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Borderline Personality Disorder

Studies of suffering, quality of life and
dialectical behavioural therapy

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Stockholm 2006

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Abstract

The aims of the present thesis were:

- ◆ To investigate how women patients with borderline personality disorder (BPD) perceive their suffering, quality of life and encounter with psychiatric care (paper II and III).
- ◆ To describe BPD patients' and psychiatric professionals' perceptions of receiving and giving dialectical behavioural therapy, DBT (paper I).
- ◆ To investigate how starting treatment of BPD patients with DBT affected the psychiatric professionals' experience of occupational stress and professional burnout (paper IV)

Due to the different types of research questions the thesis deal with, it uses a mix of qualitative and quantitative research methods. In two of the studies (II and III) the main methods were qualitative. Data from free format questionnaires, individual- as well as group interviews and biographical texts, were analysed with content analysis or a hermeneutic approach. In study III the methods were quantitative. A summated rating scale measuring health-related quality-of-life (HRQOL) was analysed with descriptive and inferential statistics. In study IV quantitative and qualitative methods were combined. Two burnout inventories were analysed with descriptive and inferential statistics, and data from free format questionnaires and group interviews were analysed with qualitative content analysis.

The main findings were that BPD patients suffer to an extent that is often unendurable, leading to deliberate self-harm (DSH) and suicide attempts to relieve suffering or just try to get away from it all (paper II). In study III the BPD patients showed significantly poorer quality-of-life (even physical) than normal population controls of comparable age. The suffering, suicide attempts, DSH and poor quality-of-life (paper II and III) put the patients in a position of voluntarily or involuntarily getting involved with psychiatric care. Study II revealed a double role of the psychiatric care in relation to BPD patients. On one hand, psychiatric professionals can add to the suffering by not being understanding and being disrespectful, on the other hand they can be helpful and relieve suffering by being respectful, understanding and validating. There was a clear relationship between the patients' experience of validation and the experience of being helped. DBT seems (both from the patients' and psychiatric professionals' perspective) to be a treatment with a philosophy, content and structure being able to relieve BPD patients suffering and helping them to independence and a bearable life-situation (paper I). Study IV confirms previous findings that psychiatric professionals experience treatment of self-harming patients as profoundly stressful. DBT was seen as stressful in terms of learning demands, but decreased the experience of stress in the actual treatment of the patients due to its high degree of structure and specific techniques. The DBT team-work and supervision were felt to be supportive, as was one particular facet of DBT, namely mindfulness training which some professionals felt also improved their handling of other work stressors not related to DBT. This finding also corresponds to BPD patients' perceptions of the mindfulness component in DBT, which they reported as particularly helpful (paper I).

It should be noted that the patient samples in the thesis may be considered as a "worse off" subgroup among BPD patients, as they usually entered special treatment programs after a period of escalating symptoms, which standard psychiatric services had had difficulties handling. The rather small number of participants and the lack of equivalent and/or concurrent control groups in the quantitative studies limit the generalization of the results.

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På gränsen...

*En annan verklighet
98 sömnpiller och fyra flaskor Theralen
Med känslornas knytnäveslag i mellangärdet
kraften av ett godståg
försöker du använda det du lärt
av otaliga hjälpare nio till fem
Ständigt vid vägs ände
greppar du varje halmstrå
En annan verklighet
och du står till synes oberörd
behåller åtminstone halva
masken på*

*Men nu vet jag
att du varje gryning
i stiltjen
hissar dina segel
för att nå eller komma bortom
all hjälp*

“On the borderline”, translation from paper II.

Original papers

This thesis is based on following four original papers, which will be referred to in the text by their Roman numerals I - IV.

I. Perseus KI, Öjehagen A, Ekdahl S, Åsberg M & Samuelsson M (2003) *Treatment of Suicidal and Deliberate Self-Harming patients with Borderline Personality Disorder using Dialectical Behavioural Therapy; - the Patients' and the Therapists' Perceptions*. Archives of Psychiatric Nursing; 17(5): 218-227. *

II. Perseus KI, Ekdahl S, Åsberg M & Samuelsson M. (2005) *To Tame a Volcano: Patients with Borderline Personality Disorder and their Perceptions of Suffering*. Archives of Psychiatric Nursing, 19(4):160-168. **

III. Perseus KI, Andersson E, Åsberg M & Samuelsson M. *Health Related Quality-of-Life in Women Patients with Borderline Personality Disorder*. Accepted for publication in Scandinavian Journal of Caring Sciences 2006-02-02.

IV. Perseus KI, Kåver A, Ekdahl S, Åsberg M & Samuelsson M. *Stress and Burnout in Psychiatric Professionals when Starting to use Dialectical Behavioural Therapy in the Work with Young Self-Harming Women showing Borderline Personality Symptoms*. Submitted.

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Förord och förförståelse

Detta avhandlingsarbete består av två delar; det jag skrivit och det jag inte skrivit (ännu), varav det senare förhoppningsvis är det viktigaste. Med denna allusion på Wittgenstein och hans "tractatus" vill jag framföra en from förhoppning om att detta bara är en början och jag får ytterligare ett antal år att *beflita mig om* (som Marie tycker att man ska göra) psykiatrisk vårdforskning, eftersom det är det hittills roligaste i arbets- och studieväg jag har stött på. 1983 ramlade jag som 20-åring in i psykiatrisvängen på ett bananskal. Jag var under sommaren och hösten vikarierande skötare (utan någon som helst vårdutbildning) på Sankt Sigfrids sjukhus i Växjö, då fortfarande väldigt mycket av traditionellt mentalsjukhus. Den "vård" jag stötte på där i sitt omänskliggörande av lidande människor fick mig att bestämma mig för den yrkesbana jag sedan har följt. Jag skulle bli sjuksköterska, avdelningsföreståndare och ändra en psykiatrisk vårdavdelning till det bättre. Åtta år senare var jag vid detta mål, men då handlade det inte så mycket om att ändra som att som avdelningsföreståndare vara med och bygga en öppenvårdsbaserad psykos- och rehabiliteringsenhet (i Oskarshamn). Så här i efterhand kan jag säga att vi lyckades ganska bra (eller hur Björn!). Men innan Oskarshamn hamnade jag som nyfärdig sjuksköterska på en vårdavdelning i Kalmar, avdelning 64. Det var en allmänpsykiatrisk sektorsavdelning men här fanns ett alldeles speciellt engagemang, en nyfikenhet, god vilja och en ganska tydlig och fast vårdideologi (tack Leif!) som gjorde att vi fick ta emot patienter som de andra avdelningarna inte klarade av och inte ville ha (inklusive akutavdelningen), för att de var så struliga – många av dem med borderline personlighetsstörning. Mitt första uppdrag som kontaktperson var just för en ung tjej med borderline. Precis som inom psykiatrien halkade jag in i forskningen på ett bananskal, (vid namn Mats). Att det blev just borderline jag skulle komma att börja forska kring var dock en händelse som ser ut som en tanke, då det sluter cirkeln mellan mig som nyfärdig sjuksköterska och förhoppningsvis (om disputationen går bra) nybakad vårdforskare.

Att hårt arbetande forskare (som mina handledare) har lusten, viljan och orken att samla oss mer eller mindre begåvade adepter kring sig är akademiens största tillgång. "Läs så långt huvudet räcker" var min fars råd. Självt var han uppväxt i en tid då tradition och ekonomi satte upp nästan oöverstigliga hinder för torparättlingar att läsa till akademiska examina. På det sättet är jag en produkt av folkhemmet, och en av dess stora ännu kvarvarande förtjänster - att åtminstone inte ekonomin utgör oöverstigliga hinder för högre studier.

Populärvetenskaplig sammanfattning

Avhandlingsarbetet i sin helhet syftade till att:

- ◆ Undersöka hur kvinnliga patienter med borderline personlighetsstörning (borderline personality disorder, BPD) upplever sitt lidande, olika aspekter av livskvalitet och sina möten med vården.
- ◆ Undersöka BPD patienters upplevelser av att erhålla och terapeuters upplevelser av att bedriva behandling med dialektisk beteendeterapi (DBT).
- ◆ Undersöka hur att börja arbeta med DBT i behandling av unga självskadande kvinnor med BPD symtom påverkar psykiatrisk personal i termer av arbetsrelaterad stress och professionell "utbrändhet".

Delarbete I: Perseus KI, Öjehagen A, Ekdahl S, Åsberg M & Samuelsson M (2003) *Treatment of Suicidal and Self-Harming patients with Borderline Personality Disorder using Dialectical Behavioural Therapy; - The Patients and Therapists Perspective*. Archives of Psychiatric Nursing, 17(5): 218-227.

Studien syftade till att undersöka patienters upplevelser av att erhålla och terapeuters upplevelser av att bedriva behandling med DBT. 10 patienter med självskadeproblematik och Borderline personlighetsstörning samt fyra terapeuter, alla knutna till ett DBT-team i södra Sverige, intervjuades. Intervjuteexterna analyserades med kvalitativ innehållsanalys. Patienterna menar att terapin varit livräddande eller givit dem livet tillbaka, i det att de nu antingen slutat göra suicidförsök, blivit kvitt suicidtankar och självskadehandlingar eller att de minskat drastiskt. Patienterna lyfter också fram terapins förmåga att förse dem med färdigheter de själva kan använda för att hantera sina liv. Terapeuterna framhåller terapins förmåga att radikalt minska patienternas självskadebeteende samt en utveckling som går mot att patienterna blir mera självständiga och ansvarstagande. Resultatet visar på stor samstämmighet när det gäller patienternas och terapeuternas bilder av DBT och dess effekter. Respekt, förståelse och bekräftelse beskrivs som centrala komponenter i terapin.

Delarbete II: Perseus KI, Ekdahl S, Åsberg M & Samuelsson M (2005) *To Tame a Volcano: Patients with Borderline Personality Disorder and Their Perceptions of Suffering*. Archives of Psychiatric Nursing, 19(4):160-168.

Syftet med studien var att undersöka hur tio patienter (samma urval som delarbete I) med Borderline personlighetsstörning upplever sitt lidande, sin livssituation och sina möten med psykiatrisk vård. Resultatet baserar sig på en hermeneutisk tolkning av intervjutexter och

självbiografiskt material (utdrag ur dagböcker och dikter) som patienterna producerat spontant innan sitt deltagande i studien. Tolkningen visade på tre temaområden; "att leva vid branten", "kampen för hälsa och värdighet – en balansakt på slak lina över en vulkan", "det goda och det dåliga agerandet av psykiatrin i lidandets drama". Dessa områden utgör en dynamisk rörelse i patienternas liv mellan desperation och uppgivenhet och kampen för hälsa, värdighet och ett liv som är värt att leva. Vanliga föreställningar bland psykiatrisk personal kring dessa patienter och implikationer för psykiatrisk vård diskuteras i förhållande till resultatet.

Delarbete III: Perseus KI, Andersson E, Åsberg M, & Samuelsson M. *Health Related Quality-of-Life in Women Patients with Borderline Personality Disorder*. Accepterad för publicering i *Scandinavian Journal of Caring Sciences*.

Studien syftade till att: a) testa reliabiliteten (mätprecisionen) i ett instrument som mäter hälsorelaterad livskvalitet (SWED-QUAL) på kvinnliga patienter med borderline personlighetsstörning, b) jämföra patientgruppens egenbedömda livskvalitet med en normalpopulationsgrupp i jämförbar ålder samt, c) testa för skillnader i livskvalitet i förhållande till DSM IV axel I samsjuklighet i patientgruppen (andra samtidigt förekommande psykiatriska diagnoser såsom t ex depression och ångestsyndrom). Studien genomfördes som en förstudie till en kommande kostnadseffektivitets studie i SKIP-projektet*, där SWED-QUAL är tänkt som ett centralt effektmått. 42 kvinnor som ingick i SKIPs pilotfas och 33 kvinnor som inkluderades under första året av den randomiserade psykoterapi prövningen blev administrerade SWED-QUAL för egenbedömning. Instrumentets reliabilitet (mätprecision avseende undersökt grupp) utvärderades med statistiska skalanalyser (inter-item och total-item korrelationer samt kriterier för intern konsistens enligt Cronbachs Alpha). Mellangrups-jämförelsen med normalpopulationsgruppen utfördes statistiskt med s.k. t-test och inomgrupps skillnader vad gäller samsjuklighet i patientgruppen analyserades statistiskt med s.k. Kruskal-Wallis test. I resultatet uppvisade SWED-QUAL acceptabel reliabilitet och borderline patienterna uppvisade signifikant (= låg sannolikhet för slumpinverkan) lägre värden i alla SWED-QUALs tretton delskalor jämfört med normalpopulationsgruppen. Det förelåg dock inga signifikanta inomgruppskillnader i borderlinegruppen avseende DSM axel I samsjuklighet, vilket kan tyda på att det är borderline diagnosen i sig (och inte samtidigt förekommande t ex depression eller ångestsyndrom) som ger den låga graden av livskvalitet.

* SKIP-projektet (Stockholms läns landsting och Karolinska Institutets Psykoterapiprojekt för självmordsnära kvinnor med BPD, "SKIP") utgörs av en randomiserad, kontrollerad studie där två psykoterapiformer anpassade för BPD-problematik, jämförs sinsemellan och med en kontrollgrupp som erhåller standardbehandling ("treatment as usual") i den sektoriserade psykiatrin.

Delarbete IV: Perseus KI, Kåver A, Ekdahl S, Åsberg M & Samuelsson M. *Stress and Burnout in Psychiatric Professionals when Starting to use Dialectical Behavioural Therapy in the Work with Young Self-Harming Women showing Borderline Personality Symptoms.*
Inskickad för eventuell publicering i vetenskaplig tidskrift.

Syftet med studien var att i ett kliniskt sammanhang undersöka hur att börja arbeta med DBT påverkar psykiatrisk personal (refererade till som DBT-terapeuter nedan) i termer av arbetsrelaterad stress och grad av ”utbrändhet”. Studien genomfördes i samband med ett kliniskt utvecklingsprojekt i Uppsala läns landsting där syftet var att implementera DBT som standardbehandling för unga självskadande kvinnor med BPD-symtom. Samtliga 22 DBT-terapeuter under utbildning medverkade i studien. Datainsamlingen genomfördes med en kombination av kvantitativ och kvalitativ metodik. Data insamlades med hjälp av två inventories (Maslach Burnout Inventory, MBI-GS och Oldenburg Burnout Inventory, OLBI) vid fyra olika tidpunkter (före projektet, efter 6, 12 och 18 månader i projektet) i kombination med individuella, obundna frågeformulär och gruppintervjuer (efter 18 månader). Analysen genomfördes med beskrivande och analyserande statistik samt kvalitativ innehållsanalys. Resultatet visade att DBT upplevdes som stressande att lära sig, men att metoden minskade stressen i patientarbetet tack vare dess höga grad av struktur och dess många specifika tekniker. De två utbrändhets-inventorierna visade inte på några statistiskt signifikanta skillnader (sannolikheten för slumpinverkan var för stor) över 18-månaders perioden, även om det fanns en tendens till ökade nivåer av utbrändhet vid sex-månaders mätningen. I båda inventorierna var det delskalan som mäter ”utmattning” som visade sig fluktuera mest över tid, både vad gäller medelvärden och antalet personer som hamnade utanför gränsen för vad som anses vara hög grad av utmattning. Vid sex-månaders mätningen nåddes det högsta antalet med hög grad av utmattning på båda instrumenten med 7 personer (32%) på MBI-GS och 5 personer (23 %) på OLBI. Detta stämmer väl med fynden i den kvalitativa delen av studien, då många av terapeuterna menade att börja arbeta med DBT hade ökat deras stress i början av projektet när det var mycket nytt att lära sig. Något som framför allt rapporterades av dem som inte hade någon tidigare kognitiv- eller beteendearbetad psykoterapiutbildning. Det uttalade team-arbetet i DBT och handledningen upplevdes att vara till stor hjälp när det gällde att hantera stress, liksom ”mindfulness-träningen” vilken även förmådde att förbättra terapeuternas stresshantering mera generellt.

Abbreviations

APA	American Psychiatric Association
BPD	Borderline Personality Disorder
BPO	Borderline Personality Organisation
CNS	Central Nerve System
DALYs	Disability Adjusted Life Years
DBT	Dialectical Behavioural Therapy
DSH	Deliberate Self-Harm
DSM	Diagnistical and Statistical manual of Mental disorders
HRQOL	Health Related Quality-of-Life
IE	Invalidating Environment
ITT	Intention To Treat
MAOI	MonoAmine Oxidase Inhibitors
MBI	Maslach Burnout Inventory
MOS	Medical Outcome Studies
OLBI	Oldenburg Burnout Inventory
ORP	Object Relations Psychotherapy
PD	Personality Disorder
PTSD	Post Traumatic Stress Disorder
QALYs	Quality Adjusted Life Years
QoL	Quality-of-Life
RCT	Randomised Controlled Trail
SF36	Short Form 36 (items) of Medical Outcome Studies
SSRI	Selective Serotonin Reuptake Inhibitor
WHO	World Health Organisation
WTP	Willingness To Pay

Introduction

The present thesis deals with a severe psychiatric health problem: borderline personality disorder (BPD). The thesis is trying to shed some light on different aspects of BPD (that have been very little or not studied at all before), like; the patients suffering and quality of life, their perceptions of encounter with psychiatric care in general, and perceptions of being treated with dialectal behavioural therapy (DBT) in particular. In relation to DBT the thesis also tries shed some light on psychiatric professionals' perceptions of treating BPD patients and their perceptions of occupational stress and professional burnout when learning and starting to use the method.

It is the research questions that have been guiding in what theories and concepts that have been connected to in the in different parts. Due to the different types of research questions the thesis also represents a mix of qualitative and quantitative research methods.

Borderline personality disorder (BPD)

The BPD diagnosis

The term Borderline has been in psychiatric parlance for about 70 years, loosely defined as something between neurotic and psychotic by the psychoanalyst Adolf Stern in 1938 (Stern 1938). Symptoms connecting to the current DSM criteria for BPD had, however, already been described by the Swiss psychiatrist Eugen Bleuler, in 1911. When he described the diagnosis of Schizophrenia he mentioned a group of patients that he meant were concealing schizophrenic symptoms under a surface of quite normal social behaviour. He called the state latent schizophrenia (Stone 1986). During the 1940s the term Borderline was used primarily in psychoanalytic circles, slowly spreading into conventional psychiatry (Stone 2000). But already 1953 in America, Borderline was described as a “trash diagnosis”, which was given to every patient not clearly fitting any neurosis or psychosis diagnosis (Knight 1953). In contrast the American psychiatrist Adolf Meyer argued that the best diagnosis one could use in dealing with borderline states is the patient's name, as the patient's specific problems are very different from each other (Herlofsson 1991). In the late 1960s the psychoanalyst Otto Kernberg gave Borderline states a broad but more specific description in the concept of “Borderline Personality Organisation” (BPO). BPO is seen as in-between a neurotic and psychotic personality organisation and is characterised by; diffusion of identity, psychological defence mechanisms based on “splitting” and “projective identification” but with sufficient “reality testing” (Kernberg *et al.* 1989).

Narrower, descriptive criteria were introduced by John G Gunderson in 1975, with rage, depression, impulsivity, superficial social adjustment and instable close relationships as core symptoms (Gunderson *et al.* 1975). In 1980 the American Psychiatric Association incorporated BPD, with eight item criteria, into the third version of the Diagnostical- and Statistical Manual of Mental Disorders (DSM III) and its new personality disorder axis (axis II). The current very similar DSM IV criteria could now be seen as the standard definition of BPD, because of its wide use (Stone 2000). It should be noted that the DSM IV criteria of BPD often captures a more ill patient population than the BPO criteria (Stone 2000).

The present thesis deals with borderline personality disorder (BPD) as it is described in DSM IV (APA 1994):

“DSM IV describes BPD (301.83) as a pervasive pattern of instability of interpersonal relationships, self-image, affects and marked impulsivity, beginning in early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

1. Frantic efforts to avoid real or imagined abandonment. (Do not include suicidal or self-mutilating behavior covered in criterion 5).
 2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.
 3. Identity disturbance: markedly and persistently unstable self-image or sense of self.
 4. Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating). (Do not include suicidal or self-mutilating behavior covered in criterion 5.)
 5. Recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior.
 6. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).
 7. Chronic feelings of emptiness.
 8. Inappropriate, intense anger or difficulty controlling anger (e.g. frequent displays of temper, constant anger, recurrent physical fights).
 9. Transient, stress-related paranoid ideation or severe dissociative symptoms.”
- (APA 1994, pp 219).

It should be noted that the World Health Organisation (WHO) deals with the borderline diagnosis, somewhat differently to DSM IV in their “Classification of Mental and Behavioural Disorders, ICD-10”. It is here called “*Emotionally unstable personality disorder (F 60.3), borderline type*”, and has the following description:

“A personality disorder in which there is a marked tendency to act impulsively without consideration of the consequences, together with affective instability. The ability to plan ahead may be minimal, and outbursts of intense anger may often lead to violence or “behavioural explosions”; these are easily precipitated when impulsive acts are criticized or thwarted by others. Several of the characteristics of emotional instability are present; in addition, the patient’s own self-image, aims, and internal preferences (including sexual) are often unclear or disturbed. There are usually chronic feelings of emptiness. A liability to become involved in intense and unstable relationships may cause repeated emotional crises and may be associated with excessive efforts to avoid abandonment and a series of suicidal threats or acts of self-harm (although these may occur without obvious precipitants)” (WHO 1992, pp 203).

Etiology

The etiology of BPD is to a great extent unknown but different orientations within the psychiatric field have created several models of understanding BPD. The most influential are presented below.

Social environment model

Representatives of the psychodynamic orientation early called attention to negative childhood experiences leading to insufficient individuation, as important factors in the development of BPO / BPD (Stern 1938). The emotional dialogue between parent and child is here seen as not good enough to lead the child over the border to a single and genuine identity, which in turn creates BPD problems (Crafoord 1983). Similar explanations have been presented by representatives of the cognitive psychotherapy orientation in the so-called “attachment theory”, which implies that a stable and secure attachment to the parents is a crucial factor in the development of the personality. Disturbed attachment creates maladaptive cognitive structures, leading to diffusion of identity and problems in understanding and controlling emotions (Perris 1998).

There are empirical data supporting that patients suffering from BPD often have a childhood history of neglect and abuse. Figures ranging from 50 - 85 % have been suggested (Herman *et al.* 1989, Soloff *et al.* 2002, Zanarini *et al.* 2002). In a multicenter study of childhood trauma in four different types of personal disorders (PD) (n=653 adults); schizotypal, borderline, avoidant and obsessive-compulsive were compared, with major depression as non PD comparison group. The result indicates that BPD participants had the highest rate of traumatic exposure; particularly sexual traumas, including childhood sexual abuse, as well as the highest rate of co-morbid posttraumatic stress disorder, and they were younger at the first traumatic event. Furthermore, the borderline and schizotypal PDs reported more types of traumatic exposure and higher rates of physically attacks (childhood and adult) when compared to other groups. These results point towards a specific relationship between BPD and sexual trauma (childhood and adult) that does not exist among other PDs (Yen *et al.* 2002).

Sexual abuse is also associated with worse self-destructive behaviour (Soloff *et al.* 2002, Zanarini *et al.* 2002). Patients with BPD also report memories of more childhood and adolescent difficulties, such as separations, mood reactivity, poor frustration tolerance, sadness, anxiety, and suicidality, than healthy controls (Reich & Zanarini 2001). It has also been shown that BPD patients more often than healthy controls have parents who suffer from PDs, depression, drug-use disorders or antisocial behaviours (Goldman *et al.* 1993).

Biological model

Brain alterations play a major role in the development of BPD. Meares *et al.* (1999) suggest that the symptoms of BPD may be due to the failure of experience-dependent maturation of neural networks, with frontal connections, which become active, relatively late in development and which coordinate elements of CNS function. These networks are believed to serve higher psychological functions, including attentional focus and affect regulation, and underpin the reflective function necessary to the emergence of a consistent self (Meares *et al.* 1999). It is also suggested that BPD is best thought of in terms of dimensions rather than as a specific disorder, each dimension with a special biological profile. The dimensions are expressed differently in different patients as the dimensions are believed to be mild variants or at least corresponding to major psychiatric disorders, such as schizophrenia, affective disorders and organic brain disorders (Stone 1986, Schmahl *et al.* 2002). Research also suggests that the impulsive aggression in BPD involves a deficit in serotonin activity and is substantially genetically encoded (New & Siever 2002).

Biosocial model

In the biosocial model BPD is seen as a consequence of an emotionally vulnerable individual growing up within a particular set of environmental circumstances, which often are referred to as an “Invalidating Environment” (IE). An emotionally vulnerable person in this sense is someone whose nervous system reacts strongly to relatively low levels of stress and takes longer than normal to recover once the stress is removed (Linehan 1993). The term IE refers essentially to a situation in which the personal experiences and responses of the growing child are disqualified or not being confirmed – invalidated by the significant others in her life. Furthermore, an IE is characterised by a tendency to place a high value on self-control and self-reliance. Difficulties in these areas are not acknowledged and it is implied that problem solving should be easy given proper motivation. Any failure on the part of the child to perform to the expected standard is therefore ascribed to lack of motivation or some other negative characteristic of her character (Linehan 1993).

Linehan (1993) suggests that an emotionally vulnerable child can be expected to experience particular problems in such an environment. She will neither have the opportunity accurately to label and understand her feelings nor will she learn to trust her own responses to events. Neither is she helped to cope with situations that she may find difficult or stressful, since such problems are not acknowledged. It may be expected then that she will look to other people for indications of how she should be feeling and to solve her problems for her. Further, this biosocial model suggests that a particular consequence will be a failure to understand and control emotions, a failure to learn the skills needed for emotional self-regulation. Patients with BPD who describe a history of childhood sexual abuse are within the model regarded as representing a particularly extreme form of invalidation (Linehan 1993).

The model as an entirety has yet no empirical support, but parts of it are supported by research in the “environment school” as well as the “biological school”(Linehan 1993). It is also the theoretical underpinning of dialectical behavioural therapy (DBT), and as such taught to therapists as well as patients.

Epidemiology

Epidemiologic studies concerning PDs are scarce but a small number of community surveys have indicated that the prevalence of BPD is between 0.5 and 1 % (similar to schizophrenia) (Widiger & Weissman 1991, Torgersen *et al.* 2001, Samuels *et al.* 2002). About 75 % of BPD patients in contact with health-care are women (Widiger & Weissman 1991, Skodol *et al.* 2002), but gender differences in the community has been reported less striking - 0.9 % for women and 0.4% for men in a Norwegian study (Torgersen *et al.* 2001). BPD has been reported to occur in many different cultures around the world (Loranger *et al.* 1994). As is the case for PDs in general, BPD is associated with lower social class and lower levels of education (Torgersen *et al.* 2001, Samuels *et al.* 2002). For a brief overview on the prevalence of BPD within health-care settings, see further “treatment and care”, pp 20.

Co-morbidity and associated health problems

DSM axis I and axis II co-morbidity

DSM axis I (clinical syndromes) and axis II disorders (PDs) are often co-morbid with BPD. Among the most commonly occurring co-morbid axis I disorders are mood disorders with depression as the most common, (figures over 90% have been reported), anxiety disorders such as panic disorder and PTSD, substance-use disorders and eating disorders (Zanarini *et al.* 1998, Zanarini *et al.* 2004a). However, the axis I disorders seem to diminish over time along with the BPD symptoms if they remit, even in patients with initially severe symptoms of BPD. It is also suggested that substance abuse is the axis I disorder that is most closely associated with failure to achieve remission from the BPD symptoms (Zanarini *et al.* 2004a). Commonly co-occurring axis II disorders are antisocial, avoidant, histrionic, narcissistic and schizotypal PDs. It seems like also axis II disorders occur less commonly over time, particularly for patients who remit from their BPD symptoms. Symptomatic remission of BPD seem to be most restrained by co-morbidity in the anxious cluster of PDs (Zanarini *et al.* 2004b)

Suicidal behaviour and deliberate self-harm (DSH)

Suicidal and deliberate self-harm (DSH) behaviour is a characteristic feature for BPD patients (APA 1994), recent reviews suggest that at least 75% attempt suicide or engage in DSH (Black *et al.* 2004, Lieb *et al.* 2004) and approximately 10% of treated BPD patients complete suicide (McGlashan 1986, Stone 1993, Paris 2002).

The BPD patients at greatest risk for suicidal behaviour include those with most frequent prior suicide attempts, pronounced affect instability and impulsivity, co-morbid major depression or a substance-use disorder (Soloff *et al.* 2000, Black *et al.* 2004, Yen *et al.* 2004). Co-morbidity with major depression increases both the number and seriousness of the suicide attempts (Soloff *et al.* 2000, Black *et al.* 2004). Feelings of hopelessness and childhood abuse independently increase the risk of suicidal behaviour, as does, turbulent early life and the presence of antisocial traits (Zanarini *et al.* 2002, Soloff *et al.* 2002, Black *et al.* 2004).

Because BPD patients frequently are engaged in non-lethal suicide behaviour, this should not be interpreted as little desire to die. Psychiatric health professionals have an important role in preventing suicide attempts and completed suicides by understanding the risk factors. The following are some of the American Psychiatric Association's recommendations for suicide risk management in patients with BPD (APA 2001):

- ◆ Monitor patients carefully for suicide risk and document this assessment; be aware that feelings of rejection, fears of abandonment, or a change in the treatment may precipitate suicidal ideation or attempts.
- ◆ Take suicide threats seriously and discuss them with the patient. Taking action (e.g. hospitalisation) in an attempt to protect the patient from serious self-harm is indicated for acute suicide risk.
- ◆ Chronic suicidality without acute risk needs to be addressed in therapy (e.g. focusing on the interpersonal context of the suicidal feelings and addressing the need for the patient to take responsibility for his or her actions). If a patient with chronic suicidality becomes acutely suicidal, psychiatric professionals should take action in an attempt to prevent suicide.
- ◆ Actively treat co-morbid axis I disorders, with particular attention to those that may contribute to or increase the risk of suicide (e.g. major depression, bipolar disorder, alcohol or drug abuse/dependence).
- ◆ Consider involving the family when patients are chronically suicidal. For acute suicidality, involve the family or a significant other if their involvement will potentially protect the patient from harm.
- ◆ A promise to keep oneself safe (e.g. "suicide contract") should not be used as a substitute for a careful and thorough clinical evaluation of the patient's suicidality with accompanying documentation.

However, the discussion of the patient's responsibility to keep him or herself safe can be used as an additional way to monitor and minimize the risk of suicide (APA 2001).

Psychiatric patients show many types of self-destructive behaviour. Accordingly, in literature there are several concepts similar to DSH, such as; parasuicide, self-injurious behaviour and self-mutilation behaviour (Ahnemark *et al.* 2004). The present thesis deals with DSH as: "acute self-injurious behaviour, without suicide intent". In clinical practice, however, it is often hard to make a distinction between suicidal behaviour (in the present thesis defined as: acute self-injurious behaviour, with suicide intent) and DSH, as the desire and intention to die is often difficult to assess (Ahnemark *et al.* 2004). Adult BPD patients report that DSH behaviour often start at a young age. In the context it should be noted that the presence of DSH in teenagers is not uncommon. However, DSH in youth does not mean that they later in life will fulfil a BPD diagnosis, but might do so (Ahnemark *et al.* 2004). DSH takes many forms in BPD patients, most often it involves cutting but can also involve burning or banging oneself (Ahnemark *et al.* 2004). Sometimes risk behaviour such as; spending, promiscuous sex, substance use, reckless driving and binge eating is included in the DSH concept, for instance in dialectical behavioural therapy, DBT (Linehan 1993). Beside the aim of relieving painful feelings or unpleasant states of mind or punishing oneself, cutting and seeing the blood trickling has been described as an addictive habit with ritual overtones (Pålsson 2004). DSH behaviour seems to diminish over time along with the other BPD symptoms if they go in remission (Zanarini *et al.* 1998, Zanarini *et al.* 2004a).

Dissociation

There is considerable co-morbidity between BPD and dissociative symptoms, especially related to psychosocial stress (APA 1994, Brodsky *et al.* 1995). Dissociation is a process of separating thoughts, emotions, affects, or experiences from one another either purposely or involuntarily and produces a lack of connection in a person's thoughts, memories, feelings and actions, altering the sense of identity and / or reality. During the period of time when a person is dissociating, certain information is not associated with other information as it normally would be (APA 1994). Apart from BPD, dissociation is associated with several psychiatric disorders, such as PTSD, psychotic disorders and anxiety- and mood disorders (Simeon 2004). Dissociation is suggested to be a fairly common effect of trauma in childhood, most typically repeated physical, sexual, and/or emotional abuse (Shearer 1994, Brodsky *et al.* 1995, Van Den Bosch *et al.* 2003).

Violent and antisocial behaviour

Some patients with BPD engage in violent behaviour. Violence may take such forms as hurling objects at significant others during moments of intense anger or frustration. Others may commit physical assaults. Some patients are physically abusive toward their children. BPD patients with antisocial co-morbidity may engage in robbery, burglary and car theft. Acts of this sort are often associated with a police record. Psychiatric professionals should be aware that some BPD patients with antisocial co-morbidity may be extra hard to treat, especially when the clinical picture is dominated by psychopathic traits like: grandiosity, conning, lack of remorse, lying and manipulateness (APA 2001).

Physical health and life style

It is not unusual that patients with psychiatric disorders show poorer physical health than the general population. The WHO's "Country Collaborative Study on Psychological Problems in General Health-Care", showed that psychiatric illness generally was connected to substantial impairments in general health perceptions (Kaplan 1999). The physical health of patients with borderline personality disorder has not been much studied. One study, however, reports that several physical health problems co-occur significantly with non remitted BPD compared to remitted, such as; chronic fatigue, fibromyalgia, obesity, osteoarthritis, diabetes, hypertension and chronic back pain. The study also found that non remitted BPD was significantly correlated to life style risk behaviour such as; smoking much, daily consumption of alcohol, lack of regular exercise, daily use of sleep medications and sustained use of pain medications. The conclusion that was drawn from the study was; that persistent BPD seems to be associated with a heightened risk of suffering from chronic physical conditions, making poor health-related lifestyle choices and using costly forms of medical services (Frankenburg & Zanarini 2004).

The fate of BPD patients

Long-term follow-up studies of treated patients with BPD indicate that the course is variable and fluctuating (McGlashan 1986, Stone 1990, Stone 1993). Early adulthood is often characterised by chronic instability, with episodes of serious affective and impulsive dyscontrol and high levels of use of health-care resources. Later in life, a majority of the BPD patients attain greater stability in social and occupational functioning with more mature and more modulated behaviour patterns (Stone 1990, Stone 1993).

By the time of 15 year follow-up most of them function at levels approaching normality, with the majority no longer meeting criteria for the BPD diagnosis (Zweig-Frank & Paris 2002). If followed for even longer period (27 years) they seem to improve even further, with only 8% still meeting criteria for the BPD diagnosis (Zweig-Frank & Paris 2002). Some long-term follow-up studies (10 to 15 years) of hospitalised patients with BPD indicate that even though they may gradually achieve more functional roles they still have relational problems. Only about 50 % show success in intimacy, as indicated by marriage or long-term sexual partnership (McGlashan 1986, Stone 1990). The outcome is most favourable for patients coming from middle-class or upper-middle-class families. Patients from backgrounds of poverty have substantially lower success rates in the domains of intimacy and work (Stone 1990). Despite these somewhat optimistic long-term outcomes, the suicide rate among treated patients with BPD is high; approximately 10% (McGlashan 1986, Stone 1993, Paris 2002). The risk of suicide appears highest in the young adult years (McGlashan 1986, Stone 1993, Runeson & Beskow 1991, Paris 2002). Although the suicide risk endures for many years, the risk seems to decrease with each crisis the BPD patient survives (Paris 2002).

Treatment and care

BPD patients in health-care

Persons with BPD diagnosis are frequent guests in different health-care settings. The prevalence of BPD in primary care is suggested to be about fourfold higher than around the one percent that is found in general community samples (Gross *et al.* 2002). Among psychiatric outpatients the prevalence is suggested to be between 15-30 % (Widiger & Weissman 1991, Bodlund *et al.* 1993). For inpatient care figures as high as 20-50 % have been reported (Widiger & Weissman 1991, Andersson & Åsberg 2000). A high use of inpatient psychiatric services is predicted by a history of suicidal and DSH behaviour in the previous two years and by the presence of co-morbid anxiety disorders (Comtois *et al.* 2003). BPD patients often evoke uneasiness and attitudes of being troublesome and manipulative among the staff involved in the treatment (Linehan 1993, Bland & Rossen 2005). They are difficult to keep in therapy, frequently fail to respond to therapeutic efforts and make considerable demands on the emotional resources of health professionals, particular when suicidal behaviour and DSH are prominent (Kelly *et al.* 1992, Linehan 1993, Lougrey *et al.* 1997, Burnard *et al.* 2000). It has been suggested that psychiatric health-care professionals respond to BPD patients in a less empathic manner than to patients with other diagnosis (Fraser & Gallop 1993).

Medication and other somatic treatment

There is no diagnosis specific pharmacotherapy for BPD, instead medication is symptom orientated and seen as secondary to treatment with psychotherapy or psychosocial strategies (Soloff 2000). Symptoms that could be treated with pharmacological treatment strategies often fall within three behavioural dimensions: 1) *affective dysregulation*, 2) *impulsive-behavioural dyscontrol*, and 3) *cognitive-perceptual difficulties* (Soloff 2000, APA 2001).

In 2001, the American Psychiatric Association (APA) published their “*Practice Guideline for the Treatment of Patients with Borderline Personality Disorder*” which is based on a comprehensive literature review in combination with an evaluation of evidence strength for over 4000 studies ranging from 1967 to 1998 (APA 2001). The recommended treatment of *affective dysregulation symptoms* (i.e. mood lability as inappropriate intense anger, depressive “mood crashes” outbursts of temper) it is recommended that these symptoms should be treated initially with a selective serotonin reuptake inhibitor (SSRI) or related antidepressants. If SSRI treatment is insufficient, an addition of a benzodiazepine could be considered, although research on these medications in patients with borderline personality disorder is limited, and their use carries some potential risk for addiction. For patients with severe behavioural dyscontrol, low-dose neuroleptics can be added to the regimen (APA 2001). A recently published study showed that dialectical behavioural therapy (DBT) in combination with olanzapine was associated with lower dropout rates and a statistically significant improvement over placebo in depression, anxiety, and impulsivity/aggressive behaviour (Soler *et al.* 2005). Preliminary evidence also suggests that atypical neuroleptics may have some efficacy for impulsivity in patients with borderline personality disorder (APA 2001). There is also empirical support for the efficacy of monoamine oxidase inhibitors (MAOIs) for treatment of affective dysregulation. MAOIs are, however, not a first line treatment because of the risk of serious side effects and the difficulties with adherence to required dietary restrictions. Mood stabilizers (lithium, valproate, carbamazepine) are another second line treatment for affective dysregulation (APA 2001). There is little data supporting the efficacy of ECT for treatment of affective dysregulation symptoms in patients with borderline personality disorder. Clinical experience suggests that ECT may sometimes be indicated for patients with co-morbid severe axis I depression that is resistant to pharmacotherapy (APA 2001).

SSRIs are the initial treatment of choice also for symptoms in the *impulsive-behavioural dyscontrol* dimension (impulsive aggression, self-harm or risk- and self-damaging behaviour as promiscuous sex, substance abuse, reckless spending). When behavioural dyscontrol poses a serious threat to the patient's safety, a low-dose neuroleptic to the SSRI. Further, clinical experience suggests that partial efficacy of an SSRI may be enhanced by adding lithium (APA 2001).

The treatment of choice for *cognitive-perceptual symptoms* (suspiciousness, referential thinking, paranoid ideation, illusions, derealisation, depersonalisation, or hallucination-like symptoms) is low-dose neuroleptics. These medications may reduce not only psychotic like symptoms but also depressed mood, impulsivity, and anger/hostility (APA 2001).

Psychotherapy showing efficacy in randomised controlled trials

Two psychotherapeutic approaches have shown efficacy on BPD in randomised controlled trials (RCTs): psychoanalytic/psychodynamic therapy (Bateman & Fonagy 1999, Bateman & Fonagy 2001) and dialectical behaviour therapy, DBT (Linehan *et al.* 1991, 1994 1999, 2002, Koons *et al.* 2001, Verheul *et al.* 2003). While there is a great deal of clinical literature and uncontrolled studies on psychodynamic psychotherapy with BPD patients (Stone 2000), there is only one published efficacy study found that was conducted in more rigorous RCT conditions. That study assessed the efficacy of a psychodynamic partial hospitalisation treatment, of which dynamic therapy was the primary component (Bateman & Fonagy 1999, Bateman & Fonagy 2001). The efficacy of DBT is somewhat better documented with several independent (but often small scale) RCTs (Linehan *et al.* 1991, 1999, 2002, Koons *et al.* 2001, Verheul *et al.* 2003). Regardless the type of therapy, they have three key features in common: weekly meetings with an individual therapist, one or more weekly group sessions, and meetings of therapists for consultation/supervision (Bateman & Fonagy 1999, Bateman & Fonagy 2001, Linehan *et al.* 1991, Linehan 1993) There are yet no results available from direct comparisons of these two approaches, but there is an ongoing rather large scale RCT in Stockholm, Sweden comparing the two forms of psychotherapy with each other and treatment as usual (see further under "the SKIP project", pp 25 and paper III).

Other psychotherapies and psychosocial treatments

Studies of other psychotherapies and psychosocial treatments are few and uncontrolled. Perris (1994) reported findings from a small uncontrolled, naturalistic follow-up study of BPD patients who received cognitive therapy. Twelve (out of 14) patients were evaluated at a

two-year follow-up point, and all patients maintained the normalisation of functioning that had been shown at the end of the study (Perris 1994). However, studies reported in the literature of cognitive behaviour approaches (other than DBT) are difficult to interpret because of small patient group sizes and/or because the studies focused on mixed types of PDs without specifying borderline cohorts (APA 2001).

Some studies suggest that group treatment, including process focused groups in a therapeutic community setting may be useful for BPD patients (Greene & Cole 1991, Hafner & Holme 1996, Wilberg *et al.* 1998). It should be noted that group treatment also was included in the RCTs of both the psychodynamic psychotherapy and DBT reported above, (Bateman & Fonagy 1999, Bateman & Fonagy 2001, Linehan *et al.* 1991, 1999, 2002, Koons *et al.* 2001, Verheul *et al.* 2003); although the overall treatment program showed efficacy, the efficacy of the group therapy component is unknown. The effective components including the group therapy in DBT as seen by the patients and therapists in a naturalistic setting were studied in paper I in the present thesis.

The published literature on family therapy with BPD is scarce but a few studies suggest that a family approach; psychodynamic as well as psycho-educational could improve communication, diminish alienation and burden, and diminish conflicts over separation and increase independence. The literature further suggests that family therapy may be useful particularly for patients who are still dependent on or significantly involved with their families (Clarkin *et al.* 1991, Villeneuve & Roux 1995, Gunderson *et al.* 1997) A recent study showed that family intervention in addition to DBT with focus on (a) current information and research on BPD, (b) coping skills, (c) family skills, and (d) opportunities to build a support network for family members, significantly reduced grief and burden in the family members (Hoffman *et al.* 2005).

Professional care and nursing

There seem to be some common features that can guide the professional carer in their work with BPD patients, regardless of the specific type of therapy used. These features include building a strong therapeutic alliance and monitoring DSH and suicidal behaviours as well as impulsive and violent behaviour (Kernberg 1989, Linehan 1993, Miller & Davenport 1996, O'Brien & Flote 1997, Lougrey *et al.* 1997). Other components of sufficient care for patients with BPD include managing feelings (in both patients and health professionals), promoting reflection instead of impulsive action and setting limits on any self destructive behaviour

(Linehan 1993, Loughey *et al.* 1997, O'Brien & Flote 1997, Melchior *et al.* 1997, Bergman & Eckerdal 2000). Other general nursing interventions should include validating the patient's suffering and experiences as well as helping the patient take responsibility for his or her actions (Lindholm & Eriksson 1993). These last aspects of caring for BPD patients have been investigated further in study II.

BPD patients and their perceptions of suffering

The repeated suicide attempts and acts of DSH among BPD patients (McGlashan 1986, Runeson & Beskow 1993, Stone 1993, Söderberg 2001, Paris 2002, Black *et al.* 2004, Lieb *et al.* 2004) reveal something about the magnitude of suffering they are struggling with. But how is the suffering experienced by the patients themselves? The aim of study II was to find some answers to that question. Thus, being able to better understand how the patients understand may be an important step towards improved care of BPD patients. The study was largely structured by the theories of health and suffering developed by Katie Eriksson and co-workers (Lindholm & Eriksson 1993, Eriksson 1994). Eriksson sees suffering as an inseparable part of human life. It has many faces and many characteristics, but it lacks an explicit language. There are different forms of suffering in health-care: suffering related to illness, suffering related to life circumstances and existential issues, and suffering related to care (Eriksson 1994). Eriksson also makes a distinction between endurable and unendurable suffering. The unendurable suffering paralyses the human being and takes priority over possible life goals, preventing him/her from growing, while endurable suffering is compatible with health and growth as a human (Eriksson 1994). The ultimate purpose of caring is to alleviate suffering, to help the sufferer along the path from unendurable suffering to a suffering that is endurable. A human being who suffers needs validation of his/her suffering, time and space to become reconciled to the suffering (Eriksson 1994). Lindholm and Eriksson (1993) conceptualise the encounter between the suffering patient and the caring professions as a drama in three acts. In act one ("confirmation of suffering") the patient meets the carer and hopefully receives confirmation and validation of the suffering. Act two ("being in suffering") is shaped by the extent to which the carer can give support and help the patient to endure and accept the suffering, to give the patient time and space to suffer and stay with him or her and share the suffering. Act three ("becoming in suffering") is shaped by the extent to which acceptance and reconciliation is achieved. Then there is a possibility of a new understanding, further growth and development. But if acceptance is not achieved there is risk of disappointment and bitterness (Lindholm & Eriksson 1993).

Alleviating a human being's suffering implies being a co-actor in this drama. When healthcare fails to encounter and care for the sufferer efficiently it often adds to the suffering and Eriksson's third form of suffering, "suffering of care", occurs (Eriksson 1994).

The SKIP project

Trying to gather more evidence on the topic of psychotherapeutic treatment of women BPD patients, our research group is currently in Stockholm, Sweden, carrying out a randomised controlled trial (Stockholm county council and Karolinska Institutets psychotherapy project for suicidal women with BPD, SKIP) comparing two forms of psychotherapy with each other and with routine psychiatric treatment (treatment as usual). One of the psychotherapies is DBT (see pp 28) and the other is a form of psychodynamic therapy called object relations psychotherapy (ORP). ORP is a modified version of a psychodynamic psychotherapy originally developed and described in manual-form by Professor Otto Kernberg and co-workers at Cornell University in New York and called transference focused therapy (TFP), by them (Kernberg 1989). This therapy aims towards helping the patient develop a more stable identity with less affect instability and impulsivity.

The randomised phase of the project started in June 1999 and continued with patient inclusion until December 2004. 106 patients had then been included after extensive inclusion- and baseline evaluation. The treatment in the project is planned to go on for at least 24 months and effect evaluation according to intention to treat (ITT) principles will be performed at 12, 24 and 60 months after the treatment start. The SKIP project contains a health economic evaluation, with the aim of comparing treatment-costs and health-outcomes and to calculate cost-effectiveness for the different treatments, in which the SWED-QAUL (paper III) is the central outcome measure.

Health economic evaluation and health related quality-of-life measures

In health economic evaluation outcomes ideally should be expressed using effectiveness measures that can be compared to outcomes across diseases. The effectiveness measures should also ideally reflect the patients psychosocial functioning, subjective well-being and health satisfaction. Generic health-related quality-of-life (HRQOL) measures meet both these criteria (Brooten 1997, Kaplan 1999, Kobelt 2002).

Health economic evaluation

Increasing health-care expenditures, rapid introduction of new drugs, medical techniques and interventions as well as need for cost containment policies during the last decades have led to increasing interest in health economy and health economic evaluation. The assumption underpinning economics is that resources available to society as a whole are scarce and that there always are alternative ways to use resources. Often a utilitarian benefit maximization approach is used, proposing that cost-effectiveness in the use of resources implies that they are allocated in a way that makes total benefits in the population maximized. Thus, decisions must be made about their best use in order to produce the greatest benefits to the population. Health economics study how we individually and collectively use our resources to produce health (Folland 2004). Health economic evaluation is a tool for comparing costs and consequences for different interventions in health-care in order to assess “value for money”. In that way it can provide information related to decision making and resource allocation in health-care in order to maximize health. Accordingly, health economic evaluation is usually formulated as a choice between competing alternatives, with their respective benefits and costs calculated (Kobelt 2002, Drummond *et al.* 2003). There are a number of economic evaluation models and techniques:

- ◆ Cost-minimization; calculating costs only and used when the health benefits for example two alternative treatments are known and equal.
- ◆ Cost-effectiveness; comparing both costs and consequences and used when there is a single effect measure (natural effect units; for example blood pressure in mm hg or units of quality-of-life) of interest which is common to all compared interventions.
- ◆ Cost-utility; comparing both costs and consequences and used when there are multiple effects of interest which are not necessarily common to the compared interventions, often calculated as disability-adjusted-life-years (DALYs) or quality-adjusted-life-years (QALYs) gained.
- ◆ Cost-benefit; comparing both costs and consequences in monetary terms (dollars, SEK) often using a willingness-to-pay (WTP) approach for calculating the benefits (Drummond *et al.* 2003).

In a health economic pilot study related to the SKIP project (Perseus *et al.* 2004), we took advantage of data collected during the training phase of therapists, to assess costs-consequences (e.g. a cost-effectiveness approach without calculating a cost-effectiveness quota) of dialectal behavioural therapy (DBT) in suicidal women with BPD.

Under an 18 month period, 22 suicidal women with BPD were treated with outpatient DBT, with focus on reducing suicidal- and DSH behaviour. Outcome data (rates of suicide attempts and acts of DSH) and direct health-care cost data collected retrospectively 12 months before therapy-start were compared to prospective data collected up to 18 months in therapy. The results suggest that DBT may have a positive impact on treatment costs, as they decreased significantly during the last 12 months in the 18 month therapy period. The reduction of costs was due to decrease in the number of psychiatric inpatient days (Perseus *et al.* 2004). The results are encouraging and in conducting the study we have learnt a lot that might be beneficial in relation to the final health economic evaluation of the SKIP project. The conclusions that can be drawn from the study are, however, rather limited as the study was not made in RCT conditions and indirect costs to society were not assessed.

Health Related Quality-of-Life measures

In recent years health assessment has been increasingly interested in patient based assessment of psychosocial functioning and health satisfaction, beside more traditional biomedical measures. The different quality-of -life measures often combine assessment of psychosocial functioning with patient health satisfaction (Brorson *et al.* 1993). There is no overall agreed definition of quality-of -life, but in relation to health assessment the WHO's constitutional definition of health is often used as a basis, incorporating aspects of physical, mental and social well-being (WHO 2005). Thus; the "Health-Related Quality-of-Life" (HRQOL) concept includes areas of physical-, mental- and social functioning as well as general satisfaction with life (Spitzer 1987). Quality-of -life measures are often being used as a global health measure, allowing comparison between outcomes of different treatments. This is not least important in the context of health economic evaluation, and in dealing with resource allocation in health-care. Thus, HRQOL is accepted as a global measure of health-outcome within health economic research (Kaplan 1999). When studying cost-effectiveness or cost-utility of treatments, HRQOL is often part of the effectiveness or utility assessment, as the sole measure of health outcome or incorporated, additional to time and mortality variables, in the concept of QALYs (Brooten 1997, Kaplan 1999). Several of the widest spread HRQOL questionnaires are developed from the Medical Outcome Study instrument, MOS (Steward & Ware 1992). The MOS has been developed over a period of more than 20 years and its validity and reliability has been extensively tested (Steward & Ware 1992). Two examples are SF 36, (Sullivan *et al.* 1995), and SWED-QUAL, (Brorson *et al.* 1993).

SWED-QUAL has nearly twice as many items but also a wider approach to HRQOL than SF 36, including aspects of health such as: sleep, family - and partner functioning and sexual functioning (Brorson *et al.* 1993), see further under “instruments” pp 42.

Dialectical Behavioural Therapy (DBT)

In the early and mid 1990s, Linehan *et al.* published the results from a randomised controlled trial of a psychosocial intervention for BPD. The intervention in focus was a form of cognitive-behavioural therapy, called dialectical behavioural therapy (DBT) that had been developed by psychology professor Marsha Linehan and co-workers in Seattle US. The therapy especially targets the pattern of suicide attempts and DSH in BPD patients. The study showed that DBT resulted in significantly fewer suicide attempts and acts of DSH, lower treatment drop out rate and fewer inpatient days compared to the control group (Linehan *et al.* 1991, Linehan *et al.* 1994).

The theoretical underpinning of DBT is the biosocial model as described by Linehan (1993), see further, pp 12. DBT combines intervention strategies from behavioural, cognitive and supportive psychotherapies, and includes weekly individual and group therapy. The therapy applies a mixture of supportive techniques and directive problem-oriented techniques (behaviour skills training, exposure, contingency management and cognitive modification). The therapy targets three phases of general treatment goals organised in the following hierarchy:

1. “Stability and security”, aiming towards decreased suicidal behaviour and acts of deliberate self-harm, decreased therapy-interfering behaviours and decreased quality-of-life interfering behaviours.
2. Reduction of post-traumatic stress by focusing on traumatic life events.
3. Increased self-respect and achievement of individual life goals.

Both during and between sessions the therapist actively teaches and reinforces adaptive behaviours. Therapists, between sessions, ideally have a 24-hour readiness to intervene in their patients self-harming behaviour by telephone. The treatment sessions are videotaped. The videotapes are used as a basis for supervision sessions (Linehan 1993).

The term “dialectical” is inspired by Friedrich Hegel’s (1770-1831) classical philosophy. Referring to a form of argument in which an assertion is first made about a particular issue (“the thesis”), the opposing position is then formulated (“the antithesis”) and finally a “synthesis” is reached between the two extremes, holding the valuable features of each

position and resolving any contradictions between the two. This synthesis then acts as the thesis for the next cycle. In DBT theory truth is inter-subjective and seen as a process which develops over time in communication between people. From this perspective there can be no statement representing absolute truth. Truth is approached as the middle way between extremes (Linehan 1993). The dialectical approach to understanding and treatment of human problems is in DBT described as open-minded and with a systemic and communicational orientation. The dialectical viewpoint underlies the entire structure of therapy, the key dialectic being “acceptance” on the one hand and “change” on the other. Thus, DBT includes specific techniques of acceptance and validation designed to counter the self-invalidation of the patient. These are balanced by the problem solving techniques to help the patient learn more adaptive ways of dealing with her difficulties and learn the skills to do so. Dialectical strategies underlie all aspects of treatment to counter the extreme and rigid thinking in BPD patients. The dialectical world view is also apparent in the goals of therapy and in the attitudes and communication styles that is required from the therapist. The therapy is regarded as “behavioural” in that it focuses on present behaviour and the current factors which are controlling that behaviour, but without ignoring the past (Linehan 1993).

DBT describes the patient and therapist relationship as it is a real human relationship in which both parts matter and in which the needs of both have to be considered. Further, DBT is described as particularly alert to the risks of burnout to therapists treating patients and therapist support and consultation is an integral and essential part of the treatment (Linehan 1993). The approach in DBT is a team approach. The therapist is also asked to accept a number of working assumptions about the patient that will establish the required attitude for therapy:

1. The patient wants to change and, in spite of appearances, is trying her best at any particular time.
2. The patient’s behaviour pattern is understandable given her background and present circumstances. Her life may currently not be worth living, however, the therapist will never agree that suicide is a solution but always stays on the side of life. The solution is rather to try and make life more worth living.
3. In spite of this the patient needs to try harder if things are ever to improve. The patients are not to be blamed for the way things are but it is seen as her personal responsibility to make them different.

4. Patients can not fail in DBT. If things are not improving it is the treatment that is failing. In particular the therapist must at all times avoid viewing the patient, or talking about her in blaming or disrespectful terms since it is believed that such an attitude will be antagonistic to successful therapeutic intervention, and likely to be similar to the problems that have led to the development of BPD in the first place (Linehan 1993).

In DBT there is a particular dislike for the word “manipulative” as commonly applied to BPD patients, which implies that they should be skilled at managing other people when it is precisely the opposite that is implied by the DBT model. Also the fact that the therapist may feel manipulated does not necessarily imply that this was the intention of the patient. It is more probable that the patient did not have the skills to deal with the situation more effectively (Linehan 1993). The therapist relates to the patient in two dialectically opposed styles. The primary style of relationship and communication is referred to as “reciprocal communication”, a style involving responsiveness, warmth and genuineness on the part of the therapist. Appropriate self-disclosure is encouraged but always with the interests of the patient in mind. The alternative style is referred to as “irreverent communication”. This is a more confrontational and challenging style aimed at bringing the patient up with a jolt in order to deal with situations where therapy seems to be stuck or moving in an unhelpful direction. These two styles should, however, be used in a balanced way. The therapist should try to interact with the patient in a way that is:

1. Accepting the patient as she is, but which encourages change.
2. Centred and firm yet flexible when the circumstances require it.
3. Nurturing but kindly demanding. The dialectical approach is here again apparent. There is a clear and open emphasis on the limits of behaviour acceptable to the therapist and these are dealt with in a very direct way (Linehan 1993).

The therapist is encouraged to be clear about his or her personal limits in relations to a particular patient and should as far as possible make these clear to her from the start. It is therefore in the patient’s interest to learn to treat her therapist in a way that encourages the therapist to want to continue helping her. It is not in her interests to burn him or her out. This issue should be confronted directly and openly in therapy. The therapist helps therapy to survive by consistently bringing it to the patient’s attention when limits have been overstepped and then teaching her the skills to deal with the situation more effectively.

The therapist is trained and supported to adopt a non-defensive posture towards the patient, to accept that therapists are fallible and that mistakes will at times be made (Linehan 1993).

In DBT therapy is seen as entirely voluntary and depends for its success on having the co-operation of the patient. From the start, therefore, attention is given to orienting the patient to the nature of DBT and obtaining a commitment to undertake the work. Before a patient will be taken on for DBT she will be required to sign a contract and give a number of undertakings:

1. To work in therapy for a specified period of time and within reason, to attend all scheduled therapy sessions.
2. If suicidal or DSH behaviour are present, she must agree to work on reducing these.
3. To work on any behaviour that interfere with the course of therapy (“therapy interfering behaviour”) (Linehan 1993).

In view of the positive treatment outcomes reported in several independent randomized controlled studies (Linehan *et al.* 1991, 1999, 2002, Koons *et al.* 2001, Verheul *et al.* 2003), DBT seems to be a promising outpatient treatment for self-harming women with BPD. It has also been suggested to reduce treatment costs (Perseius *et al.* 2004) and appears well accepted by the patients (paper I). Thus, DBT has made its way into practice in psychiatric health-care services in several countries over the years.

Occupational stress and professional burnout among psychiatric professionals working with BPD patients

Psychiatric health professionals often suffer from high levels of occupational stress and are at high risk for professional burnout (Arnetz *et al.* 1994, Samuelsson *et al.* 1997, Thomsen *et al.* 1999, Edwards *et al.* 2000, Edwards & Burnard 2003, Jenkins & Elliott 2004). Working with psychiatric patients who are suicidal, self-harming and aggressive appears to increase the risk of experience high level stress (Loughrey *et al.* 1997, Melchior *et al.* 1997, Burnard *et al.* 2000). BPD patients are known to be difficult to retain in therapy, frequently fail to respond to therapeutic efforts, and make considerable demands on the emotional resources of psychiatric professionals, particularly when suicidal behaviour and DSH is prominent (Kelly *et al.* 1992, Linehan 1993, Bergman & Eckerdal 2000, Bland & Rossen 2005).

In the literature there are several definitions of professional burnout, partly contradictive, but its core features are prolonged stress related to the work-situation, associated with an unfavourable work-environment, in initially strongly motivated individuals who respond to the prolonged stress with physical, cognitive and affective dysfunction (Shaufeli & Enzmann 1998). The probably most influential definition of burnout has been offered by the American social psychologist Christina Maslach, who characterized burnout as a syndrome of emotional exhaustion, depersonalization / cynicism and reduced personal accomplishment / efficacy. Emotional exhaustion refers to feelings of being overextended and exhausted by the emotional demands of one's work. Depersonalization / cynicism is characterized by a detached and cynical approach to other people in the context of work. Personal accomplishment / efficacy is the self-evaluated feeling that one is no longer effective in one's work (Maslach 1981, Maslach *et al.* 1996, Maslach & Leiter 1997). Maslach *et al.* (1981, 1996) constructed an inventory (the Maslach burnout inventory, MBI) to measure these three dimensions of burnout in three different subscales. However, the choice of including "personal accomplishment / efficacy" as a dimension of burnout (instead of seeing it as a consequence of burnout) in the MBI has been debated along with the scale's psychometric properties (Demerouti *et al.* 2001). In dealing with the proposed weaknesses of the MBI, Demerouti *et al.* (2001) constructed another burnout inventory called the Oldenburg Burnout Inventory (OLBI). The OLBI measures burnout in two dimensions on separate subscales; exhaustion and disengagement. Exhaustion is operationalized not merely as an emotional phenomenon but is defined as a long term consequence of intensive physical, affective and cognitive strain. The disengagement subscale refers to distancing oneself from one's work and having negative attitudes towards the work object and / or the work contents (Demerouti *et al.* 2001). Study IV addresses the topic of psychiatric professionals' perceptions of occupational stress and professional burnout when learning and starting to use DBT in the treatment of young deliberate self-harming patients showing BPD symptoms.

Aims

The present thesis is trying to shed some light on different aspects of BPD; the patients suffering and quality of life, their perceptions of encounter with psychiatric care in general, and perceptions of being treated with dialectal behavioural therapy (DBT) in particular. In relation to DBT the thesis also tries shed some light on psychiatric professionals' perceptions of treating BPD patients as well as their perceptions of occupational stress and professional burnout when learning and starting to use the method.

The specific aims related to the different papers:

- ◆ To investigate women BPD patients' perceptions of suffering and encounter with psychiatric care (paper II).
- ◆ To investigate women BPD patients' quality-of-life and test the internal consistency reliability of an instrument (SWED-QUAL) measuring health-related quality-of-life on women BPD patients (paper III)
- ◆ To investigate BPD patients' and psychiatric professionals' perceptions of receiving and giving dialectical behavioural therapy, DBT (paper I).
- ◆ To investigate how learning and starting to use DBT in work with young self-harming patients with BPD symptoms affected the psychiatric professionals perceptions of occupational stress and professional burnout (paper IV). (See table one, pp 44, for overview.)

Participants

The studies presented in the thesis have been conducted from 2000 to 2005 and include in all 111 participants recruited from 1996 to 2003, in three different settings in the regions of Stockholm, Skåne and Uppsala respectively. 85 of them were patients with BPD (all women) and 26 were psychiatric professionals (21 women and 5 men) working with BPD patients (referred to as DBT therapists), see table one, pp 44, for overview.

The participants in study I were 10 BPD patients (who had been in therapy for 12 months or longer) and all 4 therapists connected to a DBT team in Skåne. The same 10 patients were participants again in study II. In study III the participants (N=75) were 42 patients clinically recruited for the therapist training phase in the SKIP project as well as the patients (n=33) of the first year of the randomised trail in the project. The participants in study IV were all of the psychiatric professionals (N=22) under training to be DBT therapists in a clinical development project in Uppsala County Council.

Methods - a qualitative and quantitative approach

Due to the different types of research questions the thesis deals with, it represents a mix of qualitative and quantitative research methods. In two of the studies (I and II) the main methods were qualitative and in one (III) they were quantitative. The fourth study in itself has an approach combining quantitative and qualitative methods (see table one, pp 44, for overview).

The qualitative methods

Qualitative research is concerned with humans and their environment in all their complexities and is based on the premise that in order to try to understand humans, one need to describe experiences as they are lived or narrated by the persons themselves (Polit & Hungler 1995). The distinctive feature and strength of qualitative research is that it explores human phenomena, reflects inter-subjective experiences and is able to discover patterns from which hypotheses can emerge (Patton 1991). Qualitative data generally take the form of loosely structured narrative materials such as dialogue between an interviewer and a respondent in a narrative interview with open ended questions (Polit & Hungler 1995). Many of the means to enhance trustworthiness in qualitative research focus on the use of different perspectives (data-sources, methods, investigators or theories) to cover the same topic (Polit & Hungler 1995, Sandelowski 1995).

Data collection

The qualitative studies (I and II) and qualitative parts of study IV have consistently used different perspectives regarding data-sources and methods of data collection, e.g. combinations of patients' and psychiatric professionals' perspectives (study I), free-format questionnaires in combination with group interviews (study I and IV), and individual interviews (study I and II) in combination with biographical material (study II). Study I and II have one part of the data-collection in common (the same individual interviews), who were conducted with a twofold aim and combining two different interview-techniques. They were more narrative in the first part, with research questions mostly related to study II (the patients perceptions of suffering), and more focused in the second part, regarding the patients perceptions of DBT (study I). See table 1, pp 44 for overview.

Paper I: The data collection in the patient part of the study was made by individual interviews (more focused than narrative in the parts related to study I). An interview guide was used, focusing on the following areas: a) Perceptions of symptoms, suffering and life situation before and after entering therapy. b) If and in what way the therapy has had impact on their suffering and life situation? c) What components in the therapy they believed have had effect? d) Their perceptions of DBT as compared to other contacts and treatments in psychiatric care. The interview guide was used freely allowing the respondents to narrate perceptions in their own words. Background data concerning socio-demographic variables and symptoms was collected by a semi-structured questionnaire, which was given to the respondents prior to the interview. The interviews took place in the premises of the DBT team (located in a hospital) and lasted between 50 to 90 minutes each. All interviews were audio taped. The first author conducted all data collection. The interviewer had not met any of the respondents prior to the study. Questions were asked using a funnel approach starting with a narrative approach using quite wide, open-ended questions like: “How come you were offered DBT-treatment?”, “What was your life situation like before entering DBT?”, “What is your life situation like today?”, followed by more focused and specific and treatment oriented questions, like: “Has DBT helped you in any way?” and “Is there something about the therapy that you feel has been hard or troublesome?”, “Is there something about the therapy that you feel has been good or pleasant?”.

In the therapist group, data was collected by individual, free format questionnaires and a group interview. The questionnaires as well as the interview focused on question areas corresponding to the patient group. The therapists had three weeks to fill in the questionnaires. The questionnaires were then sent by mail to the first author, who performed a preliminary analysis. The result of the preliminary analysis was used as basis for an interview guide in the group interview. In the group interview the interview guide was freely used, allowing the respondents to narrate perceptions in their own words. The group interview took place in the premises of the DBT-team and lasted 90 minutes. All interviews were audio taped. The first author conducted all data collection in both groups. The interviewer had not met any of the participants prior to the study.

Paper II: In this study data-collection was made by individual interviews (the same patients and occasion as in study I, but with a more narrative approach in the parts related to study II) and biographical material. An interview guide was used, focusing on two areas: a) Perceptions of symptoms, suffering and life situation.

b) The informant's perceptions of contacts and treatments in psychiatric care. The interview guide was used freely allowing the informants to narrate perceptions in their own words. Questions were asked using a funnel approach starting with quite wide, open questions like: "Can you describe what your life situation was like before entering the treatment program?", "What is your life situation like today?", followed by more specific and exemplifying questions, like: "Could you tell me more about...?" and "In what way...?", "Could you give an example...?". Transcribed, the interviews in all comprised 107 pages of text.

In connection with the interviews the informants were asked to provide biographical material (produced spontaneous and prior to the study), that reflected their life situation and suffering. Five of the ten informants provided such material. Diary excerpts in three cases, poems in one case and diaries as well as poems in one case. The diary excerpts were provided as Xerox-copies direct taken from the original hand-written diaries. The poems were in some cases Xerox-copies of hand written material and in some cases printed out of a computer word-processor. The patients themselves decided on what material to share, with the notion that it should reflect their life-situation and suffering before entering the special treatment program. Transcribed, the biographical material in all comprised 37 pages of text.

Paper IV: In qualitative part of study IV an individual, free format questionnaire in combination with a group interview was used, both addressing; a) feelings about the work situation before and after starting working with DBT, and b) perceptions from occupational stress before and after starting working with DBT. The free format questionnaires were administered by mail at the end of the project (18 months) and the group interviews took place 2 months later. The therapists had three weeks to fill in the free format questionnaires. The questionnaires were then sent by mail to the first author, who performed a preliminary content analysis. The result of the preliminary analysis was used as basis for an interview guide in the group interview. The group interview took place in the premises of the DBT-project and lasted 70 to 90 minutes. The interview guide was used freely allowing the respondents to narrate perceptions in their own words. Questions were asked using a funnel approach starting with quite wide, open ended questions like: "How come you started to work with DBT?", "What was your work situation like before starting with DBT?", "What is your work situation like today?", followed by more specific questions, like: "Have your perceptions of occupational stress changed in any way?" and "How come?". All interviews were audio taped. The first and third author conducted all data collection. The interviewers had not met any of the subjects prior to the study.

Data analysis - qualitative content analysis (paper I and IV)

Content analysis can be applied to written or oral communication. It involves describing the characteristics of the contents of a message, as opposed to its style or structure (Polit & Hungler 1995). Content analysis can be quantitative or qualitative. In quantitative content analysis the researcher engages in the counting of words or concepts of interest (Findahl & Höijer 1981). Qualitative content analysis is a method concerned with meanings, intentions, consequences and context (Cavanagh 1991). In study I and IV the qualitative data (interview transcripts and free format questionnaires) was analysed by qualitative content analysis influenced by Burnard (1991).

The aim of such an analysis is *“to produce a detailed and systematic recording of the themes and issues addressed in the interviews and to link the themes and interviews together under a reasonably exhaustive category system”* (Burnard, pp 461 – 462). If the data consists of interviews it is seen as important that they have been recorded in full and transcribed into a text (Burnard 1991).

The analysis in the patient part of study I was performed according to the following steps:

1. All individual interviews were transcribed *verbatim* (into a “Word-document”).
2. The text from the interviews was read as open-mindedly as possible, in order to gain an overall impression of the text and the respondent’s situation and “frame of reference”.
3. The text was reread several times with the question: “what is this about”, in mind. By open coding phrases, sentences or parts of sentences bearing meaning (meaning units) were underlined and then copied from the Word-document into a another data program (Excel).
4. The meaning units were (in the Excel-program) organised into categories and sub-categories that were given in interplay with the text as an entirety.
5. The found categories and sub-categories were then connected to the area of research questions that they answered.
6. To enhance credibility the first and the third author independently analysed the interview text in step two, three, four and five.
7. The first and the third author together reflected on and discussed the independently found codes, categories and sub-categories into agreement.

The analysis in the therapist part of study I and the qualitative part of study IV was performed according to the following steps:

1. A preliminary content analysis of the free format questionnaires were made by the first author. a) The text from the questionnaires was read as open-mindedly as possible, in order to gain an overall impression of the text and the respondents' situation and "frame of reference". b) By open coding phrases, sentences or parts of sentences bearing meaning (meaning units) were underlined and then written into a data program (Excel). c) In the data program the meaning units were preliminary organised into categories.
2. The result of the preliminary analysis was used as basis for an interview guide in the group interview.
3. The group interviews were transcribed *verbatim* (into a "Word-document").
4. The text from the interviews was read as open-mindedly as possible, in order to gain an overall impression of the text and the respondents' situation and "frame of reference".
5. The text was reread several times with the question: "what is this about", in mind. By open coding phrases, sentences or parts of sentences bearing meaning (meaning units) were underlined and then copied from the Word-document into another data program (Excel)
6. In the data program the meaning units were organised into categories and sub-categories that were given in interplay with the text as an entirety.
7. The found categories and sub-categories were then connected to the area of research questions that they answered.
8. To enhance credibility the first and the third author independently analysed the interview text in step four, five, six and seven.
9. The first and the third author together reflected on and discussed the independently found codes, categories and sub-categories into agreement.

The preliminary results of study I (and partly study II) was first summarised in a report in Swedish, as well as presented orally in a seminar. Both patients and therapists that were participants in the study got access to the report and were specially invited to the seminar to listen and comment the results. The preliminary results of study IV were presented orally in a seminar, to which the participants were specially invited to listen and comment the results.

Data analysis - hermeneutic interpretation (paper II)

Hermeneutic interpretation aims towards deeper understanding of human and cultural phenomena. Human language and text is a way to open the human life-world. One can not fully understand another person's experience of being in the world, but one can get a glimpse of it when communicating or reading texts (Ricoeur 1991). The process of understanding comes in the context of relations and dialogue. Through the ambition to get these glimpses of another person's life-world with the baggage of ones own life-world as reference, one can achieve new understanding (Ricoeur 1991, Gadamer 1993). Thus, hermeneutic interpretation considers the researcher's own pre-understanding of the phenomena under investigation and is striving for a "fusion of horizons" - the horizon of the text with the horizon of the interpreter and the horizons of pre-understanding with new understanding (Gadamer 1993).

Further, hermeneutic interpretation follows hermeneutic circles, which are described as circular movements between the whole and the parts, between question and answer and between nearness and distance to the text (Gadamer 1993). There are different traditions within hermeneutics around the topic of "exactly what" or "whose perspective" one should try to better understand. A more psychological tradition represented by for example Wilhelm Dilthey (1833-1911) and Gordon W Allport (1897-1967) mean that it is the person behind a text (the author or the utterer) that should be in focus (Åkerberg 1986, Helenius 1990), while Hans-Georg Gadamer (1900-2002) and Paul Ricoeur (1913-2005) mean that the interpretation aims to better understand the message carried by the text itself (Gadamer 1993, Ricoeur 1991). One condition equal for all traditions is, however, that in order to achieve a systematic interpretation, the phenomena must be able to be registered and preserved graphically as a text or a recording (Ricoeur 1991, Ricoeur 1995).

All data in study II was analysed with a hermeneutic approach inspired by the interpretation theory of Paul Ricoeur (1991, 1995) and the adaptation of these theories to methods of interpretation in caring science (Wiklund *et al.* 2002). The transcriptions of all the interviews, diary excerpts and poems were used as one coherent text in the interpretation. All the authors have several years of experience in clinical work with BPD patients as psychiatric nurses or physicians representing a pre-understanding which did thus influence the interpretation of the material.

The interpretation was performed according to the following steps:

1. All interviews and the biographical material were transcribed *verbatim* into a “Word-document”.
2. Primary reading: The first read-through of the entire text-material was a naive reading, deliberately using pre-understanding (experiences and prejudices about BPD patients, fragments of theory, and experiences from ones own life-world).
3. The text was then reread again as open-mindedly as possible (taking the perspective of “the text itself”) with the question: “what is this about” in mind, trying to lift the text out of its context and the pre-understanding.
4. Content analysis: By open coding phrases, sentences or parts of sentences bearing meaning (meaning units) were underlined. The meaning units were organised into preliminary themes and sub-themes that were given in interplay with the text as an entirety, partly using a data program (Excel).
5. The next phase of interpretation connected back to the research questions and the patients behind the text again, in asking “what question is this answer to?”
6. To enhance credibility the first and the second author independently made preliminary interpretations of the narratives in step two to five, after which they together reflected on and discussed their interpretations.
7. Structural analysis: The structural analysis in the interpretation was carried out (by the first author) on two levels; first a search for how the informants’ narratives were structured in terms of dramaturgy (tragedy, comedy, romance or satire) secondly, the search for metaphors.
8. The first author then used the preliminary interpretations and connected them with Eriksson’s “theory on health and suffering” (1994) and “the drama of suffering” (Lindholm & Eriksson 1993, Wiklund *et al.* 2002).
9. All the authors discussed and reflected on the interpretations.

The quantitative methods and statistical analysis

In contrast to qualitative research, a quantitative approach optimally requires a maximum of researcher imposed structure and rigorous control over extraneous variables as well as the influence of chance. It also requires means of describing, classifying and quantifying variables in order to perform statistical procedures used in hypothesis testing, predicting outcomes or generalizing results from a sample to a whole population (Graziano & Raulin 2004).

Paper III

In the HRQOL study (paper III) the SWED-QUAL instrument (see further under “instruments”, pp 41) was administrated for self-assessment at home between the first and second (out of three) baseline evaluation sessions in the SKIP psychotherapy trail. All subjects (N=75) agreed to fill in the questionnaire. Items were all used according to a “during last week” time frame. Statistical scale analysis were used to evaluate the extent to which the multi-item scales satisfied criteria for reliability, (e g inter-item correlation, total-item correlation and internal consistency criteria). Mean inter-item- and total item correlation as well as the Cronbach`s alpha coefficient were calculated (Spector 1992). In order to compare the BPD patients SWED-QUAL results to a female normal population sample of comparable age, data was extracted from a published study (Brorson *et al.* 1993). Differences of the SWED-QUAL results between the BPD group and the normal population group were analysed by two tailed, one-sample t-tests, as individual scores were not available in the published study. Due to the risk of a mass-significance phenomena occurring when performing several analyses, p-values = 0.01 or lower were considered statistically significant. To test the BPD group for subgroup differences in SWED-QUAL results related to DSM axis I co-morbidity a Kruskal-Wallis test was used, comparing subgroups of patients having: a) no axis I diagnosis (n=12), b) one axis I diagnosis (n=8), c) two (n=19), d) three (n=18) and e) four to five axis I diagnosis (n=18). A nonparametric analysis was used in this part due to the small sized groups and the partly skewed distributions. Statistical significance were set to p-values = 0.05 or lower.

Paper IV

In the quantitative part of study IV, data was collected by two inventories focusing the phenomena of professional burnout; the Maslach Burnout Inventory – General Survey and the Oldenburg Burnout Inventory (see further under “Instruments”, below). The inventories were administered for self assessment at the start of the education programme (baseline) and after 6, 12 and 18 months in the clinical development project. The data was analysed by descriptive statistics and two-tailed t-tests for dependent groups, in which the baseline scores in the subscales of the two instruments were compared to the scores after 6, 12 and 18 months respectively. Statistical significance was set to p = 0.05 or lower.

General comment on the statistic tests

Regarding the choice between parametric and nonparametric statistical tests the present thesis follows the advice from Polit & Hungler (1995) that parametric tests are preferable as they are more powerful and easier to communicate. Nonparametric test are most useful when dealing with small groups, markedly non-normal distributions and data that in any manner cannot be constructed as at least an interval scale (Polit & Hungler 1995).

Instruments

SWED-QUAL (paper III)

The SWED-QUAL questionnaire (paper III) consists of 69 items which form twelve multi-item scales and one single-item scale. The scales are representing the following HRQOL aspects: physical functioning (seven items), satisfaction with physical functioning (one item), pain (six items), limitations in role functioning due to physical and mental health problem (three items each), emotional well-being (positive and negative affect, six items each), cognitive functioning (six items), sleep (seven items), family functioning (four items), partner functioning (seven items), sexual functioning (five items) and general health perceptions (eight items). The items are formed like questions or statements (positive or negative worded).

The questions are scored on a four point scale with response alternatives like: “without difficulty” = 4; “with some difficulty” = 3; “with great difficulty” = 2; “not at all = 1”, and statements on a four point Likert format scale ranging from “I completely agree” to “I completely disagree”. Scale scores are calculated by summing items measuring the same construct, and are then transformed linearly into a 0 – 100-health index for each scale, 0 and 100 being assigned the poorest and the best possible health respectively (Brorson *et al.* 1993). A study of a Swedish randomly selected normal population sample (n=1 443) and a random sample (n= 1 396) from the Swedish Registry on Traffic Accidents (that had been seriously injured in traffic accidents), has given support for satisfactory psychometric properties and construct validity in the SWED–QUAL instrument (Brorson *et al.* 1993). Compared to SF 36, (Sullivan *et al.* 1995), another more well known HRQOL instrument developed from the MOS (Steward & Ware 1992), the SWED-QUAL is more extensive, with a wider approach to the concept of health, (69 items in 13 scales compared to SF 36’s 36 items in 8 scales). Unlike SF 36 the SWED-QUAL includes aspects like sleep, family - and partner functioning and sexual functioning on separate scales (Brorson *et al.* 1993, Sullivan *et al.* 1995)

The Maslach Burnout Inventory General Survey (MBI-GS), and the Oldenburg Burnout Inventory (OLBI), (paper IV).

The MBI (General Survey, GS) measures burnout in three dimensions on separate subscales: exhaustion, cynicism and personal efficacy. The MBI-GS contains 16 items with a response format ranging from zero (never) to six (every day), with five items concerning exhaustion (negatively worded), five concerning cynicism (negatively worded) and six items for personal efficacy (positively worded). The score on each subscale is the mean score of the items in the subscale with higher degree of burnout the higher the score (Maslach *et al.* 1996, Shutte *et al.* 2001). The OLBI contains two subscales (exhaustion and disengagement) with 8 items each, half positively and half negatively worded. The response format ranges from 1 (do not agree at all) to 4 (perfectly agree). The score on each subscale is the mean score of the items in the subscale with higher degree of burnout the lower the score (Demerouti *et al.* 2001, Joneborg *et al.* 2001). An unpublished study (Peterson, Perseius & Samuelsson) of the two instruments in 140 employees in the Swedish Social Insurance Agency (Försäkringskassan) had suggested that their internal consistency is satisfactory; with Cronbachs alpha values of 0.89 (exhaustion), 0.78 (cynicism) and 0.78 (personal efficacy) for the MBI-GS subscales and 0.78 (exhaustion), 0.77 (disengagement) for the OLBI subscales.

Table 1: Displaying; participants, sampling method, data collection method and method used in data analysis in the thesis four studies.

PAPER	PARTICIPANTS	SAMPLING	DATA COLLECTION	DATA ANALYSIS
I	10 patients, 4 DBT therapists	Clinical	Individual interviews, free format questionnaires, group interview	Qualitative content analysis
II	10 patients (same as in paper I)	Clinical	Individual interviews (same occasion as paper II), biographical material	Hermeneutic interpretation
III	75 patients	Clinical	Psychometric instrument	Descriptive and inferential statistics
IV	22 DBT therapists	Clinical	Psychometric instruments, free format questionnaire, group interviews	Descriptive and inferential statistics, qualitative content analysis

Research ethics

In study I, II and IV all the participants gave their informed consent to participate in the study. The information about the study was given in writing as well as orally. The information towards the participants especially underlined that their choice to participate or not was voluntary and that they could abort their participation at any time. The information towards the studied patients also underlined that their possible choice to reject or abort participation would not influence their future treatment. The participants were also informed that presentations of the material would be anonymous in a way that statements could not be traced to an individual participant. The studies were approved by the Research Ethics Committee in Lund (paper I and II) and the Research Ethics Committee in Uppsala (paper IV). There was no dependency between the participants and the researchers. The risk that the interviews with the patients (paper I and II) would evoke uneasiness or worsening symptoms was considered, therefore they were held in a separate room in the premises of the treatment program (at hospital), with staff nearby (no such complications occurred, however).

In study III the participants were clinical referrals from psychiatric clinics all over the Stockholm region to the psychotherapy trial in the SKIP project, and were informed that their therapists were in the process of learning a new treatment procedure. The patients consented to participation, after having the aims and procedures explained to them orally and in writing. The information especially underlined that the choice to participate or not was voluntary and that they could abort their participation at any time and that their choice to do so would not influence their future treatment. They were referred to treatment as soon as a therapist was available. There was no dependency between the participants and the researchers. The study was approved by the research ethics committee of Karolinska Institutet.

Results

Participant drop-out

One patient (out of 11 asked) refused participation in study I and II. None of the DBT therapists in study I (out of the four asked) refused or aborted participation. In study III there were no drop-outs among the 75 patients in the study. Four DBT therapists (out of 22) dropped out of the development project and the study in paper IV, between month 12 and 18. Two of them dropped out due to altered circumstances in their work situation beside DBT, one moved to another city and one dropped out as she experienced DBT as “too complicated”.

Suffering and quality-of-life in BPD patients

Study II revealed that the BPD patients suffer. They are living a life on the edge, in a world of emotional pain, a pain that is a chaos of anxiety, feelings of emptiness, hopelessness, meaninglessness, anger and powerlessness, feelings that they can neither understand nor control. It is also a world of self-hate and darkness. In moments when things are better and the pain merely is bubbling under the surface they are able hold up a mask of normality. However, the mask of normality cracks up under flashes of acute and unendurable emotional pain. Thus, they show two different (sometimes rapidly shifting) faces to the world; the tormented face of emotional pain and the mask of normality. The mask of normality is narrated as representing a will and a struggle to be normal – “if I act normal I may be regarded as normal and then I may become normal”. At the same time it is a gesture of compassion towards people around them, a will not to upset and harm others by showing their pain and distress. The many suicide attempts and acts of DSH reported in study I and II enhance the image of the suffering patient.

These acts of DSH and suicide attempts tend to occur during episodes of unendurable pain and could be seen as an attempt to alleviate the pain and make it endurable or just getting away from it all (paper II). Study II also revealed ambivalence in the BPD patients; fearing life, longing for death and yet longing and struggling for life. They are also split between their wish for love and fellowship and the self-hate that tells them that they are not worth to be loved. The patients’ struggle for health, dignity and a better life might be seen as “a balance act on a slack wire over a volcano”, the volcano being the rapidly shifting feelings and mood-swings - the world of emotional pain and self-hate that always is bubbling underneath the surface.

The suffering of BPD patients revealed in study II, may be an explanation of the poor quality-of-life in the BPD patients displayed in study III. The results showed that the patients had significantly lower HRQOL in all scales of the SWED-QUAL instrument, compared to normal population women of comparable age. As BPD is a severe psychiatric disorder, impairments in the mental and social dimensions of HRQOL could be expected. But somewhat surprising considering their relatively young age the BPD patients also described highly significant impairments in the physical dimension of HRQOL. The patients in study III also suffered from considerable psychiatric co-morbidity. As it has been shown that DSM axis I disorders like depression and anxiety disorders are predictors of poor HRQOL outcome, (Ettigi *et al.* 1997, Candilis *et al.* 1999, Saarijarvi *et al.* 2002, Simon *et al.* 2002), we tested for the impact of axis I co-morbidity in the BPD sample. The results showed no significant subgroup differences, which indicates that BPD in itself can be a predictor of substantial HRQOL impairment.

BPD patients' perceptions of encounter with psychiatric care

The suffering leading to suicide attempts, DSH (paper II) and the poor quality-of-life (paper III) put the patients in a position of voluntarily or involuntarily getting involved with psychiatric care. The interviews in study II revealed a double role of psychiatric care in the patient's suffering. On one hand, personnel can add to the suffering by not understanding and being disrespectful, on the other they can be helpful and relieve suffering by being respectful, understanding and validating. In the narratives of study II there is a clear relationship between the patients' experience of confirmation and validation and the experience of being helped. Furthermore, the patient's experience of being helped when they were supported to endure their suffering without constantly trying to escape appears as a foundation for change and development. Getting help to see themselves as responsible for their own lives as well as for their treatment was narrated as another helpful component in the struggle for health.

The patients in study I and II described experiences of not being understood and meeting disrespectful and condemning attitudes from psychiatric personnel. Not being understood implied that the personnel was trying to make contact, but not succeeding very well. Disrespectful attitudes meant that the patients felt that either no one seemed to care or listen at all, or the personnel at hand were hostile and condemning in their attitudes. The perceptions of meeting disrespectful attitudes also contained feelings of not being allowed to take part of the decisions concerning themselves.

Some of the patients stressed that the experience of discontinuity added to their suffering, when for different reasons psychiatric professionals interrupted the contact with them, leaving them with feelings of betrayal.

BPD patients' perceptions of DBT

The patients in study I meant that DBT had been life saving and given them a bearable life-situation. Before entering DBT their lives were overshadowed by the suffering of anxiety, depression, lack of impulse-control, suicide ideation, suicide attempts and DSH. The patients stressed that the therapy had provided them with skills, which enabled them to handle self-harm impulses, symptoms and problematic situations more constructively. They also described that the mindfulness training in the therapy had helped them accept themselves better, condemning neither themselves nor others the same way as before. In all they described the therapy method as very well worked-out and adapted to their specific problems.

The respect, understanding and validation they had met in the DBT therapists was narrated as the foundation for the therapy effect. Some of the patients meant that it was the first time, in a long history of psychiatric contacts that they felt respected, understood and validated. The therapy contract was seen as supportive as well as a challenge. It is described as especially supportive in the beginning of the therapy, when the patients were ambivalent about continuing. But as they had "signed up" for an entire year of therapy, they described that they struggled hard to honour that agreement. The contract was also seen as a challenge as it postulates progress in therapy as a criterion for continuation after the end of every 12-months contract period. Several of the patients describe the group therapy as the most difficult part of the treatment. At the same time it was described as beneficial, because of the skills training and the validation that came through meeting others in the same situation.

The telephone coaching was seen as a crucial crisis support. Nevertheless, several of the patients described that they had to practice, in order to get over their reluctance phoning the therapist.

The therapists' perceptions of DBT

The patients' and the therapist' perceptions of DBT (paper I) were mainly concordant. In their narratives the therapists underline the same effect-areas as the patients did. They described that the therapy enables radical change for the better in the patients' lives, in the sense that it decreases suicide ideation and DSH impulses as well as improving social functioning more generally.

The therapists also described a development in which the patients are becoming more independent and responsible. The patients' and the therapists' narratives also were concordant concerning the effective components of the therapy; the understanding, respect and validation of the patients was seen as important also by the therapists. The therapists' descriptions of the effective components of therapy linked directly back to the therapy method as described in the treatment manual (Linehan 1993). They stressed that the effective components lie within the therapy's theoretical underpinnings, high structure and in the therapeutic techniques; the personality of the therapist being of minor importance. Even so, they did not believe all personalities to be attracted by DBT, or fit to be DBT therapists. The therapists also underlined the benefits of the treatment manual (Linehan 1993), which stresses the importance of taking the symptoms and suffering of their patients seriously and at the same time making them responsible for their own lives, as well as for the therapy. The treatment manual was also described as providing techniques needed to enhance the patients' skills, so they can handle their symptoms and social life better.

The therapists described that they, while working with DBT, developed a more positive view of the BPD patients than before, with other perspectives of understanding. As the therapists were trained to treat the patients and their efforts with great respect, they changed from regarding patients as troublesome and sometimes manipulative, to regard them "as doing their best under tough circumstances". Sticking to the treatment manual and the team support of DBT therapists were two factors described as crucial for treatment success. The consulting team (in which the colleagues watch and discuss each other's videotaped therapy sessions) was seen as necessary for support and supervision. The therapists also stressed the importance of a straightforward communication, respectfulness and acceptance towards each other in the team. The therapy contract was described as another important supportive component, especially in making the patients more responsible. In all; working with DBT was described as tough and hard work but also a positive and personally developing experience. The tough part consisted of components described as; always being available to the patients, always being focused on the task and struggling to learn more. Mostly for better but also for worse, DBT was described as influencing not only work, but also how the therapists dealt with situations and relations in their private lives. Further, the therapists felt that the organisation of psychiatry was something that brought more problems than support, as it was seen as hierarchic, inflexible and not understanding the needs of the patients or the needs of the personnel.

Occupational stress and burnout in psychiatric professionals starting to use DBT

Study IV confirms previous findings that psychiatric health professionals experience treatment of self-harming patients as profoundly stressful (Loughrey *et al.* 1997, Melchior *et al.* 1997, Burnard *et al.* 2000). DBT was seen as stressful in terms of learning demands, but decreased the experience of stress in the actual treatment of the patients due to its high structure and specific techniques. The two inventories for professional burnout, the MBI-GS and the OLBI, showed no significant changes over the 18 month period, although there was a tendency for increased burnout levels, and increased number of DBT therapists passing the cut-off level for professional burnout at the 6 month assessment, which had returned to baseline levels at 18 months. In both burnout inventories, the exhaustion subscale showed most fluctuations over time, both in terms of mean scores and number of persons scoring above the cut-off for high degree of burnout. At 6 months the highest number of participants scoring outside the limits of high degree of burnout was reached with 7 persons (32%) in the MBI-GS and 5 persons (23 %) in the OLBI. This is concordant with the qualitative findings as many of the respondents stated that starting to work with DBT increased their occupational stress in the beginning of the project (related to learning demands). This was most pronounced by the therapists who had no previous cognitive behavioural psychotherapy training.

The team-work and supervision were felt to be supportive, as was one particular facet of DBT, namely mindfulness training which some therapists felt also improved their handling of other work stressors not related to DBT. This finding also corresponds to BPD patients' perceptions of the mindfulness component in DBT, which they reported as particularly helpful (paper I).

Discussion

Findings - implications for psychiatric care and further research

The main findings of the present thesis was that the BPD patients suffer to an extent that is often unendurable, leading to deliberate self-harm (DSH) and suicide attempts (paper II) as ways to relieve suffering or just try to get away from it all. The suffering may explain the poor quality-of-life the BPD patients showed in study III. The suffering, suicide attempts, DSH and the poor quality-of-life (paper I, II and III) put the patients in a position of voluntarily or involuntarily getting involved with psychiatric care. Study II revealed a double role of psychiatric care in relation to BPD patients. On one hand, psychiatric personnel can add to the suffering by not being understanding and by being disrespectful, on the other hand they can be helpful and relieve suffering by being respectful, understanding and validating. In the narratives of study I and II there is a clear relationship between the patients' experience of validation and the experience of being helped. DBT seems (both from the patients' and the DBT therapists' perspective) to be a therapy with a philosophy, content and structure that are able to relieve BPD patients' suffering and help them towards independence and a bearable life-situation (paper I). From the psychiatric professional' perspective, caring for self-harming patients with BPD is a profoundly stressful task (paper IV), but the DBT team-work, supervision and mindfulness training seem to reduce that stress. The mindfulness training also seemed to enhance stress coping skills more generally.

The life-world of BPD patients – general human predicaments taken to the extreme

The patients in study II might be seen as performing “a balance act on a slack wire over a volcano” in their struggle for health and dignity, the volcano being the rapidly shifting feelings and mood- swings - the world of emotional pain and self-hate that is always bubbling underneath the surface. Kreisman & Straus (1989) point out that to one degree or another we all struggle with the same type of suffering as BPD patients; that is with feelings of emptiness and boredom, wish for love and fear of rejection, experiencing moments of darkness and hopelessness, intense emotional pain and sometimes even self destructiveness (Kreisman & Straus 1989). The difference is not one of kind but of degree. Longing for life, fearing death, fearing life and sometimes longing for death could be seen as a general human predicament. A person suffering from BPD takes these feelings to the extreme. In other words – we all sometimes perform “balance acts” in our struggle for health, dignity and a bearable life-situation, but we do not perform them “on a slack wire over a volcano”. Understanding this difference may be essential for an optimal care of the BPD patient.

BPD patients: manipulative – or just trying to cope in their world of emotional pain?

The finding that BPD patients (paper II) show two different (sometimes rapidly shifting) faces to the world; the tormented face of emotional pain and the mask of normality, has implications for psychiatric care. If the act of normality is good, personnel may have a hard time to see beyond it, into the world of emotional pain. Thus, the outbursts of unendurable pain and DSH can be perceived as “acting out”, “attention seeking” and attempting to manipulate. If personnel feel manipulated it is more difficult for them to be respectful, understanding and validating, which was found essential for helping BPD patients endure their suffering (paper II). This might create a vicious circle of increased suffering and self-destructive behaviour in the patients, a phenomenon which Eriksson (1994) refers to as a “suffering of care”. Again, for the personnel; this might lead to increased stress, more of disrespectful and condemning attitudes and other non functional behaviour. On the other hand; if personnel can see beyond the mask of normality into the world of emotional pain it should be easier to validate and give BPD patients credit for doing a good job with themselves under tough circumstances, which in turn might produce a “good circle” leading to decreased suffering and less self-destructive behaviour in the patients. Maybe the DBT model has a major point here. In DBT there is a particular dislike for the word “manipulative” as commonly applied to BPD patients. The fact that the personnel may feel manipulated does not necessarily mean that this was the intention of the patient (Linehan 1993). The findings in study I and II empirically support the DBT model in this aspect.

BPD patients testing relations: manipulative – or just being deadly afraid of rejection?

A finding that also relates to the topic of manipulation is the profound self-hate among the BPD patients in study II, often leading to a strong fear of being rejected. They have to check over and over again if the other person really likes/loves them and can be trusted. This in turn can explain the rather common tendency of far reaching testing of relations among these patients. Maybe BPD patients’ self-hate makes them more vulnerable, in need of even more understanding and validation than other psychiatric patient groups, something that might be reflected in the large proportion of treatment drop-outs (Kelly *et al.* 1992).

Being there, sharing the suffering – the beginning of being helpful

The results of study I and II suggest that personnel within psychiatric care can be helpful in the BPD patients' balance act by; being there, sharing the suffering, being respectful and validating and helping them to see themselves as responsible for their own lives as well as their treatment. These findings are in agreement with the theories of Lindholm & Eriksson (1993) and their concept of "the drama of suffering" and the ways in which the drama can be brought to a happy ending (paper II).

Acceptance – the beginning of change

The results of study I and II also suggest that the beginning of positive change lies in getting help to accept things and feelings as they are, and to endure the suffering. This seems like a paradox, but the DBT model has made the balance act between acceptance and change to one of its core dialectics, (Linehan 1993), something that the results of this thesis empirically support.

BPD patients and physical health problems

Study III enhances the image of the suffering BPD patient while pointing towards their poor quality-of-life. It is not unusual that patients with psychiatric disorders show poorer health (even physical) than the general population. The WHO's "Country Collaborative Study on Psychological Problems in General Health-Care" showed that psychiatric illness generally was connected to substantial impairments in general health perceptions even when controlling for physical health status and socio-demographic variables (Kaplan 1999). Study III showed that the BPD patients had highly significant impairments in the physical dimension of quality-of-life, in spite of their relatively young age. On one hand this could be part of their psychiatric illness, on the other hand, actual poorer physical health could be the explanation. The latter is suggested in one of very few studies on the topic, which reports that physical health problems are significantly more common in non remitted BPD compared to remitted (Frankenburger & Zanarini 2004). Physical health among BPD patients seems to be a neglected issue, in need of more research and clinical attention.

Caring for BPD patients - a balance act for the psychiatric professionals

It seems like psychiatric professionals caring for self destructive BPD patients are performing a balance act of their own. Study IV confirms previous findings that it is profoundly stressful to care for self-harming and suicidal patients (Loughrey *et al.* 1997, Melchior *et al.* 1997, Burnard *et al.* 2000). It is particularly stressful to fear that one may not be able to help, and that one's patients may actually commit suicide.

The personnel need strategies for coping with that fear in order to be able to support the patients' own responsibility for the therapy and their lives. Samuelsson and co-workers (2000), have pointed towards the delicate balance act between trusting and respecting the integrity of the patients, on one hand, and seeing to their security on the other, in caring for suicidal patients (Samuelsson *et al.* 2000). Study I and IV suggest that the DBT model is successful in supporting the therapists to achieve well in that balance act - the therapy contract, team-work and supervision being helpful components.

Mindfulness training – helpful for both patients and psychiatric professionals

The mindfulness training in DBT is taught to therapists as well as patients (Linehan 1993). In study IV the therapists described the mindfulness training as making them able to accept feelings of frustration better, being more patient and relaxed and coping better with stress. These findings are similar to BPD patients' perceptions of the mindfulness component in DBT, which they reported as very helpful (paper I). DBT is (to my knowledge) the first psychotherapeutic intervention providing therapists as well as patients with mindfulness skills such as meditation-, relaxation- and acceptance techniques. The therapeutic potential of mindfulness meditation is currently being recognized and researched in a range of health care settings, and the findings of the present thesis agree well with the growing scientific support for its benefits (Grossman *et al.* 2004, Cohen-Katz *et al.* 2005, Åsberg *et al.* submitted).

Psychotherapy for BPD patients – need for more research

As mentioned above not only DBT (Linehan *et al.* 1991, 1999, 2002, Koons *et al.* 2001, Verheul *et al.* 2003), but also a form of psychodynamic therapy has shown efficacy in BPD patients in a randomised controlled trial (Bateman & Fonagy 1999, Bateman & Fonagy 2001). Both these psychotherapies are very complex and have several features in common: weekly meetings with an individual therapist, one or more weekly group sessions, and meetings of therapists for consultation/supervision (Linehan *et al.* 1991, Linehan 1993, Bateman & Fonagy 1999, Bateman & Fonagy 2001). Their complexity makes them difficult to evaluate, and the relative importance of various treatment components is not known. Some uncontrolled studies suggest that group therapy (on its own) may be useful for BPD patients (Greene & Cole 1991, Hafner & Holme 1996, Wilberg *et al.* 1998). Group treatment was one of the key components in both the DBT and the psychodynamic psychotherapy in the RCTs referred above (see further pp 22), (Linehan *et al.* 1991, 1999, 2002, Koons *et al.* 2001, Verheul *et al.* 2003, Bateman & Fonagy 1999, Bateman & Fonagy 2001). Although the overall treatment program showed efficacy, the efficacy of the group therapy component remains unknown.

Thus, several questions need to be answered, for example:

- ◆ What is the relative efficacy of DBT compared to psychodynamic psychotherapy?
Which types of patients respond to which type of psychotherapy?
- ◆ What components of DBT and psychodynamic psychotherapy are responsible for their effect? What common elements of these treatments are responsible for their effect?
- ◆ To what extent is a good outcome due to the unique components of these treatments *versus* the amount of treatment received?
- ◆ How effective are DBT and psychodynamic psychotherapy when used in the community, rather than in specialised treatment settings and how can these treatments be optimally implemented in community settings?

Hopefully our research group will come up with some answers to these questions in relation to the ongoing RCT in the SKIP project, as well as in current DBT implementation studies in Uppsala County Council, Stockholm County Council and Kalmar County Council.

Methods – limitations and strengths

General

It should be noted that the patient samples in the present thesis may be considered as a “worse off” subgroup among BPD patients, as they usually enter special treatment programs after a period of escalating symptoms, which standard psychiatric services have had difficulties handling.

The quantitative methods

The rather small number of participants and the lack of equivalent and/or concurrent control groups in the quantitative studies limit the generalization of the results.

In study III the SWED-QUAL (Brorson *et al.* 1993) was preferred in measuring HRQOL as it is rather brief with a wide approach to the concept of health. Unlike the more well known HRQOL instrument SF36 (Sullivan *et al.* 1995), it includes aspects of health such as sleep, family- and partner functioning and sexual functioning on separate scales. A disadvantage compared to the SF36 is that it is not so widely used, leading to lack of other psychiatric health problem groups for comparison.

The use of historical “normal women” controls in study III is somewhat problematic, since it is not known whether the HRQOL of women in the normal population has changed over the nearly ten years that passed between the two studies. It can not be excluded that the HRQOL has decreased as for instance the number of women on sick leave for psychiatric disorders has increased from 1989 to 1999 (RFV 2000).

In the quantitative part of study IV we used the Maslach Burnout Inventory – General Survey (MBI-GS), and the Oldenburg Burnout Inventory (OLBI), to assess professional burnout. They were both developed in the mid 1990s trying to overcome some of the weaknesses of the original MBI instrument, the MBI-HSS (Maslach & Jackson 1981), especially its narrow focus on human services employees which limited its use and comparability across occupational groups (Maslach *et al.* 1996, Schutte *et al.* 2000, Demerouti *et al.* 2001). Using more general or more specific assessment instruments in an area of research has both advantages and disadvantages, the advantages in this case being that the MBI-GS and the OLBI measure burnout more generally, which facilitates comparison across professional groups. The greatest disadvantage was, however, that both instruments have been developed quite recently and lack studies to compare results with, as well as lack of evidence supporting their reliability and validity. However, the MBI-GS translation we used has shown satisfactory reliability as well as criterion- and factorial validity in a Swedish sample (Schutte *et al.* 2000). There are to my knowledge no published studies of the OLBI on Swedish data. The purpose of the study was not to test the OLBI for reliability or validity. We used it as it looked promising - short, straight forward, and based on sound psychometric ideas. For the time being we accept its good internal consistency reliability (Peterson, Perseius & Samuelsson unpublished) together with its obvious face validity, but more research is needed on the psychometric properties of the Swedish translations of both instruments.

Furthermore, the lack of statistically significant findings in study IV may partly be due to a low sensitivity of the instruments and that they were not designed to be used on small numbers of subjects. Similarly, Hallberg (1994) found no significant differences in a small scale study comparing nurses (n=11) before and after clinical supervision using the MBI-HSS, while another burnout instrument, the so-called Tedium Measure (Pines *et al.* 1981) did show a significant effect in its mental exhaustion subscale.

The statistical analysis

The choice of using a combination of parametric and nonparametric statistical tests in study III could be debated. However, we followed the advice from Polit & Hungler (1995); that parametric tests usually are preferable as they are more powerful and easier to communicate, and that nonparametric tests are most useful when dealing with small groups and/or markedly non-normal distributions. Accordingly, we used parametric statistics in the analysis of group differences between the BPD patients and the normal population group, as we felt there were enough observations (N=75) and the distributions were not skewed to an extent that would call for a nonparametric test. In the analysis of axis I subgroup differences within the BPD sample, however, the combination of small size groups and partly skewed distributions made us choose a nonparametric test.

In the quantitative parts of study IV the choice to use a bivariate statistical test (t-test for dependent groups) could be a matter of discussion. It might be argued that the state of the art when having more than two repeated measures would be a multivariate test as for instance “general linear modelling, repeated measures”. However, with the quite small number of participants a more reasonable alternative to the t-test would have been a nonparametric (Friedman or Wilcoxon signed rank) test. Again, we followed the advice from Polit & Hungler (1995); that parametric tests usually are preferable as they are more powerful and easier to communicate. The reason for preferring the t-test to a multivariate test was its greater robustness, tolerating skewed distributions and small groups with maintained accuracy in the analysis (Aron & Aron 2003).

The combination of quantitative and qualitative methods

In study IV the use of two different methodological approaches (two psychometric instruments and statistical procedures in combination with free format questionnaires and interviews analysed with qualitative content analysis) had the advantage that the qualitative part provided data to build hypothesis around how to understand the results in the quantitative part. It also gave more specific information on the perceived benefits and problems when implementing DBT clinically. I believe that a combination of quantitative and qualitative approaches are one accessible way of designing naturalistic follow-up-, and implementation research without having access to equivalent control-groups, if wanting to (loosely, but way better than as a pure assumption) tie effects on dependent variables to an intervention (independent variable).

A combination of qualitative and quantitative methods is also a way to assess both the statistical significance and the narrative relevance of a phenomenon. In the qualitative part of study IV the participants' narrated increased stress in the beginning of the DBT project (due to learning demands). The burnout instruments were, however, not sensitive enough to pick that up as statistically significant in the t-test comparing the baseline and 6 months measuring points. In this case the increased stress was not statistically significant but a clearly relevant issue for the participants in their narratives.

The qualitative methods - data collection

The individual interviews with patients performed in relation to study I and II had multiple aims and used a combination of a more narrative (paper II) and a more focused (paper I) interview technique. The interviews were more narrative in the beginning of each interview (related to the aims of study II) and more focused later on (related to the aims of study I). To perform interviews with multiple aims and a combination of interview techniques may be more demanding for the interviewer, but has the ethical advantage of avoiding repeated research interviews with vulnerable patients. It might also be seen as a beneficial data gathering approach when dealing with a patient group known for high drop-out rates in research- as well as in clinical settings (Kelly *et al.* 1992).

In study I there are some potential factors that could have biased the patients to narrate perceptions of DBT as more positive than they actually were. The data collection was conducted in one single, rather small care setting. It would therefore have been rather easy for the DBT therapists or someone else who had investments in a "DBT-favourable" outcome of the study, to put pressure on the patients in that direction. However, the fact that the patients had been ensured that there was no dependency between the researchers and the clinic that the DBT-team is organised in, may have facilitated for them to speak freely also about negative perceptions. In the beginning of the interviews the patients were asked to narrate both positive and negative reactions towards the treatment, and they were especially asked about things in the therapy that had been hard and troublesome, but maybe even more questions should have been posed leading the respondents to reflect on negative aspects. Furthermore, the choice of place for the interviews (the premises of the DBT-team) might also have influenced the result in a more positive direction. This choice was, however, made for the comfort of the participants in order to ensure a feeling of security, most of them being easily stressed and some afraid and suspicious towards strangers.

A choice of more neutral interview premises would have reduced the risk of such bias, but at the same time perhaps resulted in higher drop-out rates.

In study I the respondents in the patient group had all been in therapy for at least 12 months. It is likely that patients who dropped out of the therapy (2 out of 16 patients that had signed the therapy-contract until the summer 2001) would have narrated more negative experiences, and patients in earlier stages of the therapy would have been more ambivalent in their judgements. However, the patients would also have been less experienced concerning DBT, if they had been recruited for the study at an earlier stage.

One other thing that should be considered in relation to the studies presented in study I and II (and interview based research more generally) is that the participants' state of mind at the time data is gathered is likely to influence the result. In our case the interviews took place when most of the participants were expressing that they felt quite well. Most of the biographical material in study II, on the contrary, had been produced at times when they did not feel well at all. In that sense the results all in all, may represent a "balanced picture" of the participants' life situation and suffering.

Comments on the hermeneutic interpretation process

As mentioned above; there are different traditions within interpretation theory and hermeneutics around the topic of "exactly what" or "whose perspective" one should try to better understand. With a more psychological tradition represented by for example Wilhelm Dilthey (1833-1911) and Gordon W Allport (1897-1967) suggesting that it is the person behind a text (the author or the utterer) that should be in focus (Åkerberg 1986, Helenius 1990), while Hans-Georg Gadamer (1900-2002) and Paul Ricoeur (1913-2005) suggest that the interpretation should aim to better understand the message carried by the text itself (Gadamer 1993, Ricoeur 1991). The research questions of the hermeneutic study in paper II were aiming "behind the text", however, through the interpretation process I was working with different perspectives. When I met the informants in the interviews, I also first met their "life-world" and "frame of reference" and the interpretation process started there – "behind the text". The first read-through of the entire text-material was a naive reading, where I deliberately let pre-understanding flow (experiences and prejudices about BPD patients, fragments of theory, and experiences from my own life-world). The following content- and structure oriented interpretation phase had its emphasis on "the text itself" asking the open-minded question of "what is this about" and "how is it narrated", trying to lift the text out of

its context and the pre-understanding. The last phase of interpretation connected back to the research questions and the patients behind the text again, in asking “what question is this answer to?” During this last phase I also definitely decided to use the theory of health and suffering by Katie Eriksson and co-workers. Through the process there had, however, been several other ideas; Arthur Schopenhauer’s philosophy about suffering and compassion (“världen som vilja och föreställning”), Paul Tillich and “the courage to be”, and the work of the Swedish poet Gunnar Ekelöf. The choice fell on Katie Eriksson whose model appeared most relevant for psychiatric care issues. In agreement with Eriksson and co-workers interpretation model, the structural analysis was carried out on two levels; first a search for how the informants’ narratives were structured in terms of dramaturgy (tragedy, comedy, romance or satire) secondly, the search for metaphors (Wiklund *et al.* 2002). Largely, the biographical material (produced before the study and before the patients had entered a special treatment program) was structured as tragedies (e.g. suicide notes), with plots building up towards catastrophe and death. The interview-texts, however, were partly structured as romance (darkest before dawn) with happy endings and partly (the narratives around psychiatric care before entering the special treatment) as satire, painting caricatures of treatment as well as psychiatric professionals.

The qualitative methods and their trustworthiness

Qualitative research is concerned with humans and their environment in all their complexities and is based on the premise that in order to try to understand humans, one needs to describe experiences as they are lived or narrated by the persons themselves (Polit & Hungler 1995). In qualitative research, phenomena are often assumed to be “constructions of mind”, and “reality” as well as “truth” to be multiple and inter-subjective. Accordingly, one tends to avoid using concepts like validity and reliability. The quality of qualitative research is rather discussed in terms of trustworthiness (Sandelowski 1993). Like validity and reliability in quantitative research the concept of trustworthiness is complex and comprises the whole process from sampling through data-gathering to data-analysis (Polit & Hungler 1995), thus, only some aspects of it will be discussed here. The components of trustworthiness (credibility, transferability, dependability and confirmability) largely link back to an assumption that inter-subjective “truth” is better than pure subjective “truth” (Polit & Hungler 1995). However, when confronted with the same interpretive task no two researchers will in detail produce the same results. But if somewhat skilled in text interpretation and acquainted with context,

they will hopefully produce results that are similar enough to be considered trustworthy (Sandelowski 1995).

Accordingly, many of the means to enhance trustworthiness in qualitative research focus on inter-subjectivity, and the use of different perspectives (data-sources, methods, investigators or theories) to cover the same topic (Polit & Hungler 1995, Sandelowski 1995). The qualitative parts of present thesis have consistently used different perspectives regarding data-sources and methods of data collection, e.g. combinations of patients' and therapists' perspectives, free-format questionnaires in combination with group interviews, and individual interviews in combination with biographical material. It has also consistently used an approach in the data analysis where two researchers independently have analysed data, compared results and asked themselves and each other: "has this interpretation support in the data?" Another approach to this is letting the participants themselves check the trustworthiness of the interpretation, also known as "member validation" (Sandelowski 1993). This latter approach has only been used to some extent (oral seminars on preliminary results), mainly for practical reasons but when concerning patients also for ethical reasons, as it was felt to be unethical to involve them in the analysis of suffering that was for many of them a thing of the past, at the time the analyses were made.

Qualitative data analysis - induction *versus* deduction

When interpreting texts I believe that different personalities get the text "to talk" and "reveal meaning" in mainly two different ways. One way being, "the long road of systematic induction"; persistently looking for meaning units and slowly building sub-themes, themes and comprehensive theme-areas and forming a data grounded, credible answer to the question of "what is this about?". The other way being, "the short-cut of intuition" (or "natural induction" as Karl Popper called the phenomena in "The logic of scientific discovery", 1992), when the answers to the question of "what is this about?" emerge in the mind of the researcher directly as comprehensive theme-areas or complex metaphors already in the phase of naive reading. However, the "short-cut of intuition" is not truly a short-cut as it merely (like in all research beginning with hypothesis and seemingly half-crazy ideas) is the starting point of "the long road of systematic deduction"; leaving the researcher with the persistent work of locating meaning units (observations) in the text in search for a credible answer to the question - "is this really supported by data?" Personally I am more of the later kind (even if the process in the method part of the qualitative studies is drawn up like it was mainly inductive), but both roads are, I believe, equally accessible and valid.

Future research

Karl Popper (1992) has stated that; - “Any research project starts in questions and ends in even more questions”. For me this is very true. The work with the thesis has directly connected and pointed towards some further research – ongoing or needed. However, while working with the thesis, also associated research questions have emerged. For me the future research could be divided into three categories: “ongoing”, “needed” and “wanted” (that is: by me personally).

Ongoing are:

- ◆ The effect evaluation and the health economic evaluation in the SKIP RCT.
- ◆ More detailed DBT implementation studies in Uppsala including a study of health economic consequences when implementing DBT clinically.
- ◆ A qualitative study of perceptions being significant other to BPD patients, partly aiming towards the development of an instrument measuring “burden”.
- ◆ Partly ongoing and partly planned are further DBT implementation research in Kalmar County Council and Stockholm County Council viewing both the patients’ and the DBT therapists’ perspectives, including also evaluations of support-programs for significant others.

Needed are:

- ◆ Further investigations of the physical health of BPD patients, as well as a further look into the psychometric worlds of the Swedish translations of MBI-GS and OLBI.

Wanted are:

- ◆ Designing a study with long-term follow-up (10-15 years) on the topic of early intervention for youth with self-harming behaviour.
- ◆ A further and deeper investigation of the connection between the concepts of “health”, “acceptance” and “dignity”, maybe in the context of the mindfulness tradition and the Buddhist philosophy around suffering.

Conclusions

The main findings of the present thesis were that the BPD patients suffer to an extent that is often unendurable, leading to deliberate self-harm and suicide attempts as ways to relieve suffering or just try to get away from it all. The BPD patients also reported very poor quality-of-life (even physically) compared to normal population controls.

Psychiatric personnel can add to the suffering of the BPD patient by not being understanding and being disrespectful, on the other hand they can be helpful and relieve suffering by being respectful, understanding and validating. There was a clear relationship between the patients' experience of validation and the experience of being helped. Further, BPD patients' profound self-hate may make them even more vulnerable, in need of even more understanding and validation than other psychiatric patient groups. The beginning of positive change for the BPD patients seem to lie in helping them to accept things and feelings as they are and to endure suffering, as well as in helping them to see themselves as responsible for their own lives and their treatment.

The BPD patients as well as the psychiatric professionals perceive DBT as a therapy whose philosophy, content and structure are well adapted to help relieve BPD patients suffering and help them towards a bearable life-situation. The thesis also empirically supports the DBT model in the notion that BPD patients are not being intentionally manipulative, but lack the skills that would allow them to deal with their suffering in a more effective way.

From the psychiatric professionals' perspective; caring for self-harming patients with BPD is a profoundly stressful task, but DBT seems to have means to reduce that stress as well as enhance stress coping skills. Overall the DBT model seems successful in "caring for the carers". Apart from the mindfulness training - the peer support in the treatment team and the frequent supervision were seen as especially helpful in the handling of occupational stress.

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