

In an evidence-based update, five out of six interventions with the highest ranked quality for self-injurious thoughts and behaviors in youth include active family therapy or parental training [139]. In general, specialized family-based interventions improve the adjustment of adolescents with a history of self-harm and attempted suicides [161]. The importance of family involvement in treating self-harm cannot be underscored enough. The question is probably not whether the family should be involved but rather how and to what extent.

2.3.2.3 Intensified and integrated treatments

It is generally considered that treatments for persons with self-harm mainly should be offered in outpatient care, partly because there is a risk of adverse effects caused by inpatient care in this group. If hospitalization becomes necessary, the time at the ward should be as short as possible and the patient should be involved in the design of the care plan [168]. For patients with severe self-harm and comorbidity, a well-functioning collaboration between municipality and county council is often required to achieve as high level of treatment outcome as possible. An estimated 260 persons per 100 000 inhabitants and year are cared for in inpatient care due to self-harm in Sweden [169]. There is currently no evidence that inpatient adolescent care is an effective method to treat or prevent further self-harm or suicide attempts and rates of rehospitalizations are usually high [170-172]. Sometimes outpatient care is not enough to meet the needs of youth with high symptom burden and extensive suffering. In these cases, it is common with referrals to inpatient care or residential treatment. In addition to the high societal cost of residential care there are known disadvantages. Youth in residential care homes are at an increased long-term risk of premature death, conviction for serious crimes, hospitalization for psychiatric problems, teen pregnancy, economic problems, and a poor educational situation [173]. Moreover they do not receive health care on equal terms as other youth as their psychiatric conditions are not always taken into account [174]. In sum integrated and intensified treatment options are highly warranted.

Most interventions designed for adolescents include at least a small family component even if it is mainly designed as an individual treatment package. It is therefore no clear cut between pure family therapy models and integrated models. One example of an integrated intervention is Safe Alternatives for Teens and Youth, the SAFETY program [175]. This treatment includes multiple approaches such as CBT, DBT, family therapy and social-ecological theory. A RCT with 42 adolescents with recent and/or repetitive NSSI, suicide attempts, or DSH showed that the SAFETY treatment program reduced suicide attempts significantly compared to TAU.

ICT. To prevent long periods of hospitalization and residential treatments for adolescents with severe self-harm and/or suicidal behavior, Intensive Contextual Therapy (ICT) [176] was initiated by the county council in Uppsala, Sweden. ICT has similarities to the SAFETY program regarding treatment structure and content.

ICT has four targets: to increase 1) frequency of effective emotion regulation, 2) functional communication within the family, 3) school attendance or other scheduled activities, and 4)

to enhance motivation and reduce barriers to care. ICT includes principles from FFT, DBT, and Motivational Interviewing [177].

ICT treatment structure

- Manual-based, distinct phases, 3 months
- Intensive, with designed dose of treatment at a minimum of one family session and one individual session per week. The aim is to offer a treatment that is more frequent than commonly offered in outpatient care
- Outreach treatment, with sessions often held at families residence. Facilitates for the whole family to participate, contributes to equal care.
- Both a family therapist and an youth therapist are engaged in each case to achieve synergy.
- Collaboration with schools and social services
- Weekly consultation with a case-manager and regular supervision
- Adherence monitored via checklists
- Varied sessions. Sometimes with combined family meetings, sometimes parent meetings and sometimes individual meetings

The purpose of this integrative approach is to engage the parents and restore their empowerment and self-efficacy. The parents met in ICT are often paralyzed and tormented by guilt for their children's suffering. During the treatment it is communicated to them that even if they may not have caused the child's suffering, they are important keys in recovery.

Yet another aspect of this integrative approach is that most parents present with their own emotional or relational problems which is also important to address. The families referred to ICT have experienced a great deal of suffering. They often express a lot of hopelessness, grief and shame. It is also very common that the families are stuck in vicious cycles where the parents either directs their frustration towards the child or have capitulated and stopped making demands due to fear of triggering their vulnerable child. Some families describe that they feel like they are walking on eggshells as they have become overcautious. Other examples are installing different kinds of alarm or traps to always be prepared and stay one

step ahead. Although risk remediation/means restriction might be important at certain points, it is also important to restore some kind of normality.

ICT also focuses on addressing misinterpretations as these are often important links in the chain-analyzes. For example, sometimes there might be an ironic jargon that is appreciated by most of the family members but perceived as offensive by someone. The Biosocial Theory is often used as a rationale regarding how persons in the same family can have different thresholds and react differently. If there is overt criticism and blame in the family system this is addressed early in treatment, with techniques like reframing from FFT. However, there is quite often a general lack of communication whereby co-therapy is used in a constructive way. The youth therapist often acts as an advocate for the youth to facilitate that sensitive issues and topics can be addressed in the family setting.

Parents often have an inherent drive to act resolutely and try to fix or solve problems. This is not always desirable on behalf of the youth, who often report that they just long for someone to listen and validate their feelings. Sometimes this is highlighted as the "solution trap" and parents are instructed to resisting the impulse to e.g., make that phone call and instead offer comfort and validation.

A salutogenic approach is characteristic of FFT as well as for ICT. The focus is on strengthening the individuals' context and meaning. The salutogenic approach means that one sees the individual as a whole human being by attending to factors that maintain and contributes to well-being rather that poor health and dysfunction.

Lastly, a common thread through treatment is to examine the different behaviors' relational functions. Sometimes it may be the case that the only time the parents communicate with each other is when the child presents with self-destructive behavior. It can also be that parents are preoccupied and fail to attend to minor signals from the child, leading to an escalation of the child's self-destructive behavior for the purpose of being seen or heard.

2.3.2.4 Other treatments

When searching for ongoing trials (for example, at www.clinicaltrials.gov) there is obviously a lot of research going on for adolescents with self-harm. There are adaptations from established treatments, interventions delivered on-line, and interventions targeting different minority groups. Quite a few trials have also narrowed the focus to specific components such as mindfulness or emotion regulation. Emotion Regulation Individual Therapy for Adolescents

(ERITA) [178] is an adapted version of Emotion Regulation Group Therapy (ERGT) [179]. ERITA contains components from CBT, DBT, and Acceptance and Commitment Therapy. The overall goal of ERITA is to increase emotion regulation skills. During the treatment, both the youth and their guardians have the opportunity to learn new ways of dealing with emotions and thoughts. The intervention is 12 weeks, manualized and therapist guided and provided as an add-on to TAU. ERITA also provides six modules for parents, with the focus on NSSI and other risk-taking behaviors as well as emotional awareness and validation skills. A pilot study of ERITA suggests that it is a both acceptable and feasible treatment for adolescents with NSSI [178]. A RCT of ERITA has just completed the recruitment phase, and the study results will probably be published soon.

2.4 ECONOMIC BURDEN OF SELF-HARM

Health economics is a field that involves the application of economic principles on health and healthcare [180]. As available resources are limited in the society and the demands for care are increasing, methods are needed to make priorities in the healthcare sector. The intention is not to save money per se, but to allocate resources in such a way that as much health as possible is added to the population. The aims of economic evaluations are to support decision-makers by presenting evidence regarding costs of the marginal benefit of implementing a new approach compared to its alternative (opportunity cost). Theories about production, efficiency, disparities, competition and regulation are applied as means to inform private and public sectors [181]. Cost of illness studies are common in the medical literature and apply a variety of study methods, perspectives and cost categories. By measuring and comparing the economic burden of disease (i.e., mortality, morbidity, and disability) to the society, cost of illness studies can inform more advanced evaluation techniques such as cost-benefit analyzes or cost-effectiveness analyzes [182, 183].

There is a growing body of research recognizing the increased disease and cost burden of mental health problems and disorders [184, 185]. However the application of economic evaluations related to interventions of mental health is still limited [186]. There is often a disparity between burden and budget for mental health [187, 188]. Mental health problems are associated with both direct cost such as provision of health and social care for the individual and society and indirect cost including for example lost employment [189, 190].

Self-harm and suicide represents major global health concerns and in 2010 the behaviors resulted in nearly 850,000 deaths and 36 million disability-adjusted life years lost [190].

Assessment and treatment of people who self-harm involves a substantial amount of national health service recourses. The major part of the direct costs is accounted for by attendance to emergency departments and subsequent medical and psychiatric care [190]. In year 2009, a total of 6800 people were admitted to hospital as a consequence of self-harm in Sweden [191].

As self-harm is one of the most common presentation to general hospitals, has a strong tendency of recurrence and increased severity, it constitutes a profound economic burden to the families, the healthcare system, and the society at large [192]. Moreover, adolescent self-harm is associated with social disadvantages in later life when compared to those with no history of self-harm [193].

As previously mentioned, there is a lack of evidence-based studies for treatment of self-harm and even fewer economic evaluations. One exception is a German study, that examined the healthcare consumption of patients with BPD one year before, during, and after DBT. The conclusions were that the economic burden of these patients is significantly higher than that of other mental disorders, but that DBT substantially reduced the overall societal cost of illness. The cost savings were mainly attributed to reduced hospital days [189].

Even if the relationship between self-harm, use of resources and associated costs is complex, it should be a priority to examine the costs of treatment as well as changes in healthcare consumption, especially for treatment that might impose a higher cost in the short term.

2.5 SUMMARY

Self-harm among adolescents is common and associated with a wide range of interpersonal and intrapersonal factors. The Biosocial Theory is a transactional model explaining how biological and environmental factors interact and sometimes cause destructive behaviors such as self-harm. Variables and correlates related to self-harm that are worth examining further are emotional awareness, perceived invalidation/validation, and SGM-status. It exists few treatments that have shown promising in reducing adolescent self-harm. DBT-A is currently regarded as well-established. For some cases, integrated and intensive outreach treatments are warranted. ICT is based on principles from DBT and FFT and was initiated to prevent long periods of hospitalization and residential treatments for adolescents with self-harm. There is also a scarcity of economic evaluations of interventions for self-harm.

3 AIMS OF THE THESIS

The aims of the present thesis were to study clinical and psychosocial correlates associated with self-harm, to evaluate an intensive, integrated treatment, ICT for adolescents with self-harm and suicidal behavior, and to estimate the costs of ICT and its impact on healthcare consumption.

The specific objectives and hypotheses for each study in this thesis were:

Study I: **Objective:** To examine the relationship between perceived invalidation/ validation, emotion regulation, and self-harm

Hypothesis: We hypothesized to find significant correlations between frequency of self-harm and perceived invalidation/validation and that this relationship would be statistically mediated by emotion dysregulation.

Study II: **Objective:** To investigate the associations between emotional awareness, emotion dysregulation, and self-harm and the mediation pathways between the concepts. Also, to examine these associations with specific focus on SGM youth.

Hypothesis: We expected to find significant associations between self-harm and emotion dysregulation as well as emotional awareness. We also expected that a significant part of the association between emotional awareness and self-harm would be mediated by emotion dysregulation. We hypothesized that SGM youth would score a higher symptom burden and possibly different patterns of correlations among variables.

Study III: **Objective:** To investigate the feasibility, acceptability, and preliminary outcomes of ICT.

Hypothesis: We expected ICT to be feasible in terms of for example utilization of the treatment content, rates of completers, and appreciation of the model. We also expected significant improvements from pre- to post-treatment in terms of reduced frequency of self-harm and suicide attempts as well as improvements in emotion regulation, internalizing and externalizing symptoms, and adaptive functioning. We expected the parents to report lower symptomatology (i.e., own anxiety, depression, stress) after ICT.

Study IV: **Objective:** To examine the cost of ICT compared to other treatment options and to explore the changes in healthcare consumption from one year before ICT to one year after ICT.

Hypothesis: We expected that the total cost of healthcare (especially inpatient care) would be reduced one year after ICT in comparison with one year before. We also hypothesized that treatment responders would decrease their consumption of care significantly more than non-responders.

4 EMPIRICAL STUDIES

This thesis includes studies that cover a broad field of research including cross-sectional demographic studies, intervention study and an economic evaluation within the field of self-harm. First, I describe how we examined the pathways between perceived invalidation /validation and self-harm through emotion regulation in a large anonymous non-clinical sample. Second, I present the associations between self-harm, emotion regulation, and emotional awareness with the focus on SGM youth. Third, I outline the preliminary evaluation of an intensive, integrated, individual and family therapy model (ICT) for self-harming adolescents and present the results in terms of primary and secondary variables related to both self-harm, general symptoms, and functioning. Finally, I describe the economic evaluation of ICT, presenting the cost of treatment related to other treatment options and a comparison of the healthcare consumption one year before ICT and one year after ICT. In the section below, I will briefly describe the methods and results for each study and when it is adequate, I will complement with additional information or results not mentioned in the papers. Respective paper describes the methods for the studies more thoroughly.

4.1 STUDY I: THE PATHWAY BETWEEN PERCEIVED VALIDATION/INVALIDATION AND SELF-HARM AND THE MEDIATING ROLE OF EMOTION DYSREGULATION

There is an urgency to examine factors that contribute to self-harm in young people. Although some corelates have been subjected to more extensive research there is still a need to investigate potential pathways. Since proposed by Marsha Linehan, The Biosocial Theory has been a valuable contribution to the understanding of the etiology of BPD and self-destructive behaviors. The empirical foundation has however been regarded as only partially substantiated [194]. Moreover, validation as a concept has been inconsistently described and arbitrary measured [12].

4.1.1 Methods

We conducted an anonymous Web-based study and recruited participants via an Internet based survey https://www.hsop.se/ki/sjalvskada/ . We targeted adolescents and young adults, 15-20 y, with and without a history of self-harm. Invitations to participate were distributed through social media, such as Facebook, Instagram, Twitter, and different blogs. The link to the study Website was also spread via aid organizations (e.g., BRIS, Snorkel, and 1000 möjligheter). The ads including the link were designed to attract young people’s attention

and redirected potential participants to the study site. The study site provided information about the aim of the study, its procedure and anonymous nature, contact information to the research group and information about where to seek help for self-harm. Those who chose to participate would klick on another link that would lead to a secure Website where the questionnaires were presented.

4.1.1.1 REMTA

To clarify the operationalization and measurement of validation and invalidation, Marsha Linehan, Sophie Liljedahl and Molly Adrian constructed a self-report questionnaire: Responses to my Emotions, Thoughts, and Actions (REMTA). The six levels of validation and invalidation are examined and presented in matrixes of eight different relations (see Figure 2). One example of validation statement is: *This person makes an effort to understand me. S/he does this by listening closely to what I say and do and pays attention to what is important to me.* The following is an example of an invalidation statement: *This person does not take me seriously. I am not treated as very important.*

Mother	1	2	3	4	5	1	2	3	4	5	Boy/Girl Friend
Father	1	2	3	4	5	1	2	3	4	5	Same-Sex Friend
Sibling	1	2	3	4	5	1	2	3	4	5	Other-Sex Friend
Relative	1	2	3	4	5	1	2	3	4	5	Extra Person

Figure 2. Matrix from REMTA, Responses to my Emotions, Thoughts, and Actions. 1= not at all true, 2 = hardly ever true, 3 = sometimes true, 4 = often true, 5 = always true

4.1.2 Results

We ended up with a total of 6345 responders after some exclusions were made due to exclusion criteria (e.g., age outside of the range 15-20), or too short response time. The latter means that the participants have probably responded without enough time to read each question. A total of 1910 had answered REMTA and hence were included in the present study. The validation subscale correlated to a greater extent with Difficulties in Emotion Regulation Scale (DERS) r = -.28, n = 1902, p <.0001 than frequency of self-harm measured with Deliberate Self-Harm Inventory (DSHI-9r) r = -.11, n = 1492, p <.0001, z = 2.05, p <.05. This was also the case for the correlation between the invalidation subscale and DERS r = .35, n = 1902, p <.0001, as compared to DSHI-9r r = .22, n = 1401, p <.0001, z = -.2.27, p <.05. A significant part of the relation between self-harm and perceived validation as well as invalidation was explained by the mediation of emotion dysregulation (66.4%) and (55.8%)

respectively. We also examined validation/invalidation as dichotomous variables (high and low) and there were statistically significant differences between high and low validation as well as invalidation for DERS, whereas none of the comparisons for DSHI-9r were significant, see Figure 3.

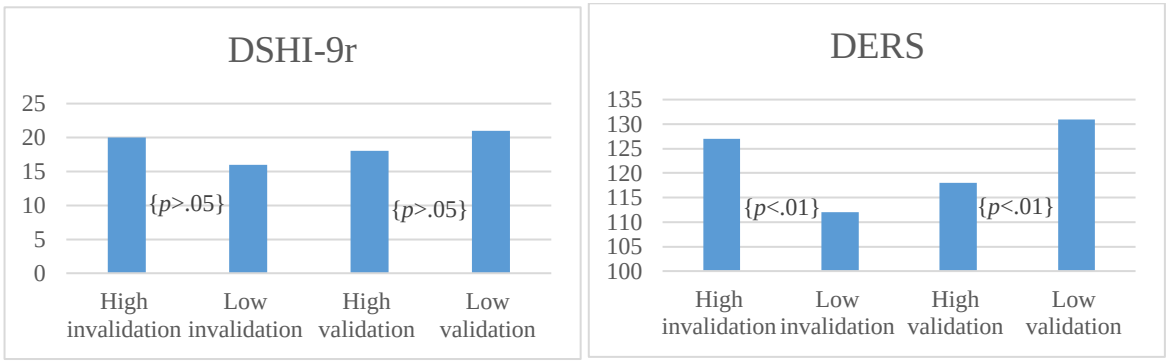

Figure 3.

Furthermore, perceived invalidation and validation from family members correlated to a greater extent with emotion dysregulation and self-harm than perceived invalidation /validation from non-relatives.

4.1.3 Conclusions

Perceived invalidation/validation measured with the novel instrument REMTA are correlated with both self-harm and emotion dysregulation. Also, the correlations differ with regard to what relation (e.g., parent, partner) examined. The relationship between invalidation/ validation and frequency of self-harm is mediated by emotion dysregulation. REMTA might be a valuable instrument for research and in in clinical settings, but its psychometric properties should be examined. The results provide further support for the biosocial model, given that invalidation/validation effects self-harm through emotion regulation.

4.2 STUDY II: EMOTIONAL AWARENESS, EMOTION DYSREGULATION AND SELF- HARM. A SPECIFIC FOCUS ON SGM YOUTH

Different subsets of characteristics have been studied in relation to self-harm. As individuals who self-harm is a highly heterogeneous group, assessment and treatment methods have to consider different correlates. Emotion regulation has been extensively studied in relation to self-harm. A related, yet distinct concept is emotional awareness. Low levels of emotional awareness have not only been related to self-harm, but evidence also points to an important role in moderating treatment response [92]. Emotional awareness has often been assessed by

self-reports such as Toronto Alexithymia Scale, TAS-20 [195]. However, it has proven difficult to reliably estimate emotional awareness through self-reports due to different confoundings [196]. SGM youth are at elevated risk of self-harm and suicide [197]. We need a better understanding of SGM groups and related health disparities including self-harm, and we need to delineate the social and psychological (e.g., emotional awareness and emotion dysregulation) determinants of such disparities.

4.2.1 Methods

The data in the present study has been drawn from the same Web-based survey as Study I.

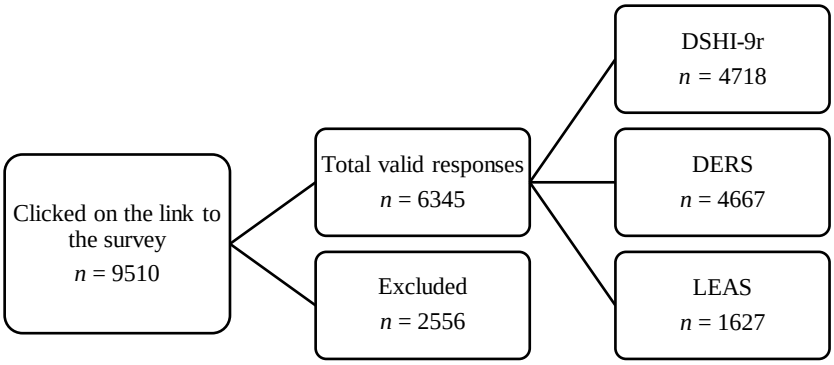

Figure 4. Flow-chart of the study participants

4.2.1.1 LEAS

The Levels of Emotional Awareness Scale (LEAS) [87] is a performance-based measure that assesses the responders' ability to be aware of their own emotions as well as a counterpart's. The scale presents ten different evocative interpersonal scenarios with open-ended descriptions of emotional responses of self and others. The emotion words used by the responders in their answers are coded according specific structural criteria. An example of scenario presented is: *You and your friend agree to invest money together to begin a new business venture. Several days later you call the friend back, only to learn that s/he has changed his/her mind. How would you feel? How would your friend feel?* The answers were coded by four different persons and the inter-rater reliability was excellent for both the total scale and the two subscales.

4.2.2 Results

Self-harm correlated to a greater extent with emotion dysregulation (r = .45**) than with emotional awareness (r = -.14**), z = 15.82, p <.0001. The correlation between emotional awareness and emotion dysregulation was statistically significant, but weak (r = -.165, n = 1582, p < .0001). Mediation analysis revealed that a significant proportion (31%) of the total effect of emotional awareness on self-harm was mediated by the different subscales of DERS. The relationship between emotional awareness and frequency of self-harm was mediated by three of the subscales: difficulties controlling impulses when experiencing negative emotions, lack of clarity of emotional responses and limited access to emotional regulation strategies perceived as effective.

SGM youth consistently reported a higher symptomatology than non-SGM youth, a larger proportion reported a history of self-harm, they reported a higher frequency of self-harm and a higher degree of emotion dysregulation. Despite the small sample, we discovered associations of medium effect sizes between emotional awareness and self-harm for the responders with queer (r = -.40*) and mixed (r = -.40*) gender identities.

4.2.3 Conclusions

Examining levels of emotional awareness, especially with a performance-based measure is a valuable contribution to the existing literature. The study gives a more nuanced picture about the relation between emotional awareness, emotion dysregulation and self-harm and elucidates important pathways. A significant and indirect association was found between emotional awareness and self-harm which was mediated by different emotion regulation strategies. The health disparities between SGM youth and non-SGM youth, i.e., higher frequency of self-harm as well as significantly higher emotion dysregulation among the SGM youth points to the importance of considering SGM status in our understanding of the development, maintenance, and treatment of self-harm.

4.3 STUDY III: PILOT STUDY OF AN INTEGRATED TREATMENT FOR ADOLESCENTS WITH SELF-HARM

Young people with self-harming behaviors are is from a homogenous group and it is therefore very important to adapt interventions to meet different needs and conditions. It is also known that self-harming and suicidal individuals are difficult to engage in treatment and dropouts are unfortunately very common. The time immediately after discharge from psychiatric ward is critical and if the gap between in- and outpatient care becomes too large there can be

devastating consequences [198]. It has been recognized that so-called outreach treatment options can be successful when the threshold for seeking outpatient care is too high [172, 199]. In Uppsala, Sweden, ICT (described in detail in the background-section) has been implemented within the child- and adolescent psychiatry, in collaboration with the municipality. The primary aim of ICT is to prevent residential care or long stays at psychiatric ward for self-destructive and high-risk adolescents with complex symptomatology. Further aims of ICT are to increase effective emotion regulation, increase effective communication within the family, increase school attendance/adjustment, and to reduce the barriers to seek and assimilate regular outpatient care.

4.3.1 Methods

We conducted a pilot study with a within-group design and repeated measures at pre- and post-treatment and six- and 12-months follow-up.

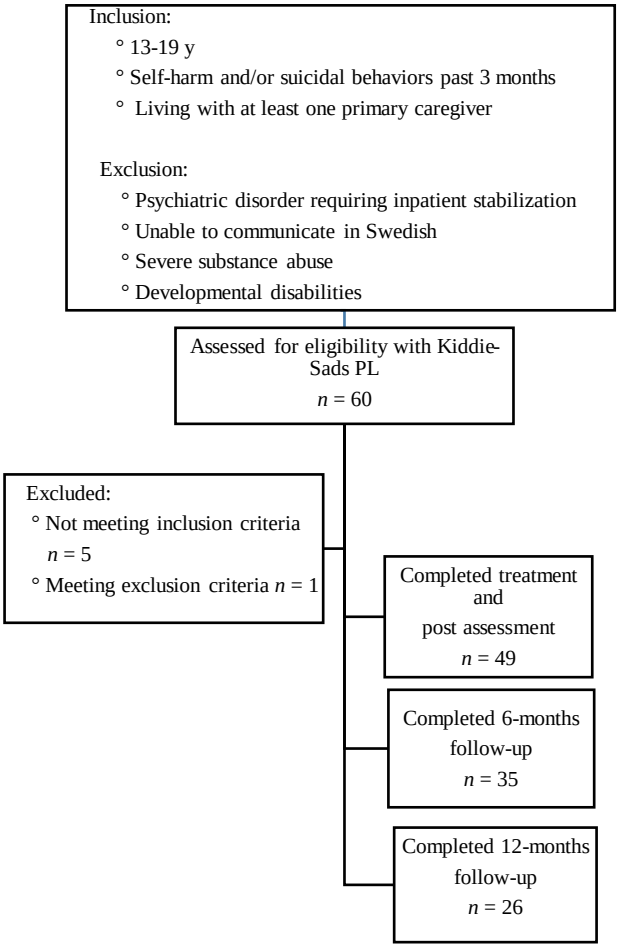

Figure 5. Flow-chart of the study participants

The participants were mainly females (85.7%) and the mean age was 14.6 years (*SD* =1.3). The primary outcomes were:

- Feasibility, in terms of treatment completion and drop-out, satisfaction, and useability of the treatment meassured with Family Satisfaction Survey, FSS
- Suicide attempts (reported by adolescents, parents, clinicians)
- Self-harm measured with Deliberate Self-Harm Inventory, DSHI-9r
- Internalizing and externalizing symptoms meassured with Youth Self-Report, YSR and Child Behavior Cecklist, CBCL
- School hours and adjustment (parents' and adolescents' reports)
- Stress meassured with Perceived Stress Scale, PSS
- Emotion regulation measured with Emotion Regulation Questionnaire, ERQ

Secondary outcomes were:

- Criticism and blame measured with Questions About Family Members, QAFM
- Emotional (over)involement measured with QAFM

4.3.2 Results

Out of 54 adolescents recruited to the study, five were lost to post assessment of various reasons. The Family Satisfaction Survey (FSS) [200] showed that the treatment was appreciated by both the adolescents (M = 3.25, SD = 0.50) and their parents. The adolescents especially valued the attitude from the therapists and the possibility to ask questions during assessment and treatment, also the statement "would you recommend the treatment for others" was rated high. Almost all the parents regarded the therapists as open and caring, that the treatment was very helpful for their adolescents and that they would recommend it to others.

One adolescent had to be admitted to residential care home during the treatment period and another one during the follow-up. The number of in-patient days decreased from the equivalent time before enrollment (M = 11.09, SE = 4.33) to post-treatment (M = 6.19, SE = 1.82) however, the decrease was not statistically significant $F(1, 135) = 1.41$, $p = 0.24$, $d = 0.20$ There were no attempted suicides during the treatment.

From pre to post-treatment adolescents reported significant reductions in frequency of self-harm $F(1, 151) = 10.91$, $p = .001$, $d = 0.54$, suicide attempts $F(1,45) = 21.51$, $p = .0001$, $d = 1.38$, internalizing symptoms $F(1, 152) = 17.12$, $p = .001$, $d = 0.67$, stress $F(1, 143) = 10.32$,

p = .002, d = 0.54, emotion regulation, subscale Cognitive Reappraisal $F(1, 150) = 10.05$, p = .002, d = 0.52, school attendance $F(1, 117) = 4.85$, p = .03, d = 0.41, and school adjustment $F(1, 148) = 5.11$, p = .03, d = 0.37. There were no further symptom reductions by six months follow-up but the effects were mainly maintained. By 12 months, however there were further reductions of self-harm frequency. In terms of reliable change index regarding self-harm, the proportions of male participants who improved or recovered from pre to post was 28.6%, from pre to six months follow-up it was 60%, and from pre to 12 months follow-up it was 50%. The proportions of females who improved or recovered was 27% from pre to post, 33.3% from pre to six months follow-up, and 45.5% from pre to 12 months follow-up.

Regarding the secondary measure QAFM, the adolescents reported significant reductions of perceived criticism and blame from their mothers from post treatment to the follow-ups $F(1, 151) = 28.62$, p = .001, d = 0.87. They also reported significant reductions of perceived criticism and blame from their fathers from post treatment to both follow-up assessments $F(1, 121) = 5.26$, p = .02, d = 0.42. The adolescents did not report any statistically significant changes in perceived emotional involvement, over time.

The parents reported significant improvements on most outcomes variables from pre- to post treatment. They confirmed a significant reduction in symptoms among adolescents (CBCL). Regarding the parents' own symptoms both mothers and father reported significant reductions in stress (PSS). The mothers reported decreased levels of anxiety and depression (HADS) from pre- to post treatment, while the fathers reported increased levels of anxiety and depression (HADS) from pre- to post treatment.

4.3.3 Conclusions

The results from this pilot study show feasibility, acceptability, and utility of ICT. The preliminary evaluation suggests that ICT could be beneficial at individual, contextual and family levels as the adolescents and their parents show symptom reduction and increased function. Most of the results are maintained by six months follow-up and further improved by one-year follow-up. Lastly, the results indicate that ICT might have the potential to prevent fulltime institutional and inpatient care, however, to be more certain ICT would have to be replicated and show similar results.

4.4 STUDY IV: AN ECONOMIC EVALUATION OF AN INTEGRATED TREATMENT FOR SELF-HARMING ADOLESCENTS

The issue of scarce resources is noticeable and charged in the healthcare system. The individuals' lives are profoundly affected by their access to healthcare and the availability of appropriate services. Economic evaluations have not been used extensively in psychiatric services [186, 195]. The cost of mental healthcare is in fact increasing and self-harm and suicide represent large expenses. As ICT has a pronounced focus on preventing in-patient care it is of great concern to evaluate if it also may have economic benefits.

4.4.1 Methods

Data on ICT-intervention costs were routinely collected during the trial (Study III) for all initial 49 study participants. Data on healthcare consumption (outpatient and inpatient care, pharmacological treatment) were collected retrospectively, during one-year pre-treatment, during the treatment period and during one-year post-treatment, from medical records of the 25 study participants who had given informed consent. All the unit costs were collected in Swedish krona and adjusted to Euro 2019 prices using purchasing power parities and inflation indexes. We also compared changes in healthcare consumption in relation to primary outcome (self-harm, assessed with DSHI-9r) and secondary outcomes (internalizing and externalizing behaviors, assessed with YSR).

4.4.2 Results

The treatment cost of ICT was estimated as an average of €5293 per patient (*SD* = 2031, min = 3515, max 12207, Mdn = 4436). There was no difference in treatment cost between study participants and the drop-out group. When we examined the differences in treatment costs between YSR-responders and DSHI-responder and non-responder we found no significant differences either.

Despite lower average costs for most of the specialized treatments, none of the differences between pre- and post-treatment were statistically different (see Table 1). The cost of prescribed medication however increased significantly from one year before ICT to one year after. This increase was mainly attributed to prescriptions of Central stimulants.

Table 1. *Healthcare consumption and related costs (in Euro, 2019), 1 year before and after treatment*

	Before treatment	**After treatment**	**Difference**
Inpatient care (psychiatry) costs	1942	649	>.05
Outpatient care (psychiatry) costs	1164	1000	>.05
Total hospital costs	7895	7632	>.05
Total primary care costs	821	1074	>.05
Total health care costs	8716	8705	>.05
Total medication costs	284	579	<.05

4.4.3 Conclusions

The cost of ICT is comparable to other similar treatment options. Also, the estimated cost of ICT tells us that one avoided case of residential placement could pay for five patients in ICT. The healthcare costs during one year before and one year after ICT are quite similar, however certain patterns become clear. The adolescents seem to have consumed more outpatient and primary care, and less specialized and inpatient care after treatment.

4.5 ETHICAL CONSIDERATIONS

When conducting research, one has to weigh the potential benefits and importance against the risks and burden of the study participants. The studies included in this thesis have been reviewed and approved by ethics committees. Study I and II (2015/815-31/5) were approved by the Regional Review Ethics Board in Stockholm. Also, Study III (2011/1593-31/5) was approved by the Regional Review Ethics Board in Stockholm and so was the supplementary application for Study IV (2018/1902-31).

4.5.1 Informed consent/assent

When children/adolescents are involved as research subjects, informed consent is important however complex. The researcher must assure that the adolescents fully comprehend what it means to participate in the research study. In Study III separate documents for informed consent were used for the adolescents and their parents/guardians. Information was also given orally to ascertain that they understood that participation was voluntary, what they could expect if they chose to participate and their rights to discontinue at any time. The adolescents were also encouraged to ask questions about study participation and contact information was given in case of further questions or uncertainties. Importantly, the families were informed

that declining participation in the research study would not affect the treatment they were given, as ICT is delivered within regular care.

Study I and II involved Internet-mediated research, making it more complicated to assure that the principles of participation were based on valid consent. For example, verifying that that the responders met necessary requirement regarding age and other characteristics and to establish that they had properly engaged with the consent procedure. When designing the Webpage there were several considerations made to compensate for the typical lack of face-to-face presence between researcher and participant in internet-mediated research. The lower age limit was set to 15 years, to make sure the responders were mature enough to consent to participation on their own. The information on the introduction page was carefully balanced regarding length and content. Too lengthy information pages can potentially be quickly skimmed or not read at all but at the same time relevant information has to be covered. Before the participants were directed to the questionnaires, they had to confirm that they had read the information and tick a checkbox to an explicit consent statement on the information page.

4.5.2 Assessing symptoms

Self-harm is associated with multiple psychiatric issues, poses an imminent risk of physical harm, and is a risk factor for attempted suicide. Together, this means that researchers and clinicians are faced with several ethical challenges that warrant consideration when treatment studies are conducted. In order to ensure patient safety in Study III, adverse events were thoroughly monitored by both clinicians and researchers. Assessment and screening of frequency and severity of self-harm and suicidal behaviors were conducted weekly. To ensure adherence, selected therapy sessions were filmed and supervision and meetings with case manager were held on regular basis. Filming sessions, however, raises concerns about patient integrity. The procedure of uploading, reviewing, and storing of the filmed sessions was given special security caution. Also, the audio recordings that were used at pre- and post-treatment were handled with the same secure procedure.

Therapists also received extensive training and supervision in the safety routines. As the ICT model includes family therapy with a close collaboration with caregivers, the parents were acting as gatekeepers during both assessment and the treatment.

To minimize harm and potential content specific triggers evoking aroused feelings, the Webpage (Study I and II) included gate questions before assessments with sensitive items

were presented and the responders could choose to skip an assessment. At the start and end of the survey, contact information to different aid organizations was presented. The survey also had its own specific domain for marketing. Qualified persons involved in the research project were assigned user data to be able to maintain and monitor the comments and discussion among responders on social media.

Careful considerations were made as to how many and which instrument were used (Study I, II, and III). The majority of constructs were measured using established questionnaires with known psychometry. For the phenomena where there had been a lack of valid and reliable instruments, the research group constructed adequate questionnaires in collaboration with internationally renowned researchers in the field.

4.5.3 General research ethics

Study III was a pilot study. The ICT intervention is however not completely untested as it has been evaluated in the context of regular care. Clinical pilot studies are important of several reasons: they provide information regarding participant recruitment rate and feasibility. Although pilot studies due to their low power cannot lead to a robust evaluation of outcome, the information gained in terms of feasibility and preliminary outcome is valuable for decision about whether to run a RCT or not. Based on ethical principles, we do not expose a large number of patients to a treatment with unknown feasibility or some indication of effect.

Efforts were made to assure research subjects integrity and confidentiality. As Study I and II were Internet-mediated the responders' IP-addresses were deleted, which they also were informed about. In Study III, data was collected in such a way that anonymity of the adolescent and caregivers could be guaranteed when data were compiled, analyzed, and presented. Also, the register data from Study IV which contained information about healthcare data, was protected by the use of unique identification codes.

Participation in Study I, II, and IV did not bring any direct benefits for the participants. Links to treatment centers, help organizations or various channels for receiving support for difficulties with self-harm, as presented and provided in Study I and II might have been helpful. Research using cross-sectional designs and registers can however advance our knowledge and inform assessment and treatment for others.

4.5.4 Internet-mediated research

Besides the points mentioned earlier, the most salient difference between face-to-face research and Internet-mediated research is the level of control over research procedures and environment. For example, Internet-based research provides limited possibilities to control or verify the age of the participants, the environmental conditions under which participants are responding, and observing and addressing responders' feelings or reactions to the research process.

5 DISCUSSION

First, the two related cross-sectional studies are described and then the evaluation of ICT both regarding the preliminary outcomes and the economic evaluation. I will present and discuss study hypothesis, main findings, my own reflections, implications of our findings in a broader context and methodological considerations.

5.1 RELEVANT CORRELATES

There is today no dearth of defined correlates of self-harm. Since the group is highly heterogeneous, there are likely to be an infinitive number of combinations of significant factors. Research findings, however, emphasize the importance of considering both biological and environmental factors to improve our understanding and develop interventions for self-harming adolescents.

STUDY I AND II

5.1.1 Validation and self-harm- the complexity of etiology

One of the most overwhelming, challenging, and significant effort people encounter in life is thought to be parenting. A child's behavior is expected to be modulated and shaped by parental strategies and behaviors. Invalidation/validation is one of many constructs that has been studied in relation to children's emotional development.

Study I confirmed our hypothesis that frequency of self-harm would be positively related to perceived invalidation and negatively related to perceived validation. This is in line with both observational, cross-sectional, and longitudinal studies [201-203]. In a large cross-sectional study with 2474 university students, correlations of similar magnitudes as in our study were found between self-harm and maternal invalidation (r = .17) and paternal invalidation (r =.18) [202].

The results from Study I indicate that invalidation/validation from family members seem to have a stronger association with self-harm than from non-family members. This was perhaps not that surprising as the majority of the responders still lived with parent(s). However, adolescence is a period in life when peer environment and interaction is particularly significant, and also a sense of belonging and acceptance is of great importance. Invalidation from peers have been operationalized as bullying or more covertly social rejection. Yen and colleagues [204] examined the longitudinal relationships between both family and peer

invalidation and adolescent suicidal events. They found that baseline as well as follow-up ratings of perceived family invalidation predicted suicidal events in boys only. Whereas perceived peer invalidation predicted self-harm in general, the effect only remained statistically significant for girls though when it was investigated by gender. Invalidation from peers and its association with self-harm has not been examined to the same extent as invalidation from parents/caregivers. Perceived partner invalidation and the relation to self-destructive behaviors have been investigated to an even lesser extent [205]. However, extensions of the Biosocial Theory have been made, by Fruzzetti [7, 194] suggesting how current interpersonal dysfunction is potentiated by both the effect of past childhood invalidation and mediated by current invalidation by a meaningful other. This transaction is presumed to explain how emotion dysregulation and the extreme response styles associated with BPD are maintained. In this regard REMTA offers advantages as it captures invalidation/validation pertaining to different significant others who can have an impact through the course of life.

Interestingly, invalidation/validation correlated to a lager extent with emotion dysregulation than self-harm. And a fairly large part of the of the association between invalidation/ validation and self-harm was mediated by emotion dysregulation. As described earlier Linehan's Biosocial Theory has had an important theoretical influence regarding the clinical understanding of self-harm development. The model suggests that children growing up in an invalidating family environment do not develop appropriate emotion regulation skills comprising, the ability to identify and label emotion, to tolerate negative emotional experiences, and to apply effective coping strategies. The skills deficits resulting from growing up in such environment are assumed to pose a risk of the development of suboptimal coping mechanisms such as self-harm [5].

Even if the REMTA not explicitly examines the four primary characteristics of invalidation (communications of inaccuracy, misattribution, discouraging of negative emotional expression, and oversimplification) [5, 12] it does make a valuable contribution as it disentangles the different levels of invalidation/validation. The results from Study I did not yield clear conclusions regarding the different levels of invalidation/validation and the associations. However, certain patterns can be discerned. Higher levels of invalidation/ validation seem to correlate to a slightly greater extent with both emotion dysregulation and self-harm.

The Biosocial Theory also highlights the concepts of multifinality (i.e., one single factor being associated to multiple outcomes) and equifinality (i.e., different risk factors related to the same outcome) [206]. Many different pathways, or risk factors may in fact result in BPD symptomatology such as self-harm and an invalidating environment may also result in a multitude of developmental outcomes not necessary those that characterize BPD [206]. In line with developmental psychology a relevant question is whether there are particular aspects of parent-child relations that are exclusively related to BPD, or if parent-child related variables constitute non-specific risks for psychopathology in general.

5.1.2 Emotional awareness, emotion regulation and related concepts

Current conceptualizations of psychopathology have transferred from categorical diagnoses in favor for focusing on latent dimensions that that cut across mental disorders in a broader sense. There is empirical evidence suggesting a transdiagnostic psychopathology factor, also called general factor or p-factor [207-209]. Just as emotion dysregulation, lack of emotional awareness has been proposed to be a transdiagnostic mechanism contributing to an increased risk of multiple forms of psychopathology beginning in adolescence [210]. Low levels of emotional awareness has been associated with a wide range of psychopathology, including depression [211], anxiety [210], post-traumatic stress disorder [212], and somatoform disorder [213]. There is however a scarcity of studies examining the link between emotional awareness and self-harm. On the other hand, research exploring the association between alexithymia and suicidality as well as self-harm has recently begun to be summarized [214].

The aim of Study II was to examine the potential mediating effects of emotion regulation strategies in the relationship between emotional awareness and self-harm in a sample of adolescent and young adults using a cross-sectional design. To interpret the result and put it in context it is first important to clarify differences and similarities between emotional awareness and alexithymia. When digging into the research there is obviously a confusion and the two constructs are used more or less interchangeable [196]. Both alexithymia and emotional awareness encompass difficulties in identifying one's own and other's feelings and difficulties to verbalize emotions. It has been proposed that emotional awareness is a delimited part of alexithymia since it does not include limited imaginal ability and external oriented thinking [215]. A meta-analysis [196] found a statistically significant, however weak correlation between the most commonly used measures for alexithymia and emotional awareness, TAS-20 and LEAS. The authors state several different explanations for this puzzling result. First, suggesting that the two instruments might be conceptually related but

not empirically. They also discuss the fact that associations between self-reports and performance-based measures usually are low derived from the difficulty to reliable interfere one's own awareness capacity using a self-report measure.

It was somewhat surprising that the correlation between emotional awareness and emotion dysregulation was that weak, (r = -.165) Generally, both emotional awareness and emotion dysregulation have been studied in relation to youth psychopathology, however it is uncommon that the two factors are studied simultaneously, rather they have been considered in isolation [216]. This is regarded unfortunate since the two factors are likely to be closely intertwined in the same emotional process [217]. Also, the correlation between emotional awareness and self-harm in Study II was unexpectedly weak (r = -.144) although statistically significant. Van Beveren and colleagues [216] conducted a cross-sectional study with a similar procedure as in Study II, except the dependent variable was youth depressive symptoms. Their result suggests that adaptive emotion regulation strategies have a critical mediating role in the relationship between emotional awareness and youth depression. This is interesting in light of our findings, where some of the emotion dysregulation subscales mediated the indirect association between emotional awareness and self-harm.

Among the subscales that had a significant contribution in the mediation analysis, difficulties with impulse control, stands out. In fact, greater levels of self-reported impulsivity have been found among both clinical and community samples of self-harming persons compared to persons who do not self-harm [218, 219]. There might be different explanations to this association. As previously described the most commonly endorsed function of self-harm is to decrease negative emotional states. In line with the Urgency Theory [220], it is possible that the link between self-harm and impulsivity is explained by a tendency to act rashly to diminish negative emotions, engaging in behavior that offer a short-term gain.

I believe that it is inevitable to also be curious about the relationship between emotional awareness, emotion dysregulation and Theory of Mind and consequently autism spectrum disorder. Deficits in Theory of Mind is a core feature of autism spectrum disorder, and have been described as a social-cognitive skill that involves the ability to imagine both the own an others mental states, including emotions, desires, beliefs and knowledge [221]. As stated earlier emotion dysregulation is regarded a transdiagnostic process, however the mechanisms that underlies and contributes to emotional dysregulation and how it is manifested are proposed to be more disorder-specific [222]. It has been recognized that many characteristics

of autism spectrum disorder may interfere with effective emotion regulation and that both deficits in theory of mind and emotional awareness are plausible underlying factors [88, 223]. Furthermore, LEAS has been found to correlate positively with Theory of Mind measures, even after controlling for positive and negative affect [224].

5.1.3 SGM youth

SGM youth face many challenges such as victimization and bullying [225, 226]. It is of great importance that their unique experiences are made visible, not least in healthcare. SGM youth are often an invisible patient group presumably due to heteronormativity biases [227]. In a review, Laiti and colleagues [228], concluded that SGM youth whished for health professionals to offer a diversity-affirming care and support their specific needs.

Study II shows the health disparities with which SGM youth struggle. They reported, for example, higher frequencies of self-harm and higher degrees of emotion dysregulation. The results indicating a higher correlation between emotional awareness and self-harm for queer and mixed gender identities are difficult interpret in such a small sample but may very well be worth to examining further.

5.1.4 Findings in context - theoretical and practical implications of study I & II

Studies examining invalidation/validation include a plethora of different operationalizations of the construct. In a recent systematic review, Musser and colleagues [12] discovered that of 77 empirical studies, 47 different measures of negative parenting practices related to BPD were used. The research area could certainly benefit from a more uniform conceptualization. There are also a lot of misconceptions about invalidation, e.g., that it equals harsh, aggressive, abusive, critical, or dominant parenting. The concept is however more complex than that. The transactional and reciprocal aspect is also sometimes overlooked. In my own opinion I think the most beneficial way to present and clinically use the Biosocial Theory is to emphasize the non-blame and transactional characteristics. The metaphors such as a tulip in a rose garden or a circle among cubes have been helpful for many families. Invalidation is also not per se deliberately malicious comments or acts. If a parent says to the child “what, you can’t be hungry, you have just eaten” this is by definition invalidation. Most children would however not be offended by such a comment, while a child with an emotional vulnerability may suffer.

Using a performance-based measure to assess emotional awareness can be of both theoretical and practical use. Overestimations of a person's emotional awareness could potentially affect the outcomes of therapeutic interventions [196]. It has been shown that a lower emotional awareness capacity, as measured with LEAS, moderate treatment effectiveness of both CBT and psychodynamic psychotherapy [229].

Some of the adolescent referred to ICT have difficulties pertaining to emotional awareness that are not directly addressed with interventions from DBT. Sometimes they also have great difficulties to translate the treatment into practice in their everyday lives. The length of treatment time then often is perceived as too short when it takes time to establish a relationship and to generalize skills. In these cases, the use of a performance-based measure such as LEAS could inform treatment approach and reduce the risk of misdirected interventions and too high demands on patients with a low degree of emotional awareness.

A core assumption of DBT is that the patient cannot fail in treatment. However, in recent years a need for adaptations of DBT to different populations has been noted [230]. One such population is persons with autism spectrum disorder [231, 232] where emotional awareness is lower.

5.1.5 Methodological considerations, study I & II

The choice to use a cross-sectional design was multiple. It is relatively efficient to conduct as data are only collected at one time point. The use of social media channels enabled us to reach a greater number of individuals and facilitated anonymous participation. Although Internet offers new possibilities in research, it poses some challenges including verification of responders' identities, informed consent, support for vulnerable groups, and integrity. These issues are discussed under the section ethical considerations.

It is always a matter of consideration when using a newly developed instrument such as REMTA in research. With as yet unknown psychometric properties, reliability and validity can be questioned. The REMTA was constructed as there is a lack of self-report measures that captures both validation and invalidation related to different levels and different relations. However, the psychometric properties of REMTA have to be examined.

To use a performance-based measure such as LEAS in such a large anonymous sample was novel and I was surprised to see how thoroughly and generously the responders shared their thoughts. However, there were some concerns about the reliability of the answers.

STUDY III AND IV

5.2 FEASIBILITY AND PRELIMINARY OUTCOMES

In Study III we evaluated ICT using a within-group design with repeated measures. The study provides preliminary support for the feasibility, acceptability, and utility of ICT regarding the treatment of self-harm and related difficulties. In line with our hypothesis patient participation was associated with significant improvement from pre- to post-treatment in frequency of self-harm, suicide attempts, internalizing symptoms, stress, emotion regulation, school attendance, and school adjustment. The results were largely maintained at six-months follow-up and further improved at one-year follow-up.

Importantly, Study III has a remarkably low attrition rate as only five out of 54 discontinued the treatment. The majority of those who dropped out did so due to their needs of other specialized care. The low attrition rate is encouraging as improving treatment compliance is an inevitable first step in providing effective treatments for adolescents with self-harm [138]. Furthermore, the low attrition rate in combination with the high scores on the FSS [200] suggests that ICT is feasible for both adolescents and their families. The utility and applicability of ICT as an intervention that constitutes an intermediate care, has been acknowledged by policymakers in Sweden. ICT has been implemented in two additional regions so far and also evaluated with promising preliminary results [233].

The results found in Study III are similar to those found in effectiveness trials of both integrated treatments and treatments with a primarily individual focus. The SAFETY trial, described earlier, showed statistically significant improvements regarding suicidal behaviors, social adjustment, and depression among youth participants as well improvement in depression among parents, from pre- to post-treatment [175]. In the multisite RCT conducted by McCauley and colleagues [151], there was a statistically significant reduction of suicide attempts and self-harm following DBT-A when compared with individual and group supportive therapy. Needless to say, the results from Study III must be interpreted with caution because the lack of a control group. However, several well-established measures pointing in the same direction and reported by different informants increase the credibility of the results.

5.2.1 Youth outcome

In Study III, the average episodes of self-harm were reduced by half from pre- to post treatment. The result was significant with a medium effect size. The use of p-values has often been criticized since it says little about the actual importance of the result. It is often recommended by scientific journals to also report other measures of inference such as effect size or odds/hazard ratio. However, also those measures give little indication whether changes are of practical importance in relation to the outcome of interest. Taking a behavior such as self-harm, it is neither of practical nor clinical significance if a person has self-harmed 11 or 12 times during the last month. A few studies have calculated the proportion of participants who reported self-harm absenteeism. In the McCauley-study [151] the proportion of participant reporting an absence of any self-harm after six months of DBT-A was 46,5% and by 12-months follow-up it was 51,2 %. In the evaluation of ICT 45,7% reported zero self-harm by post-treatment, 50,0% by six months follow-up, and 30,8% by one-year follow-up. This comparison is promising for our study with a shorter time duration of the intervention. It is however important to note that the average number of sessions were rather similar, 35 in ICT and 37 in DBT-A, in the aforementioned study.

Regarding suicide attempts ICT also compares favorably to other treatments [151, 175] as none of the adolescents reported suicide attempts during the course of treatment. However, the unfortunate deterioration, with average suicide attempts similar as baseline, from post-treatment to follow-up raises questions of whether an extended version of ICT might be preferable in some cases to bring about lasting benefits. A satisfactory transition to regular outpatient care has sometimes been a challenge, especially as it is often hard to match the flexibility and intensity of ICT. The ICT treatment is perceived by the families as very different from the regular outpatient treatments where they are offered 45-minutes appointments every second week, with limited possibilities to reschedule, and they are expected to come to the clinic instead of home visits.

Increased effective emotion regulation is an important target of ICT. Reduced frequency of self-harm is supposedly a proxy of this outcome. The adolescents did report somewhat more frequent use of cognitive reappraisal (CR) and a slight reduction of expressive suppression (ES) after treatment. Both of which (low CR and high ES) have been proved significantly related to psychopathology, especially internalizing symptoms [234]. The fact that there was a more prominent change in CR, might have different explanations. It has been suggested that cognitive behavioral therapies do not directly address ES and also that ES has a limited

association with symptom change in general [234]. We also noted that the adolescents found it difficult to give differentiated answers on ERQ, and some of them especially the younger tended to score in the middle range, a tendency that was most evident on the ES scale. It is also possible that ER is a strategy that is used at more conscious level and hence easier to estimate.

The adolescents' internalizing symptoms (YSR) also decreased significantly from pre- to post-treatment. Reduced externalizing symptoms (YSR) were also observed, although not statistically significant. The parents, however reported significant reductions pertaining to both internalizing and externalizing symptoms. I have often thought about informant discrepancies when analyzing and interpreting the data and the temporal order when the informants detect or report a change in symptomatology. In a critical review [235] different causes of informant discrepancies are listed, many of which may possibly apply to Study III. Parents and adolescents may, for example, enter the treatment and assessment process with different motivation for participating and they may also have discrepant attributions of adolescent's behaviors. Parents usually report as many or more externalizing problems among their children compared to children's own report. On the contrary, parents tend to underestimate the severity of their children's internalizing problems. These discrepancies are often attributed to the fact that externalizing behaviors are more easily observable and public, while internalizing behaviors are of more private nature [235, 236]. With this in mind it is encouraging to see that the parents after completing ICT reported reduced levels of the adolescents' externalizing symptoms.

5.2.2 Parental outcome

Self-harm often has an extensive impact in the sense that families and caregivers naturally react with intense emotions upon discovering a child's self-harm [237, 238]. Moreover, parents describe that their children's self-harm effects their mental health and relationships with partners, children, and friends [237]. Parents' emotional states and mental health, especially anxiety and stress are associated with the difficulty of making sense of self-harm in their children [239]. In our study, the most obvious change of parent's ratings from pre- to post treatment was the level of stress, which decreased significantly for both mothers and fathers. Within ICT there is a pronounced functional perspective on self-harm, examining both intrapersonal and interpersonal triggers and antecedents in family sessions. In connection with the increased communication between parents and adolescents it possible that the parents' level of stress diminished upon seeing the functional patterns. Regarding the

parents' anxiety and depression-scores on HADS, the results are ambiguous. It is however quite clear that both mothers and fathers exhibit levels of depression and anxiety just around the border of clinical cut-off by all assessment-points. This is important to note as parental internalizing symptoms have been found to elevate adolescent levels of stress and strain the parent-adolescent relationship [240]. There is clearly a reciprocal and dynamic relationship between the adolescent that self-harm and family functioning [241].

5.2.3 Family outcome

QAFM [242] is a self-rating scale with the aim to assess expressed emotions (EE) in dyads. As mentioned earlier, an association between parental expressed emotions and youth psychopathology as well as self-harm has been found [124-126]. As FFT specifically targets expressed emotions and one important aim of ICT is to increase functional communication within the family, it was an obvious choice to select QAFM as an outcome measure. QAFM has 30 items, which are scored on a five-point Likert-scale. The scores are further divided into four subscales: two factors pertain to "given" EE (critical remarks and emotional over-involvement) and two factors pertain to "perceived" EE (perceived criticism, and perceived emotional involvement). Higher scores on the three subscales critical remarks, perceived criticism, and emotional over-involvement reflect a more strained relationship whereas higher scores on perceived emotional involvement is regarded beneficial [242].

Study III yield mixed finding regarding both adolescents' and parents' rating on all four subscales. Although both mothers and fathers reported being less critical toward the adolescents after ICT this was not clearly perceived by the adolescents until the follow-up assessment when the results are significant. These patterns are familiar to me, it usually takes a while for young people to dare to trust that their parents' behavioral changes are lasting. Common descriptions from adolescents when practicing communication skills and validation in sessions are that it feels unnatural and artificial, at first. Sometimes they also express worries that the parents' altered behaviors will only be performed during the time of the therapy.

It is possible that other assessments would have given a clearer picture about family relations and communication. As an index of family function and changes, SCORE 15 [243], is for example now used to an increasing extent in evaluations of family therapy.

5.2.4 Contextual outcome

Emerging evidence suggests an association between school absenteeism and both self-harm and suicidal ideation among adolescents [244]. School is also an essential part of the social world of many young persons as it serves as a basis for their sense of connectedness to the community outside the family [130]. In light of this, it is encouraging that the adolescents after completing ICT not only report extended hours at school but also report a higher degree of adjustment. Among things, they reported getting along better with teachers and peers, feeling a greater sense of safety, and doing home-assignments to a larger extent. In a qualitative study [245] examining the views of people who self-harm about the most commonly used outcome measures, the informants agreed that meaningful improvement not necessarily included reduced frequency of self-harm and less visits to the emergency wards. In addition, they requested a greater focus on outcomes entailing daily activities and achievements, which can have positive effects on wellbeing and be a means of sustained improvements [245].

School absenteeism and refusal also have detrimental effects on the families and on the contrary certain relational patterns have been detected in families of adolescents who school refuse. It has been suggested that for effective treatment of school absenteeism/refusal it is crucial to formulate a systemic understanding of the nature of the problem [246].

5.2.5 General factors contributing to the outcome

In addition to the specific content of ICT, there are likely components of the structure itself that have been helpful to bring about change. One aspect is the cohesiveness of the treatment. The holistic approach with regular contact with both schools and social services is described as relieving some of the burden by the families. They report that they appreciate the assistance in communicating with different authorities, and not having to constantly repeat their stories.

It has been noted that so-called assertive outreach treatment options can be successful when the barriers are too high to receive regular outpatient care [175, 247]. A clear advantage with this approach is the reduced strain on the families when they do not have to struggle to try to motivate the adolescent to come to the clinic. The outreach approach also contributes to equal care as geographical distance from the clinic and financial as well as time resources of the families do not become obstacles. Experiences from Study III also indicates that home-based treatment increases the preconditions for generalization of skills and changes that last over time as we meet the families in their everyday lives.

Both the above-mentioned factors are probably related to the reduction of stress perceived by both the adolescents and their parents.

5.2.6 Cost of ICT and subsequent healthcare consumption

After the pilot study of the preliminary outcomes of ICT it was a logical next step to calculate the cost of the model and also examine changes in healthcare consumption among the study participants. As ICT is a specialized unit with no equivalent, all advantages as well as disadvantages are presumably of interest to policy makers. It is also important to remember that the primary reason why the model was created and implemented was to decrease the municipalities' high expenses for placements of children and young people with self-harming behaviors. In times of continuously shortage of societal resources, the utility of a model like ICT with two therapists traveling sometimes a long distance to see the families, can always be questioned. Unfortunately, the social services do not have a systematic way of documenting when they make considerations about residential treatments. It is rather decided on a case-by-case basis based on an overall assessment of risk and protective factors. Some kind of register would have been of great value to be able to estimate averted residential placements.

Study IV shows that ICT's economic measures compares well with treatments of similar intensity, length, or approach [248, 249]. Additionally, the average placement cost for one adolescent corresponds to the cost of treating five adolescents in ICT and this is important to emphasize.

The modest result from the comparison of healthcare consumption between one year before and one year after ICT does not give a clear indication of whether ICT is economically advantageous for the healthcare system. However, I would like to highlight two aspects, which we unfortunately could not estimate as it was precluded by the design of the study. The first aspect is related to spill-over effects. It has been recognized that the savings of child health promotion strategies often are underestimated [250]. It is likely that improved mental health and functioning of one family member brings benefits to the whole family system. Furthermore, the outreach approach of ICT with home-visits contributes to the possibility to attend to the health care needs of other family members, such as siblings for example. Sometimes this implicate assisting them with referrals.

The other aspect important to underline is potential long-term savings for individuals and society. We have shown that the adolescents after ICT increased both their school attendance and adjustment and improvements in those outcomes will likely pay off in the long run. School refusal and problematic school absenteeism involves major challenges for children, parents, teachers, and clinicians. Moreover, it imposes high expenses to society [251].

5.2.7 Findings in context- theoretical and practical implications of study III & IV

Family therapy treatment approaches used to be the first choice within child and adolescent psychiatry is Sweden. However, it has now been displaced by other more medical and individual treatment perspectives [252]. As self-harm is an alarming behavior, parents are normally included in treatment, often considered as partners, or as having a co-therapist role in providing care and engagement with treatment services. Committed parents are an important and invaluable resource. They can implement security plans and assist the adolescents when they are practicing their skills. However, sometimes it seems to me that too much focus on psychoeducation and monitoring overshadows relational aspects.

In the field of self-harm, one of the largest (N=832) and most expensive studies [253] was recently conducted. This study concluded that family therapy interventions were not superior when compared to treatment as usual, treating self-harm. This trial has however been discussed extensively and some researchers have even condemned family therapy as a treatment of self-harm. The most obvious shortcoming of this study however is that the intervention should have been explored stepwise [254], with pilot studies before an extensive trial or large-scale implementation.

Integrating individual and family therapy when treating self-harm can be challenging and sometimes there might be inconsistencies in how to conceptualize, choose, and address key behaviors. A family distress cascade theory [241] has been proposed to explain the reciprocal and dynamic relationship between the adolescent who self-harm and the family. The dynamics are described as cycles starting when self-harm is disclosed to the family and often followed by the parents reacting with escalations of controlling behavior. When the adolescents are faced by those reactions it is perceived as a threat to their autonomy, resulting in increased self-harm frequency and severity and withdrawal. This, in turn increase parental worries and suspicion and further intensify a need for security and control [241]. ICT as an adaptation and combination of two well-established treatments, DBT and FFT, has the

potential to pinpoint those kinds of reciprocal patterns. The experience is that components from DBT and FFT potentiate each other in a constructive way.

5.2.8 Methodological considerations, study III & IV

In the planning phase and during the course of Study III different methodological issues had to be considered. The assessments used were intended to capture the core targets of ICT, namely, to increase effective emotion regulation, increase effective communication within the family, and increase school attendance or other scheduled activities. To assess these variables a variety of self-rating scales were used. The families referred to ICT are often in the middle of a crisis, filling out questionnaires was not always a top priority for them. We had to be considerate, respectful, and sometimes persistent to get them comply for evaluation of treatment for each family, above and beyond the research questions. Use of briefer questionnaires might have enabled us to measure the outcomes relevant to ICT for clinical and research purposes and decrease the parents' and their youths' response burden.

The results from Study III and IV are all based on self-report measures. We did however assess EE using Five Minutes Speech Samples (FMSS) [255]. FMSS is a procedure whereby the caregiver is instructed to talk for five minutes uninterrupted and describe the child and the relation to the child. These speech samples are recorded, transcribed and coded. The EE coding system entails specific elements of the caregiver's speech and vocal tone. Categories of EE are criticism, hostility, and emotional over-involvement, adding these together yield final scores of high or low EE. However, a decision not to include this measure was made as it became quite clear after some scorings had been done that the parents met in ICT express very limited emotional content.

To conduct a RCT of ICT would be difficult due to ethical reasons. The families referred are often experiencing severe crises reactions and great suffering and have faced many failed treatments. Hence, they cannot be randomized to a waitlist or a placebo condition due to the risks (suicide and severe self-harm). Our efforts to find a reference group, as a next best option in the absence of a comparison group, did not succeed either as there were no suitable matching treatment options in terms of duration and intensity. We contacted several residential care facilities. Most of them refrained from being a reference group. In a couple of instances where there was an interest to collaborate, it was not possible to use the same evaluation package as in our study in their routine evaluations.

5.3 LIMITATIONS

When interpreting the results of this thesis some limitation should be considered. In Study I and II the most important limitation is the cross-sectional design, which makes it difficult interpret the associations and precludes causal interference. This kind of anonymous design is also susceptible to biases such as recall bias. The external validity of the study may also be affected by the fact that the responders were self-selected and hence we cannot be sure about the representativeness of the sample. Study I and II aimed for adolescents and young adults with and without self-harm, even so the majority (75,8%) reported a self-harming behavior.

Study III and IV are uncontrolled studies precluding any conclusion regrading causal inference of treatment effects. Without a control group we cannot rule out other factors that may have accounted for the result, such as passage of time, motivation, or non-specific factors such as therapeutic alliance. Despite the shortcomings of uncontrolled trials, they can provide essential information about a treatment's acceptability and feasibility. The results from a pilot study can also inform future RCT's regarding for example procedure, hypothesis, sample population and choice of instruments.

Study III and IV have high drop-out rates at follow-ups. Which also contributes to an uncertainty in the interpretation of the results. In Study IV the result of the cost comparison between one year before and one year after ICT, is based on a small sample and should be interpreted with caution. The procedure of collecting written informed consent could have been done in a more efficient way.

Despite an ambition to use a consistent nomenclature for self-harm, several different terms are used in the studies included in this thesis. This is obviously a disadvantage and can preclude the generalization and comparison of the results.

5.4 FUTURE DIRECTIONS

The results from the cross-sectional studies contributed to some interesting lines of inquiry. The specific temporal connection between perceived invalidation/validation, emotion dysregulation and self-harm could preferably be examined in longitudinal studies. Another valuable research endeavor for future studies would be to test the psychometric properties of REMTA in both clinical and community samples.

The pilot study of ICT indicates that ICT might be a feasible treatment for adolescents with self-harm. RCT's are warranted with long-term follow-ups to confirm the results and provide more rigorous data. Ideally, such studies would include measures of self-harm functions and other measures to capture family communication and functioning.

In future research it would also be interesting to investigate proposed mechanisms of change in ICT. A multiple baseline single-case design [256] could allow for richer details of the therapy process and provide a more thoroughly understanding about how ICT works. With a design where the independent variable is systematically manipulated in terms of dose, timing, and components, it could be possible to investigate the additive effect of family therapy interventions to individual therapy. We initially planned to do a multiple baseline single-case study. However, during data collections such a study in addition to the regular assessments, turned out to put too high burden on the families.

As Study III was not sufficiently powered it precluded subgroup analyzes. A larger trial had possibly enabled us to study potential predictors of treatment outcome. Subsequently that kind of information could give us valuable information in tailoring the treatment and make adjustments to the specific needs and conditions of the families and adolescents, e.g., those with low emotional awareness

Ecological momentary assessment (EMA) [257] is a method involving repeated registrations of a subject's behaviors, experiences or symptoms in real time. Frequent sampling and monitoring through for example smartphones make it a convenient and useful approach. One advantage of EMA is that it minimizes recall bias and allows for the studying of microprocesses. A systematic review concluded that EMA potentially can be beneficial in assisting clinicians to understand predictors and risk factors of self-harm and suicide [258]. EMA could possibly also shed light on the reciprocal dynamics between the parents and the self-harming adolescent.

6 CONCLUSIONS

Taken together, invalidation/validation and self-harm are indirectly associated through the mediation of emotion dysregulation. In assessing perceived invalidation/validation, the novel instrument REMTA could be useful in both research and clinical practice, however the psychometric properties need to be investigated. Emotion dysregulation is a well-established risk factor for self-harm. In addition to emotion dysregulation, it could be valuable to examine levels of emotional awareness as it has an indirect association with self-harm via emotion dysregulation. The health disparities among SGM youth are also important to highlight especially regarding various sorts of mechanism, such as combinations of cognitive, affective, behavioral, and social pathways. Although tentative, ICT could be a feasible and effective therapy model for adolescents with self-harm and high symptom burden. The attrition rate is low and FSS suggests that ICT is appreciated by both adolescents and parents. The preliminary evaluation suggests that ICT is beneficial when it comes to reduction of self-harm, suicide attempts and general symptomatology. Parents also report reduced levels of stress and lower levels of criticism after completing ICT. ICT might also have the potential to prevent fulltime institutional and inpatient care, but the results have to be replicated. The treatment cost of ICT is comparable to other similar treatment options, but economically favorable compared to full-time residential care. After ICT the adolescents consumed more outpatient and primary care, and less specialized and inpatient care than before treatment.

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