# Depression in primary care:

Detection, treatment, and patients' own perspectives

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To my parents, Britt and Christer Hansson

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## **ABSTRACT**

**Background** Depression is a very common disorder that causes great suffering for the patient. Recognizing depressed patients in primary care (PC) settings is a challenge and only about half are identified as depressed by their general practitioner (GP). Among patients receiving antidepressants (AD) about 70 % are improved, but only about 35 % reach remission. Hence, there is a need to identify depressed patients and to develop optimal treatment strategies in PC. Self-rating scales can be helpful in assisting the recognition. Patients' beliefs about the cause of depression and their attitudes towards treatment options have been found to influence their help-seeking behavior, coping strategies, treatment preferences and adherence. To increase depressed patients' knowledge about their disorder and to help them reach and stay in remission, the "Contactus program" was launched in Sweden, containing patient education and group counseling, as supplement to the usual care in PC.

**Aims** To explore patients' beliefs about causes and improvement factors for depression, and evaluate if the Contactus program could help to improve treatment outcome. Also, to investigate the psychometrics of two commonly used self-rating scales for depression, HADS and PHQ-9.

**Methods** Treatment outcome among patients participating in the Contactus program (N=205) was compared to a control group (N=114) treated as usual. The outcome was measured by HADS, GAF-self and by questionnaires. Both groups also answered an open-ended question about the cause of their depression at baseline and another question about improvement factors at follow-up after six weeks. To compare HADS and PHQ-9, patients (N=737) visiting their physician because of depression filled in both scales. The scales cut-offs were compared with Cohen's Kappa, internal consistency was calculated and factor analysis was performed.

**Results** Depressed patients participating in the Contactus program had a response rate of 55 % compared to 29 % in the control group (p=0.006). Also, remission was reached among 42 % in the Contactus group and 21 % among the controls (p=0.02). The patient's subjective evaluation of the outcome after six weeks showed that 72% of the Contactus patients considered themselves improved vs. 47% among controls (p=0.01). The most common described reason for depression was current stress, most often work related, and own personality traits. Very few mentioned biological factors. For improvement, the most commonly mentioned aspects were participation in the Contactus program and AD. When comparing HADS to PHQ-9 their agreement at recommended cut-offs, HADS-D≥11 and PHQ-9≥10, was low (k=0.35). The highest Kappa value (0.56) and also equal prevalence of depression were found at HADS-D≥8 and PHQ>12. Both scales had a high internal consistency ( $\alpha$ =0.9).

**Conclusions** The results of this thesis indicate that patient education and group counseling are valuable supplements to usual treatment of depression in PC. It is also clear that patients and professionals often have different opinions about the causes of depression, at least concerning biological factors. The patients were generally positive to professional help. The patients' own beliefs about their illness must be considered when developing new types of interventions and when trying to reach an understanding in the patient-doctor encounter. Finally, there are many self-rating scales for depression. Here two scales were compared and both showed good psychometric properties in terms of internal consistency and factor structure. However their optimal cut-offs were questioned. In conclusion, self-rating scales are useful in identifying depressed patients in PC and might also be apt for measuring treatment outcome. Offering the patient education about their disorder and possibility to share experiences seems to increase response and remission rates, substantially. More studies are needed to explore the effects of educational programs, group interventions, and how patients' own believes interact with the choice of treatment, adherence and outcome.

# POPULÄRVETENSKAPLIG SAMMANFATTNING

**Bakgrund** Depression är en sjukdom som drabbar en stor del av befolkningen och innebär ett stort lidande för individen. Av de patienter som söker till primärvården har ungefär 15 % av alla patienter depression. Då många patienter med depression söker sjukvård för kroppsliga symptom istället för psykiska problem är det en utmaning för distriktsläkaren att upptäcka depressionen under det ofta korta mottagningsbesöket. Tidigare studier har visat att bara ungefär hälften av fallen upptäcks. Det finns självskattningsskalor som innehåller frågor kring depression som patienten själv kan fylla i. Dessa kan underlätta i diagnostiken och förhindra att patienter med depression missas. Behandling av depression i primärvården består idag vanligtvis av stödsamtal och antidepressiva läkemedel. Denna behandling har oftast god effekt men många patienter har kvarstående symptom och det finns ett behov av att utveckla nya behandlingsstrategier. Contactusprogrammet är ett utbildningsprogram som innehåller både föreläsningar och handledda gruppsamtal för deprimerade som behandlas i primärvården.

**Syfte** Att undersöka Contactusprogrammets effekt på behandlingsresultatet vid depression samt att undersöka vad deprimerade patienter trodde var orsaken till att de drabbats av depression och vilka faktorer som de själva upplevde hade bidragit till en förbättring. Syftet var även att jämföra två självskattningsskalor för depression som används inom primärvården.

**Metod** Frågeformulär och självskattningsskalor fylldes i av 205 patienter som deltog i Contactusprogrammet och 114 patienter i en kontrollgrupp, som erhöll sedvanlig depressionsbehandling. Alla patienterna tillfrågades också om orsaken till deras depression och vid uppföljningen en fråga om förbättringsfaktorer. Självskattningsskalorna HADS och PHQ-9 fylldes i av 737 patienter och en jämförelse gjordes mellan skalorna.

**Resultat** Av patienter som deltog i Contactusprogrammet kände sig 72 % förbättrade subjektivt jämfört med 47 % i kontrollgruppen, och 55 % var förbättrade enligt HADS jämfört med 29 % av kontrollerna. Patienterna trodde oftast att orsaken till depressionen var pågående stress, vanligtvis relaterad till arbete och även egna personlighetsdrag. Väldigt få nämnde biologiska orsaker såsom ärftlighet. Bland dem som blivit förbättrade vid uppföljningen var antidepressiva mediciner och Contactusprogrammet de vanligaste svaren på varför de blivit bättre. De två självskattningsskalorna visade sig båda vara stabila mätinstrument för depression men de skilde sig åt i vilka patienter de skattade som deprimerade.

**Slutsatser** Avhandlingen visar på att patientutbildning och gruppsamtal är värdefulla komplement till behandlingen av depression i primärvården. Den visar också att patienter i låg utsträckning såg biologiska faktorer som orsak till deras depression utan trodde mer på att orsaken var pågående stressfaktorer. Patienterna var generellt positiva till den professionella hjälp de fått. Självskattningsskalor är bra hjälpmedel vid diagnostik av depression i primärvården. Det är dock alltid i det kliniska samtalet som den avgörande bedömningen görs.

## **ORIGINAL ARTICLES**

- I. Hansson M, Bodlund O, Chotai J. Patient education and group counselling to improve the treatment of depression in primary care: A randomized controlled trial. J Affect Disord 2008: 105 (1-3); 235-240.
- II. Hansson M, Chotai J, Nordström A, Bodlund O. Comparison of two self-rating scales to detect depression HADS and PHQ-9. Br J of Gen Pract 2009; 59: 650-654.
- III. Hansson M, Chotai J, Bodlund O. Patients' beliefs about the cause of their depression. J Affect Disord (in press), published online 2009. doi: 10.1016/j.jad.2009.10.032.
- IV. Hansson M, Chotai J, Bodlund O. What made me feel better?
  Patients' own explanations for the improvement of their depression. (Submitted)

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## **ABBREVIATIONS**

AD Antidepressants

BDI Beck Depression Inventory

CBT Cognitive Behavioral Therapy

DSM-IV Diagnostic and Statistical Manual of Mental

Disorders IV

GP General Practitioner

HADS Hospital Anxiety and Depression Scale

HCC Primary Health Care Centers

ICD-10 International Classification of Diseases - 10

MADRS Montgomery Åsberg Depression Rating Scale

MD Major Depression

NS Non Significant (p>0.05)

PC Primary Care

PHQ-9 Patient Health Questionnaire

POC Psychiatric Outpatient Clinic

SD Standard Deviation

SNRI Serotonin and Norepinephrine Re-uptake

Inhibitor

SSRI Selective Serotonin Re-uptake Inhibitor

## INTRODUCTION

#### **Depression**

#### Definition

Feelings such as sadness, sorrow and guilt occur normally in humans but depression is more than just sad feelings. Depression is a painful illness where a compilation of symptoms such as feelings of depressed mood, loss of interest or pleasure, feeling of guilt and low self-esteem, low energy and concentration takes over ones mind through long periods of time and also creates difficulties in everyday life.

Mental disorders are diagnosed according to criteria in terms of symptoms, their duration and effect on functioning. According to the American Psychiatric Association, major depression (MD) is defined through the following symptoms in the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) [1]:

- Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g. feel sad or empty) or observation made by others (e.g. appears tearful).
- Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others).
- 3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5 % of body weight in a month), or decrease or increase in appetite nearly every day.
- 4. Insomnia or hypersomnia nearly every day.
- 5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
- 6. Fatigue or loss of energy nearly every day.
- 7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
- 8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
- Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

For the diagnosis of MD, at least five of the above symptoms have to be present, causing significant distress or impairment of functioning in social or occupational activities. The core symptoms are depressed mood and anhedonia (i.e. the first two symptoms) and at least one of these must be present. The duration of these symptoms must be at least two weeks. Also they should not be better explained by mixed episode (bipolar disorder), somatic illness, effect of a substance intake or bereavement (i.e. loss of a loved one) [1].

MD is one of the diagnoses within a spectrum of depressive syndromes. A patient with minor depression has between 2 to 4 of the above symptoms, where at least one from the core symptoms of depression. Presence of at least two symptoms during at least two years means that the patient qualifies for the diagnosis of dysthymia. Melancholic depression is a serious condition and generally consists of a total loss of all pleasure, early awakening with anxiety, marked psychomotor retardation or agitation, feelings of guilt and major loss of appetite and weight.

In ICD-10 (International Classification of Diseases) there are three levels of severity of depression: mild, moderate and severe [2]. Mild and moderate depressions are the most frequently occurring depressions in primary care (PC) patients. Classification of depression according to ICD-10 [2] contains almost the same criteria as in DSM-IV but is not multiaxial. In DSM-IV on the other hand, five axes are taken into consideration: the symptom diagnosis (e.g. depression, anxiety), personality disorders and mental retardation, somatic illnesses, stressors and level of functioning.

The above mentioned diagnostic systems for depressive disorders are to a high extent based on consensus and they are categorical and not dimensional. They have received some criticism, mostly since depressive disorders are also believed to exist on a continuum rather than as diagnostic categories, and patients with minor/mild depression can also have significant suffering, disability and a high use of health care [3-6]. Among men, symptoms of depression have been shown to be different from those in women. Symptoms related to male depression include signs of aggression and alcohol abuse and it has been suggested that the above diagnostic criteria of depression consequently make some of the depressed men go unrecognized [7, 8].

#### Etiology

There is no consensus about any single etiological factor for depression. The etiology of depression is mostly described as being multifactorial [9]. Most researchers agree upon the existence of a genetic component that constitute vulnerability to depression, and that the onset is triggered by external stressors [10, 11]. This genetic basis is probably polygenetic, i.e. several genes are involved [12]. There is evidence that the first episode is often more associated with stressful life events whereas the recurrent depressive episodes have a lower association with external stress and are believed to be more dependent on biological factors such as genetics [13].

The relationship between life events and genetics is complex. There is an individual vulnerability, probably to a high extent genetic, which is why we react differently to life stressors. Also, a tendency to get exposed to different life events and stressors can be, at least partly, explained by biological factors [9]. Personality traits have shown to be important in the development of depression, where neuroticism seems to be the most important trait [14-17]. These personality traits are most likely modulated by both genetic and environmental components.

Since psychopharmacological treatment most often involves the serotonin and norephinephrine systems, these neurotransmitters are thought to have an important role in the pathophysiology of depression. Caspi et al (2003) showed in their longitudinal study that the risk of depression as a reaction to stressful life events differed between participants with different genetic make-up of the serotonin transporter gene [18]. However, the interaction between the gene for the serotonin transporter and stressful life events has recently been investigated in a meta-analysis, and although the amount of stressful life events was found to increase the risk for depression, no association with the serotonin transporter genotype was found [19]. Hyperactivity and regulation of the hypothalamus-pituitary-adrenal axis (HPA-axis) has also been a target of interest as a mediator between stressful life events and depression [20]. However, depression itself can also lead to stress and thereby influence the HPA-axis. The immune system has also been considered to be involved to some degree in depression. The relation between the immune mediators (cytokines) and depression is far from resolved and has been discussed in a review by Capuron and Dantzer [21].

In this thesis the actual causes of depression will not be explored but rather the patients' beliefs about the etiology of their depression.

#### **Diagnostics**

When diagnosing depression in clinical practice there are so far no specific blood samples, x-rays, physiological examinations or gene tests available. The anamnesis is crucial since it is by asking and listening to the patient and his or her history that the physician determines whether the diagnostic criteria for depression are fulfilled.

As a help in the diagnostics there are structured interviews that can be performed by trained professionals. These interviews are often used in research but since they are highly time consuming and require specific training, they are difficult to implement in PC. A commonly used diagnostic interview is SCID-I (Structured Clinical Interview for DSM) [22]. Diagnostic interviews for use in PC are for example PRIME-MD (Primary Care Evaluation of Mental Disorder) in which psychiatric illnesses according to DSM-IV are diagnosed [23]. The MINI-International Neuropsychiatric Interview (MINI) [24] is another diagnostic interview developed for use outside of psychiatric settings and in research. It is shorter than SCID-I and takes both the ICD-10 and the DSM-IV criteria for depression into consideration. Diagnostic interviews do not primarily evaluate the severity of depression but only render a diagnosis.

Rating scales are more useful than diagnostic interviews to measure treatment outcome at follow-up. These can be used either in an interview based form or as self-rating scales. Dimensional assessments such as rating scales and self-rating scales provide the advantage of the possibility of rating the severity. A commonly used rating scale for depression is the Montgomery Åsberg Depression Rating Scale (MADRS) [25]. It exists both as an interview and as a self-rating version (MADRS-S). Hamilton Depression Rating Scale (HAM-D) is also a very common scale, used in most research [26]. Self-rating scales should not be used as a single diagnostic tool but rather as an instrument to aid in the recognition of depressed patients in PC [27]. The result from the self-rating scales should be followed-up by a clinical interview to confirm the diagnosis, a so called two step approach.

## **Epidemiology**

Mental disorders are common in the population. In a review performed by Wittchen and Jacobi in 2005 it was estimated that 27 % of the adult population in Europe suffered, or had suffered from a mental disorder during the preceding 12 month period [28]. The most common mental disorders are anxiety, depression, impulse control disorder and substance

abuse, and almost half of the patients have more than one disorder simultaneously [29].

The prevalence of MD in the United States has been explored in the large population studies called the "National Comorbidity Survey" and its repeated version. The life time prevalence was found to be 17 %, the 12 month prevalence 7 % and one month prevalence 5 % [29-31]. Another large study from Norway confirms these results with a life time prevalence of 18 % and a 12 month prevalence of 7 % [32]. In a review by Paykel et al from 2005 the 12 month prevalence was calculated to be 5 % in the general population [33]. In the study by Ayuso-Maetos a higher point prevalence of 8.6 % was found in the general population in several European countries [34].

In a recent large population based psychiatric study from an area in the south of Sweden (Lundby study) it was found that the annual incidence of depression had decreased among women from 5.5 per 1000 person-years to 4.1 per 1000 person-years, when comparing data for the period 1947 to 1972 with that of the period 1972 to 1997 [35]. It is difficult to say if the incidence of depression in general is changing. Many studies suggest that it is increasing, but results from the Lundby study have shown the opposite trend at least among women. Our awareness and knowledge about depression has increased with time, and one can assume that significantly more patients are identified and treated for depression today. According to statistics from the National Board of Health and Welfare in Sweden about 6 % of the Swedish population is on AD and it is one of the most commonly used drugs in Sweden.

A higher prevalence of depression among women compared to men has been shown in many studies [30, 31]. Lifetime prevalence of at least one depressive episode has been estimated to about 25% for women and 15% for men [31]. The reason for this gender difference has no single established explanation [36]. In contrast to most other studies, a large Norwegian study employing the self-rating scale Hospital Anxiety and Depression scale to screen over 62 000 individuals found no difference in prevalence when comparing men with women [37].

In PC the prevalence of depression is much higher. About 15 % of the patients in PC suffer from depression [28, 38-44]. Swedish studies have shown that at least one fourth of the patients visiting PC suffer from depression or anxiety [38, 45, 46].

**Table 1.** Prevalence of major depression (MD) in the general population, according to epidemiological studies [29-31, 34, 47-51].

Author, year	Prevalence	Area	N	%
	interval			MD
Kessler, 1994	12 months	<b>United States</b>	8098	10.3
Kessler, 1994	Life time	United States	8098	17.1
Blazer, 1994	1 month	<b>United States</b>	8098	4.9
Lépine, 1997	6 months	Europe	78 463	6.9
Lindeman, 2000	12 months	Finland	5993	9.3
Andrews, 2001	1 month	Australia	10641	3.8
Kringlen, 2001	12 months	Norway, Oslo	2066	7.3
Kringlen, 2001	Life time	Norway, Oslo	2066	17.8
Ayuso-Maetos 2001	Point	Europe	8764	8,6
Kessler, 2003	12 months	<b>United States</b>	9090	6.6
Kessler 2005	12 months	<b>United States</b>	9282	6.7
Kessler 2005	Life time	United States	9282	23.2

The risk of recurrence of depression after recovery from the first depressive episode is high. The risk of having one more episode increases with each depressive episode, whereas a longer period of recovery decreases the risk of recurrence [52]. In a study investigating the recurrence after one episode of MD the cumulative recurrence proportion after 15 years was as high as 85 % [53]. Studies exploring the recurrence of depression among PC patients are few, but these studies show a better prognosis than in psychiatric settings, with a recurrence rate of about 30 to 76 % depending on the length of follow-up ranging from 5 years to 50 years [54-56].

#### Global burden and costs

Depression is a major public health problem which causes substantial suffering and disability for the patient [57]. The disability can be measured according to DALY (disability adjusted life-years) where both years lost due to premature death (YLL) and years lived with disability (YLD) are taken into consideration. It has been shown that depression is the fourth leading cause of disability (DALY) worldwide and causes most years lived with disability (YLD) of all diseases [58, 59]. It is also predicted to be the second leading cause of disability in the year of 2020 [60]. The disability also increases with the severity of the depression [61].

Patients with depression have an increased risk of mortality both due to natural and un-natural deaths [62-64]. The mortality risk in cardiovascular diseases is up to four times higher among depressed patients as compared to

non-depressed [65-67]. Also, there is a higher risk of death caused by suicide among depressed patients, and this risk has been shown to decrease with the increased use of antidepressants (AD) [68, 69]. The use of AD has also been shown to increase the quality of life [70].

The yearly financial costs due to depression in Sweden were estimated to 10.4 billion Swedish crowns in 1997 [71]. Of these, 8.3 billion were estimated to be due to indirect costs such as sick leave, early retirement and suicide. Since 1997, the sick leave rate has increased dramatically. Sobocki et al compared the costs of depression in Sweden in 1997 with that in 2005, and found that the costs had risen from 1.7 billion Euros to 3.5 billion Euros, where indirect costs (mostly sick leave and early retirement) were estimated to about 3 billions [72]. If patients with depression (and anxiety) were identified and treated to a larger extent, it is likely that the number of patients who are on sick leave also would decrease, thereby lowering the economical burden for the society.

#### Co-morbidity

Co-morbidity means that two or more disorders or diseases exist in the same patient at the same time. As mentioned above, the co-morbidity of depression and other psychiatric illnesses is high [29, 44, 73].

Among depressed patients the co-morbidity with other mental disorders exists in about two thirds of these patients and most often consists of anxiety disorders, alcohol abuse and impulse control disorders [48]. In the subject of depression, it is hard to avoid mentioning anxiety since the co-morbidity is vast. Among patients with MD, it has been estimated that 58 % also suffers from an anxiety disorder [48]. Also among patients with anxiety disorders, depressive symptoms frequently occur, perhaps as a consequence of the anxiety disorder itself. Anxiety disorders include the diagnoses generalized anxiety, social phobia, specific phobia, agoraphobia, panic disorder, obsessive-compulsive syndrome and post-traumatic stress disorder. In the "National Comorbidity Survey" it was found that during a lifetime about one fourth of the general population will suffer from an anxiety disorder [31].

Also, there is a high correlation between the occurrence of depression and the occurrence of physical illness [33, 74-78]. Pain in various forms is found in at least 50 % of depressed patients and is the most frequent reason for visiting the GP [46, 74, 77]. Depressed patients visit physicians more often than non-depressed patients, and they are high consumers of medical care in general [79]. Identifying and treating these patients have been shown to be effective in lowering the health care costs [80].

## Recognizing depression in Primary care

The PC is most often the patients' first contact with health care. The assignments of the primary health care centers (HCC) in Sweden are to act as the first platform of prevention, diagnostics, care, treatment, and rehabilitation for all illnesses in all age groups [81]. This also includes depression, and patients with mild to moderate depression can most often be completely managed in PC [82].

Several studies, among which one is a recent review, have shown that only about half of the depressed patients are recognized as depressed by their GP [33, 38, 40-43, 83, 84]. When the patients are not recognized as depressed, they cannot be offered an adequate treatment.

In PC, patients seek help for a wide range of problems and for the GP it is necessary to both help the patient with the problems they seek for and also to keep the time-limit. It can be a huge challenge to recognize depression, since most patients with depression instead seek care for somatic problems, such as pain, infections and fatigue [44-46]. If the patient suffers from physical symptoms at the same time, there is a higher risk for the physician to fail in recognizing the depression [40]. Also if the patient is not familiar with the GP, he or she will be more likely to present somatic symptoms instead of depressive or anxiety symptoms as the main reason for seeking help [78].

## **Self-rating scales**

In order to recognize depression, self-rating scales can be useful among groups of patients with increased risk for depression [27, 39, 85]. These scales are valuable for detecting patients, evaluating treatment outcome and the course of the depression. Self-rating scales are also independent of which physician the patient meet, hence the score is more patient bound compared to a clinical assessment. If the self-rating scale indicates that the patient suffers from depression the diagnosis must then be confirmed by a physician [39].

There are many self-rating scales and the choice of which one to use is often based on local traditions. In many European countries, including Sweden, the Hospital Anxiety and Depression Scale (HADS) is frequently used. This scale has the advantage of measuring symptoms of both depression and anxiety. HADS was initially created for use among physically ill patients [86]. In PC settings this might be considered an advantage since many patients also have somatic symptoms. The self-rating scale PHO-9 (Patient

Health Questionnaire) is derived from the criteria according to DSM-IV for depression [41]. Previous studies have shown that both HADS and PHQ-9 are valuable as case-finding instruments with a rating of severity that enables the care provider to monitor treatment outcome [87-90]. These two self-rating scales are recommended for use in PC, at least in some parts of Sweden. Further descriptions of HADS and PHQ-9 can be found in the methods section. Other commonly used self-rating scales are Montgomery-Åsberg Depression Rating Scale Self (MADRS-S) and Beck Depression Inventory (BDI). There are many self-rating scales available to choose from. In a review of several self-rating scales in PC by Williams et al [27] it is referred to as an "instrument smorgasbord". They found no significant differences in sensitivity and specificity between 16 case-finding instruments, including HADS and PHQ-9.

Since there are several self-rating scales and no consensus on which one to use and in which situations, there is a need for further evaluation of existing scales. In this thesis, the only self-rating scales investigated were HADS and PHQ-9, and there was no attempt to cover the whole spectrum of self-rating scales.

## **Treating depression in Primary care**

When evaluating the outcome of a treatment for depression there are a few concepts that are important to clarify. A response to treatment means that the patient starts to improve, which is then followed by a partial remission, meaning that the patient does not fulfill the criteria for MD but still has considerable symptoms [91]. Remission means that the patient is completely recovered, symptomatically and in terms of social functioning and this is the optimal outcome of depression treatment [92]. If the remission stays constant for a longer period it can be considered a recovery. A relapse is when the patient falls back into depression during treatment, while a recurrence is when a new episode of depression occurs after recovery [91].

Even though recognized as depressed by their GP, earlier studies have shown that only about half of these patients received adequate pharmacological treatment [38, 83, 93]. Lepine et al showed in a large European study in 1997 that only 25 % of the patients with MD in PC received AD [50]. When AD have been used, they are often found to be used in too low dosages or for a too short duration [94]. The recommendation of treatment is at least 6-9 months after remission, but up to a year has also been suggested [95]. The treatment compliance is often poor, and several studies have shown that it is as low as about 50% [96-99]. Also, follow-up and evaluation of the treatment

can fail because of a variety of reasons such as lack of time in the HCC and patient dropout because of change of HCC, to name a few.

The most commonly used AD are the selective serotonin re-uptake inhibitors (SSRI), which as its name reveals, acts on the pre-synaptic receptors to reduce the re-uptake of serotonin, resulting in an increased amount of the neurotransmitter in the synaptic cleft. Among patients treated with adequate dosages and during a long enough period, improvement (response) is achieved in approximately 70%, but only about 35% will reach full remission [96, 100-104]. The rest might be improved but with residual symptoms (mental or physical) which in turn is a risk for relapse [33, 105].

An extensive work by the Swedish Council on Technology Assessment (SBU) from year 2004 provides an update of the knowledge concerning the treatment of depression [82]. In this report, a review of the existing literature showed that mild to moderate depression can be effectively treated with different types of psychotherapy such as cognitive behavioral therapy (CBT) and interpersonal therapy (ITP). However, treatment with psychodynamic therapy has not proved to be effective, possibly due to lack of studies so far evaluating this therapy [82]. The effect of psychotherapy takes a longer time than for AD but it is likely that the effect is more persistent and that it prevents recurrence. There are some studies indicating that a combination of CBT and AD gives a better treatment outcome than each therapy alone [106, 107], which is also in line with widespread clinical experience. A major problem in Sweden is that there are as of today relatively few professionals trained in these types of psychotherapy. Patients with severe depression and dysthymia should preferably be treated with either AD or electro convulsive therapy (ECT), which has been shown to be more effective than psychotherapy [82].

In some cases the treatment of depression requires help from a psychiatric specialist. Cases that have been suggested to require specialized psychiatric care are those with severe depression, with frequent suicidal ideation, patients with psychotic symptoms, symptoms indicating mania or hypomania, or patients in whom the symptom picture does not make sense so that the diagnosis requires more thorough investigations [95]. Referral to a psychiatric clinic is also indicated if the patient has tried at least two different AD without satisfactory effect, or when there are difficult side effects even on a small dosage. Using a psychiatric consultant liaison in PC settings has also shown positive effects, and can assist the GPs when they need help in diagnosing and choosing adequate treatment [83].

The most feasible treatment strategy in PC is often a combination of AD (SSRI or SNRI) and supportive follow-ups, with a cognitive approach when possible. Even so, about 30-50 % of those treated by AD and/or psychotherapy are non-responders or only partial responders [82]. Hence, there is still a need to develop new treatment strategies for depressed patients.

A need for collaborative care for depression in PC has been increasingly emphasized [108-110]. Collaborative care interventions have included educational and organizational interventions [111], and many of them use multidisciplinary health care professionals, which has shown to lead to high clinical benefits at a low increase in health care costs [112]. In a review, Gilbody et al [111] found that more complex interventions with at least two strategies had the best results. The enhanced involvement of trained nurses for brief education, medication counseling and telephone support has also shown to be effective [109, 111, 113-115].

To improve treatment outcome and adherence it is important that the patient is involved in the decision process regarding his or her treatment [116]. The depressed patient should get proper information about the rationale for treatment, effects and side-effects, and repeated follow-ups should be arranged. Previous studies on chronic somatic illnesses such as asthma, arthritis and diabetes show that patient education can improve their care [117-119]. Education in groups about treatment adherence, illness awareness and early detection, has also proved to have a positive long-term effect on patients with bipolar disorder [120]. However, very few such studies have been conducted regarding patient education for depressed patients.

Some studies have shown that interventions including patient education for depressed patients gave better compliance to AD treatment [121-123]. In a randomized controlled trial from North America it was found that patient education in combination with education of GPs, and treatment support via the telephone had effect on treatment outcome up to 12 months among depressed patients [113]. In a review by Cuijpers et al [124] an educational method called CWD (Coping with Depression) was evaluated. This method was developed about 40 years ago and is used in many countries. It is a form of CBT that can be used by professionals other than psychotherapists and it focuses on an educational approach which can be provided individually, in groups or via the internet. Conclusions from this review were that CWD was effective in treating and preventing depression but somewhat less effective than other forms of psychotherapy [124].

It is common with support groups for physical disorders, but there are few well performed studies exploring their effect among patients with mental illness [125]. In the review by Pistrang et al [125] they found only 12 studies regarding mental health problems that were suitable to be included, and among these, 7 studies showed positive effect of participation in a support group. From the ODIN study (European Outcome of Depression International Network), epidemiological data was collected and used for an intervention study comparing individual problem solving treatment to group therapy for treatment of depression. Both interventions showed to be effective to reduce depressive symptoms and improve subjective functioning [126, 127]. When comparing group CBT to support groups, these interventions have shown to be comparable in effect [128].

In Sweden, a program with patient education and group counseling for depressed patients, called the Contactus program, was started in the year 2000. A pilot study was performed in 2003, without a control group, showing that the participants were satisfied and that they improved with regards to depressive symptoms. These preliminary results inspired to perform a controlled study evaluating the effect of patient education and group counseling in addition to treatment as usual. This was the starting point for the present thesis.

## Beliefs about cause and treatment of depression

As previously described, current research explain the cause of depression as a combination of biological factors and external stressors. It has been shown that compared to patients, professionals give a higher endorsement to biological factors and also that they have a higher faith in AD [129, 130].

Previous studies on public's perception of the etiology of depression show that they mostly believe in stress and social factors, and not so much in biological explanations, even though the etiology of depression is accepted to be multi-causal [131, 132]. Depressed patients' beliefs have in several studies also shown to be more oriented towards psychological or environmental causes than biological causes [133-137]. A previous study has shown that women believed more in interpersonal causes of depression, whereas men more often stated work related factors or physical illness as causes for depression [138]. There is also evidence that depressed patients generally prefer psychotherapy rather than receiving AD [133, 139-144]. However, there is very limited research investigating depressed the patients' perception of what led to their recovery [129, 145].

Several previous studies have pointed out that the patients' beliefs about the cause of their depression and about the treatment can influence their help-seeking behavior, coping strategies, outcome of different treatment strategies, treatment compliance and acceptance of being depressed [99, 133, 137, 146-151].

Understanding patients' beliefs about the cause of depression and their perception of what constitute an effective treatment is important in order to provide successful treatment strategies. Beliefs about causes and treatment as well as the patient's coping behavior can be modified by for instance patient education [146]. It is not clear what beliefs that are most favorable for the outcome. However, believing in biological explanations has shown to increase help seeking behavior, and be associated with higher acceptance of the depression diagnosis and more confidence in pharmacological treatment [151, 152].

Most previous studies on patients' beliefs about the causes and treatment of depression have been performed with questionnaires and rating scales [130, 133-137, 139, 140, 146, 149, 150, 152-154]. In this thesis the focus was on the patients' own descriptions of the causes and improvement factors by the use of open-ended questions without pre-formulated alternatives.

## **AIMS**

#### General aim:

To investigate depressed patients' perspective on causes and treatment of the depression, to evaluate a new treatment supplement and to compare two diagnostic tools that involves the patient's participation.

## **Specific aims:**

- To evaluate the Contactus program, an intervention strategy comprising patient education and group counseling, in addition to treatment as usual for depression in primary care. The specific aim was to investigate if this program could improve treatment outcome for depressed patients, compared to a control group. (Paper I).
- Compare the self-rating scales HADS and PHQ-9 in their psychometric properties and agreement at different cut-offs. (Paper II).
- To identify and describe patients' beliefs about the cause/causes of their depression. (Papers III).
- Investigate which factors, in life and in treatment, that patients considered had contributed to their improvement from depression. (Paper IV).

## **METHODS**

## Papers I, III and IV

#### The Contactus program

The Contactus program was a six week intervention for depressed patients in PC. It was based on collaboration between psychiatric departments and PC, and consisted of patient education and group counseling. During the six weeks program, four lectures in total were held by clinicians with different professions, e.g. psychiatrists, GPs, psychotherapists and nurses. The topics were generally about diagnosing and treating depression, both pharmacologically and by non-pharmacological alternatives such as psychological help and different forms of psychotherapy, and also medical insurance and economical aspects with some local variations.

After each lecture the patients gathered in groups of 8 to 10 for discussions which were led by a counselor and/or a nurse from PC and psychiatric clinics. The group sessions were focused on support and sharing experiences. The patients participating in the Contactus program were, besides this intervention, treated according to usual routines in general practice. The first and last group meetings were introduction and closing sessions respectively (without lectures), and during these the patients also filled in a questionnaire and self-rating scales. Six months after the intervention the patients met again for a last lecture and a group session. This time the focus was on how to keep in remission and how to recognize early signs of relapse/recurrence.

The purpose of the Contactus program was to improve the care of depressed patients in PC settings. It also aimed to increase the patients' knowledge about depression and anxiety to facilitate early identification and improve compliance. The program was initiated by the pharmaceutical company Wyeth Corp. in year 2000, and about 2800 patients, in about 100 different HCC, have participated. The program ended in 2008 and the company has given out a handbook to interested HCC in order for them to continue with the program independently.

In 2003 a pilot study was undertaken by Bodlund, with 250 Contactus participants but without a control group. In this pilot study it was found that the patients were very satisfied with the program and their improvement was reflected with a decrease in depressive symptoms according to HADS-D among 85 % of the depressed patients.

#### Procedure and participants

The Contactus study started in the spring of 2005 and included all HCC in Sweden that were going to start with new groups in the Contactus program. It was estimated that about 250 patients would participate in the Contactus program during this period. In order to evaluate the Contactus program these patients had to be compared to a control group. A power calculation was performed in order to estimate how many patients that were needed in the control group to ensure identification of differences on a significance level of p<0.05.

Since the Contactus participants were clustered to certain HCC, the control patients were selected in the same manner. To obtain as similar groups as possible at baseline, the HCC collecting patients to the control group consisted of those HCC that previously had patients in the Contactus program. During the spring 2005 these HCC were not involved in the Contactus program due to practical reasons. Also two HCC, not previously involved in the Contactus program were included. These were two HCC in the city of Umeå that cooperated with a psychiatric consultant. All HCC included for recruiting control patients were considered to have a high interest in patients with psychiatric illnesses.

The inclusion of patients to the Contactus group and the control group started at the same time. The HCC collecting patients for Contactus and Controls had both an equal proportion of rural and urban settings. In total 46 HCC were involved, with about two thirds collecting patients to the Contactus group and one third to the control group. The participating patients were all consecutively recruited by their GP. Inclusion criteria were: age between 18-69 years old, clinically diagnosed as depressed by the GP, and Swedish speaking. Neither the severity of the depression nor any other treatment (AD or psychotherapy) were any exclusion criteria. Both groups continued with their initiated treatment for depression, but the Contactus group also participated in lectures and group discussions as described above.

At baseline as well as after six weeks, all the patients filled in the self-rating scales HADS and GAF-self (Global Assessment of Functioning). They also answered a questionnaire with questions about their age, sex, occupation, sick leave, medication, psychotherapy and if they had somatic symptoms. At baseline the open-ended question "What do you consider is the cause of your depression?" was posed. At follow-up the patients responded to how their condition had changed, with the alternatives much better, better, unchanged, worse and much worse. In conjunction to this question there was an open-ended question, namely "what do you think is the reason that your condition

has changed". There was also a questionnaire corresponding to the criteria for burnout syndrome and also questions about life event/stressors corresponding to axis IV in DSM-IV, which are not included in this thesis.

In total, 248 patients were included in the Contactus group and 124 patients in the control group. Among these patients there were some (43 Contactus and 10 Controls) who did not fill in the HADS completely and were considered as dropouts. Hence the dropout rate was 17.3 % in the Contactus group and 8.1 % among Controls. In all, 205 patients in the Contactus group and 114 patients in the control group could be further analyzed in paper I. The patients who dropped out did not differ significantly from the remaining patients as regards gender, age, ongoing treatment, level of symptoms and level of functioning.

In the total sample there were 73 % women and the mean age was 44 years. AD were used by 82 % of the population while only 9 % were in psychotherapy. There were no significant differences between the Contactus group and controls as regards gender, age and treatment. The majority of the patients had used AD for a long time, mean 50 weeks and only 9 % had started their AD treatment the last four weeks. Baseline characteristics, HADS-scores, GAF-scores and treatment of the samples are given by Table 2.

In paper III and paper IV the patients came from the same population as displayed in paper I. In paper III which explored the patients' beliefs about the cause of their depression there were 16 dropouts who did not answer the question. Hence paper III included answers from 303 patients. In paper IV, we only included the 201 patients who considered themselves feeling better or much better in order to explore factors for improvement of depression. Among these, 17 patients did not answer the question about why their condition had improved and were considered dropouts. In both paper III and IV the dropouts were compared to the non-dropouts and showed no significant differences in gender, age or depression and anxiety scores in HADS.

**Table 2**. Patients' characteristics, scores according to HADS and GAF-self and treatment.

	Contactus (n=205)			Controls		
	All	Women	Men	All	Women	Men
		(n=156)	(n=49)		(n=76)	(n=38)
Women	76.1 %			66.7 %		
Mean age	43	42	47	45	46	44
Sick leave	52.7 %	52.6 %	53.1 %	38.6 %	48.0 %	21.1 %
HADS-D mean	9.2	9.1	9.6	9.2	8.8	10.0
HADS-D≥8	61.5 %	61.5 %	61.2 %	67.5 %	68.4 %	65.8 %
HADS-D≥11	39.5 %	36.5 %	49.0 %	35.1 %	28.9 %	47.4 %
HADS-A mean	11.7	11.8	11.5	11.7	11.6	11.9
HADS-A≥8	83.4 %	84.6 %	79.6 %	83.3 %	82.9 %	84.2 %
HADS-A≥11	62.9 %	62.2 %	65.3 %	65.8 %	63.2 %	71.1 %
GAF-self mean	62.0	61.8	62.5	61.8	63.3	58.9
Psychotherapy	9.3 %	9.6 %	8.2 %	7.9 %	10.5 %	2.6 %
Antidepressants	85.6 %	82.8 %	93.9 %	76.8 %	71.6 %	86.8 %
Of those:						
SSRI	75.2 %	76.4 %	72.1 %	77.1 %	84.0 %	60.0 %
Venlafaxin	14.3 %	13.6 %	16.3 %	10.0 %	6.0 %	20.0 %
Mirtazapin	5.6 %	4.2 %	9.3 %	5.7 %	4.0 %	15.0 %
Other	5.0 %	5.9 %	2.3 %	5.7 %	6.0 %	5.0 %
Number of weeks	48	54	31	56	66	34
on AD	40	54	31	50	00	34

The self-rating scales HADS and GAF-self

#### The Hospital Anxiety and Depression Scale (HADS)

HADS was created in 1983 and was initially constructed for use among somatically ill patients [86]. It is a self-rating scale that screens for both depression and anxiety and it has been widely used in several countries and validated in both hospitals and PC settings [86-88, 155-157].

HADS consists of 14 statements (items) to which the respondents indicate how much it applies to them, within the last week. There are two subscales, one for depression (HADS-D) and one for anxiety (HADS-A), with 7 items for each subscale. All items are rated from 0 to 3 and the maximum score is 21 for each disorder. A higher score depicts a worse condition. A score  $\leq$ 7 indicates no depression, a score of 8 to 10 suggests a mild disorder and  $\geq$ 11 is the cut-off for a clinically significant disorder [86]. A score  $\geq$ 15 has been suggested to reflect a severe disorder.

When using HADS in clinical practice for screening, several studies have suggested that a score of  $\geq 8$  is the optimal cut-off, with the best balance between sensitivity and specificity [87, 158]. The sensitivity and specificity of HADS is around 80 % for each disorder, and it has shown an excellent screening ability in PC settings with an Area Under the Curve (AUC) between 0.84 and 0.96 [87].

HADS focuses mostly on the mild to moderate forms of depression and therefore no item on suicidal thoughts is included [88]. HADS-D has a high correlation to other depression scales such as BDI and MADRS [87, 155, 159]. Filling in HADS takes approximately five minutes and it can be quickly evaluated by the physician.

Since the scale was originally designed as a screening instrument, the originators (Zigmond and Snaith) have not defined the demands for response and remission. However HADS has been shown sensitive to response after treatment [88]. In the FINDER study, response is defined as when the patient move to a lower severity interval, e.g. from clinically significant to mild, and remission is defined as to have moved from some level of depression to  $\leq 7$  [160]. We defined remission if the patient had moved from  $\geq 11$  to  $\leq 7$ , and response as a decrease of at least 5 scores in HADS-D.

## GAF-self (Global Assessment of Functioning)

GAF constitutes axis V of the DSM-IV and estimates the level of functioning on a scale from 0 to 100, where a higher score means a better functioning [1]. In this study, the self-rating version GAF-self was used. The patients estimated their own level of functioning during the past year and also the last weeks. The GAF self-rating scale has been evaluated in a study from 1994 [161], showing good concordance with expert evaluation.

### Analysis and statistics

## Content analysis

The answers to the open-ended questions in paper III and IV were analyzed with content analysis [162, 163]. The patients' answers were read through several times and codes containing meaning units were noted. The codes were ordered and grouped into categories explaining the same topic. All categories were exclusive and the codes included in each category could not be placed in another category. After forming categories, broader themes including categories with connected content were established. Codes,

categories and themes were compared and discussed repeatedly between two of the co-authors until consensus was reached. The patients' answers were clear and concise and most often the categories found by the two co-authors separately were identical. The analysis was close to the text and the manifest content of the text formed codes and categories.

After the formation of themes a quantitative approach was undertaken to analyze frequencies of categories and themes, and comparisons between subgroups. We investigated if there were any differences in categories mentioned by men vs. women, different age group, patients with different treatment and different severity of depression according to HADS-D. We also compared patients' beliefs about causes to their beliefs about their improvement.

#### **Statistics**

In paper I and III group comparisons were analyzed using student's t-test. In paper IV categorical variables were compared by  $\chi^2$  test or Fischer's exact test and Mann-Whitney U-test was used for continues variables. In all three papers correlations were tested by the Pearson's correlation coefficient. The level of significance was set at p<0.05. All the statistical analyses were performed by the SPSS (Statistical Package for the Social Sciences) version 10.0 to 15.0.

## Paper II

#### Patients and procedure

Patients were recruited from both psychiatric settings and HCC in the county of Västerbotten between October 2006 and June 2007. Five HCC and five psychiatric outpatient clinics (POC) included patients who visited the GP or psychiatrist with complaints of depression. Patients were included consecutively during a two week period in each setting. The inclusion criteria were age 18 or above, Swedish speaking and that the patient suffered from symptom of depression. The study also included patients with somatic and psychiatric co-morbidity.

A questionnaire was distributed including questions about age, sex, occupation and the reason for the health care visit. All patients also filled in the self-rating scales HADS and PHQ-9. This information was all collected in conjunction to the visit at the HCC or POC.

**Table 3.** Patient characteristics in paper II

	All Patients N=737
Females	71.8%
Age Mean (SD)	39.3 (14.6)
Working/student	46.4 %
Sick leave	37.9 %
Retired of Age	4.1 %
Unemployed	10.0 %

About 70 % of the patients agreed to participate in the study. In total 766 questionnaires were collected. However, some patients did not fill in the self-rating scales correctly. We decided to exclude patients who had failed to fill in more than two items in either HADS or PHQ-9. If one or two items were missing, we counted the score as the mean of the other items. After this exclusion, the sample comprised 737 patients. Among those, 126 patients came from HCC and 611 from POC. Patients were divided into three age groups: young adults (18 to 30 years), middle aged (31-64 years) and older adults (≥65 years) in order to compare age differences.

In paper II the psychometric properties of the two self-rating scales HADS and PHQ-9 were compared. HADS is described above.

#### Patient Health Questionnaire - PHQ-9

PHQ-9 is a self-rating scale for depression, developed in 1999 from the rating scale PRIME-MD [23, 41]. It is a nine-item scale that comprises all criteria for depression according to DSM-IV [1]. For each of the nine items there are four alternatives of how much the described symptom has occurred the last two weeks. As in DSM-IV, at least five symptoms should have been present the last two weeks for a diagnosis of MD. There is also a question about how these symptoms have affected the respondent's level of functioning.

Each item is rated between o-3 which gives a maximum score of 27. To enable severity rating with PHQ-9 the total score is divided into intervals. A score between 5 and 9 indicates a mild depression, 10-14 a moderate depression and  $\geq$ 20 a severe depression.

A specific cut-off for depression has been estimated at PHQ-9≥10. Previous studies have shown that PHQ-9 has a sensitivity of about 80 % and specificity around 92 % at this cut-off [89, 164, 165]. In some studies PHQ-9≥10 is found to be too low and a cut-off of ≥11 or ≥12 has been

recommended [158, 164]. Which cut-off that is the optimal for PHQ-9 in screening situations is not well established and some authors discuss a "grey zone" in the cut-off range of 10-15 [89, 164, 166].

Compared to HADS, PHQ-9 is a newer and not as validated instrument. HADS and PHQ-9 have been compared in a few earlier studies and only one found a higher case finding ability in PHQ-9 [158, 167-169]. These scales have not earlier been compared in a Swedish population.

#### Statistics

Independent sample T-test was used to compare means. The level of significance was set at p<0.05. Pairwise agreement was tested by means of Cohen's Kappa coefficient. To calculate the internal consistency of both scales, Cronbach's Alpha was used. An exploratory factor analysis was performed using Principal Component Analysis (PCA) with varimax rotation.

## **CONSIDERATIONS**

#### General considerations

None of the authors in these studies were GPs. This is of course a limitation when writing about depression in PC. However, one of the authors (OB) is a consultant psychiatrist in PC since many years.

The data collection in this thesis was achieved by means of questionnaires and self-rating scales. An approach alternative to using self-rating scales in the Contactus study would have been to measure the outcome with a structured interview. Using self-rating scales and questionnaires means that there is a risk for response bias, but on the other hand it has the benefit of eliminating an interview bias [170]. A high response rate decreases the risks inherent in response bias, which hopefully is achieved in this thesis. Also, the number of patients in this study was over 300, and using interviews to evaluate them at baseline and at follow-up would have been a challenge. It is evident that using self-rating scales is both more convenient and also a cheaper method. Filling in questionnaires and self-rating scales could also make the patients feel more anonymous and thereby give a more honest response.

### Paper I

The study was naturalistic since the research project did not affect the GP's choice of treatments or any other aspects of the care, and the inclusion of patients was consecutive. Unfortunately, we had no data on how many patients who refused to participate. Both groups were treated as usual, except that the Contactus group also attended the Contactus program. All patients were offered a follow-up after six weeks and after six months, however if more follow-up visits were needed there were no restrictions.

Performing a randomization on patient level at each HCC was considered impossible since large enough groups had to live close to the same city or town, in order for group discussions and lectures to be feasible. When including patients, a cluster method was used, i.e. a number of HCC were included which subsequently recruited patients. There was no randomization performed by the researchers, but all those HCC that were involved in the Contactus program all over Sweden were included in the study. A randomization is usually performed to make the comparative groups similar at baseline and to avoid selection bias. For an intervention such as Contactus it is necessary to have dedicated physicians, counselors and nurses in order

to run the program. Also, if the control group would have been just any HCC in Sweden, randomly selected, the two groups would have had a higher risk of being more unequal. To achieve as similar groups as possible, the HCC recruiting controls were mostly HCC previously involved in the Contactus program. The sample was spread over a larger number of HCC all over Sweden with a fairly equal amount of both rural and urban HCC in both groups. Both the HCC agreeing to include Contactus patients and control patients might be those HCC with a high interest in the treatment of depression. Also, the two groups in paper I (Contactus and controls) were similar in all measurable ways at baseline.

A disadvantage was that many of the patients in both the Contactus group and the control group had already been treated for depression for a long period of time. The majority of the patients were on AD and the mean length of preceding treatment was about one year. Among the patients 39 % in the Contactus group and 33 % among the controls were not currently depressed according to HADS-D ( $\leq$ 7). To evaluate the program's effect on response and remission we had to exclude the patients that were non-depressed at baseline and only patients with a clinically significant depression (HADS-D $\geq$ 11) were included, which were only 38 % of the total population. Another disadvantage was that the Contactus study's duration was only 6 weeks. A follow-up was performed after 6 months but the dropout rate was over 50 % and with an uneven dropout rate between the groups. Therefore, we abstained from analyzing these data.

A limitation with the use of HADS was that there is no established definition of response. Response was defined as a reduction of at least 5 points on the scale. The differences between the two groups also remained when using the classical definition used in other scales such as HAM-D and MADRS, i.e. 50% reduction of symptoms, but on a lower level.

In the questionnaire the respondents were asked to fill in their age according to five intervals, i.e. 18-29, 30-39, 40-49, 50-59 and 60-69. We did not know the exact age of the patients, only in which interval they were. This complicated the analysis, and we could not do a mean or median split as concerns the age.

A weakness with the design in the Contactus study was that both patient education and group counseling were evaluated together. At hindsight it would have been interesting to know how much each of these components contributed on its own.

#### Papers III and IV

An advantage of using both qualitative and quantitative methods in paper III and IV was that it both rendered possibilities to find new aspects and still describe the findings with numbers that are easier to relate to. In both papers the content analysis was close to the text and we focused on the manifest content in the patients' descriptions. Reading and analyzing a text is always qualitative but with content analysis the content of the text can be converted to numbers, and analyzed quantitatively [163]. Content analysis is a broad and growing method, and the data can be presented both with a qualitative or quantitative approach [162, 163].

To achieve trustworthiness in content analysis it has been recommended that one uses the terminology from qualitative methods research, namely credibility, transferability, dependability and confirmability [162, 171]. Credibility refers to whether the study has captured what was intended to be studied [162, 171]. In papers III and IV both men and women were included, the age span was vast and we had a fairly large number of patients which increases the credibility by capturing a higher variety of aspects [162]. The credibility was also improved by using two co-researchers reading, coding, categorizing and forming themes separately. The two co-authors that performed this analysis came up with about the same results. Only a few answers had to be discussed more deeply and reaching a consensus was not difficult. Also the analytic process was described thoroughly and examples of the formation of categories and themes and also quotations were presented in the papers. Dependability concerns the study's stability with regards to changes in the data and the researchers' decisions during analysis [162]. We believe that replicating the research in the same context and same patients would render similar results. Transferability means how applicable the results from the study are on other subjects in other settings [162, 171]. When comparing our results to the existing literature, previous studies have found similar results as ours. Also, since our population consisted of PC patients from all over Sweden, the findings are likely relevant to other PC patients, at least in Sweden and in countries with a similar culture. The population is described in terms of demographics, depression and anxiety scores according to HADS-D, and we have also carefully described the process of data collection and analysis in order to facilitate transferability. Confirmability refers to the neutrality of the data [171]. In both papers III and IV the patients' answers were kept on a separate file and the content analysis was performed without taking the subject gender, age or scores in the self-rating scales into consideration. In this procedure the analysis was more objective and increased the confirmability.

#### Paper II

In paper II a major disadvantage was that we did not have any diagnostic standard interview. We only included patients who visited the GP or psychiatrist with complaints of depression, which makes it impossible to estimate the prevalence of depression. However if we would have had a "gold standard" interview we could have compared the two self-rating scales sensitivity and specificity and predictive values to also get an evaluation of their ability in recognizing depressed patients. An advantage of this study was that it included many patients and even though PHQ-9 is used in Sweden there was no validation of the scale in a Swedish population.

#### Analysis and statistics

When the level of significance is set at p<0.05, the consequence is that 5 % of the significant findings could be due to chance [172]. In this thesis many of the findings had a significance level below 0.01 which decreases the risk for mass-significance. However, one should always be aware that a significant finding does not mean that it is an absolute truth.

The Independent samples t-test was used to compare differences between groups in papers I-III. Since some of the variables were qualitative, Mann-Whitney U test would have been a more adequate choice for comparing continuous variables and the  $\chi^2$  test for the comparison of categorical variables [172]. However, all data was re-calculated with the latter method and we obtained unchanged results. In paper IV we have used  $\chi^2$  test or Fischer's exact test for comparison of categorical variables and Mann-Whitney U-test for comparison of continuous variables.

#### Ethical considerations

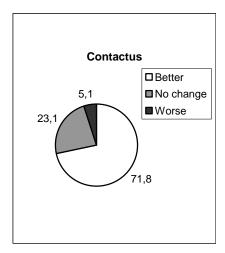
Informed consent was obtained from all the participants (papers I-IV). All studies were conducted in accordance with the ethical Declaration of Helsinki [173]. A coded number was assigned to each patient, and the researchers did not have the names, or any personal identification numbers of these patients. No medical charts were used by the researchers and all data was treated confidentially. Also, results were presented at the group level which prevents identification of the participants. All patients continued receiving customary treatment according to the routines in PC. In papers III and IV some of the individuals' written explanations were cited. We deliberately excluded examples that might enable identification of specific individuals. The Contactus study has been approved by both the central and the regional ethic committees (D-Numbers 05-013M, Ö17-2005, 08-082M).

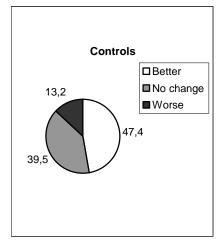
When asked by a GP to participate in a study the patients might feel obligated to agree. However consent was given both orally and in writing, and the patients were all considered to be capable of making own decisions. Also, the patients had the opportunity to leave the questionnaire unanswered if they chose to. None of the treating physicians were involved as researchers in the studies.

## **RESULTS AND DISCUSSION**

### **Paper I – The Contactus study**

At the follow-up after six weeks the depressed patients with HADS-D≥11 were improved in both groups but to a higher degree in the Contactus group with a reduction in HADS-D score with 4.6 vs. 3.0 (p=0.02). Increase in the GAF score was 10.6 vs. 5.4 in the Contactus and the control group respectively (p=0.04). The patients in the Contactus group also felt subjectively more improved as compared to the control group which is shown in figure 1. The frequency of patients considering themselves to feel better or much better was 71.8 % among the Contactus patients and 47.4 % among the controls (p=0.01).





**Figure 1.** How the patients felt, subjectively after 6 weeks. The question was: "How has your condition changed from six weeks ago".

There were significant correlations between improvement according to HADS-D, GAF-scale and the patients' opinion of how they felt. Correlation coefficient between HADS-D and GAF change was r=0.53 (p<0.001). The patients' subjective estimation of their health correlated positively with improvement in HADS-D (Pearson's r=0.43, p<0.001) and GAF-score (r=0.39, p<0.001).

Remission and response were estimated among patients with clinical depression (HADS-D≥11) and an affected level of functioning (GAF<80). The patients in the Contactus group had a response rate of 55.4 % as compared to 28.9 % among controls (p=0.006). Remission was achieved in 41.9 % of the Contactus patients and 21.1 % of the controls (p=0.02). These differences remained significant also without the functioning criteria (GAF<80). Response and remission in both groups are presented in figure 2.

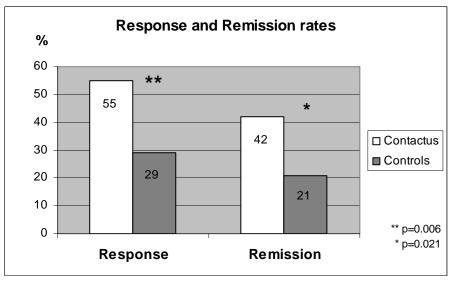


Fig 2. Response and remission rates among clinically depressed patients (HAD $\geq$ 11 and GAF<80).

In the Contactus group 6.2 % were sick-listed during this 6-week period vs. 30.0% from the control group (p<0.01). These results indicate that the Contactus program might have a positive impact on the depressed patients' recovery.

It is difficult to compare our results with previous studies since educational programs differ in structure. We found no study with a similar intervention setup as the Contactus program. However, several studies have emphasized the need for patient education [121, 174, 175]. In Norway, a study on group-based educational treatment showed that patients participating in the intervention group was about twice as improved as compared to controls when measuring outcome with BDI [176]. Patient educational strategies have also in other larger studies shown to be effective on treatment outcome with reduced symptoms of depression, better functioning and also for prevention [96, 115, 124, 126, 127]. Patient education in combination with a shared

multidisciplinary care also has evidence of improving treatment compliance, outcome and lowering the health care costs [109, 123, 177].

The male participants in this study had a higher frequency of AD compared to the women (91 % and 79 % respectively, p=0.02). They also had a tendency to be more depressed at baseline compared to the women (mean HADS-D 9.8 and 9.0 respectively, ns). This raised the reflection if men are less prone to seek help and therefore are more severely depressed. When investigating the outcome, no differences were found between men and women or between different age groups. Also, no differences were found when comparing patients with and without AD medication.

More than half of the studied population (56.1 %) also suffered from somatic symptoms. The most prevalent somatic complaints were pain in extremities or back, headache and gastro-intestinal problems which is comparable with findings from other studies [46, 77]. Among patients with somatic symptoms the mean HADS-D value was somewhat higher (9.7) compared to those without somatic symptoms (8.5), p=0.01. Women had a higher frequency of somatic symptoms compared to men (60.6 % vs. 44.0 %, p=0.009). The findings that painful somatic symptoms increase with the number of depressive symptoms and are more frequent among women are supported by previous research [77].

To summarize, the results from paper I showed that the patient education and group counseling included in the Contactus program had benefits on the treatment outcome measured with HADS and GAF-self, i.e. both reduction of depressive symptoms and increased level of functioning. Also, the patients in the Contactus group felt subjectively better in about twice as high frequency as compared to controls. An intervention such as the Contactus program should involve also other professionals than physicians such as interested nurses and counselors. Treating patients in groups has benefits over individual treatment in that several patients receive treatment simultaneously which must be considered time-efficient. The groups also provide an inner support e.g. ability to share experiences and meeting others in similar situations, which can not be provided by individual counseling.

Since the Contactus program has both lectures and group discussions, it is difficult to know exactly what component contributed the most to the improvement. The patients' opinions regarding this are further described in paper IV.

#### Paper II - Comparing self-rating scales HADS and PHQ-9

The PC patients and the POC patients had similar scores on both the self-rating scales, with a mean score of 8.6 (SD 4.4) in HADS-D and 13.4 (SD 7.3) in PHQ-9. With the anxiety subscale HADS-A it was found that 42.6 % of the patients suffered significantly from anxiety (HADS-A≥11), which was more frequent among women 45.0 % as compared to the men 36.5 % (p=0.04).

The mean score differed between men and women using PHQ-9 (12.1 vs. 13.9, p=0.003) but the HADS-D mean score showed no gender differences. Also, according PHQ-9 there were age differences, where younger patients were more depressed (PHQ $\geq$ 10) than the oldest patients (70.5 % vs. 51.0 %, p=0.02). Using HADS we found no age differences.

When comparing HADS-D and PHQ-9 with respect to their severity cut-offs we found that PHQ-9 diagnosed more patients to have severe depression while the scales recognized about an equal amount of patients with mild and moderate depression. When using the cut-off  $\geq 5$  in PHQ-9 this scale labeled 30 % more patients than HADS-D ( $\geq 8$ ) to suffer from any depression.

We also compared the scales recommended screening cut-offs for depression, i.e. PHQ-9 $\geq$ 10 and HADS-D $\geq$ 11 and found that 33.5 % of the patients were depressed according to HADS-D and 65.9 % according to PHQ-9 (k=0.35). Since the cut-off  $\geq$ 8 in HADS-D has been suggested as the optimal cut-off for screening purpose, we investigated if this cut-off had a higher agreement to PHQ-9. The frequency of patients recognized as depressed with the cut-offs HADS-D $\geq$ 8 and PHQ-9 $\geq$ 10 was 57.8 % and 65.9 % respectively (k=0.52), and 73.4 % of the patients were recognized as depressed by either of the two scales. Hence, the scales seem to detect different patients as depressed, at least to some extent. The highest kappa value (0.56) was found at PHQ-9 $\geq$ 12 and at this point the scales recognized almost the same amount of patients to be depressed (57.8 % and 56.2 % for HADS-D and PHQ-9 respectively).

These findings give rise to some reflections. Is PHQ-9 too generous? Is HADS-D too restrictive? However, the cut-off in HADS-D is thoroughly investigated in previous studies, suggesting that  $\geq 8$  is the optimal cut-off in screening purpose [87, 88]. It might be that these two scales have different advantages in different populations. Some differences were found using PHQ-9 as regards age and gender, however since no gold standard could establish the true diagnosis it was difficult to draw conclusions from this.

**Table 4.** Factor loadings with Varimax rotation of the pooled items from HADS-D and PHQ-9.

HADS-D items	Factor 1	Factor 2
(2) I still enjoy the things I used to enjoy	0,737	0,275
(4) I can laugh and see the funny side of things	0,817	0,210
(6) I feel cheerful	0,747	0,293
(8) I feel as if I am slowed down	0,591	0,396
(10 ) I have lost interest in my appearance	0,536	0,221
(12) I look forward with enjoyment to things	0,824	0,218
(14) I can enjoy a good book or radio or TV program	0,500	0,355
PHQ-9 items	Factor 1	Factor 2
(a) Little interest or pleasure in doing things	0,625	0,530
(b) Feeling down, depressed or hopeless	0,543	0,643
(c) Trouble falling or staying asleep, or sleeping too much	0,161	0,700
(d) Feeling tired or having little energy	0,302	0,729
(e) Poor appetite or overeating	0,276	0,706
(f) Feeling bad about yourself- or that you are a failure or have let yourself or your family down	0,362	0,661
(g) Trouble concentrating on things, such as reading the newspaper or watching television	0,269	0,723
(h) Moving or speaking so slowly that other people could have noticed. Or the opposite-being so fidgety or restless that you have been moving around a lot more than usual	0,228	0,738
(i) Thoughts that you would be better off dead or of hurting yourself in some way	0,376	0,502

The factor analysis of HADS resulted in two factors corresponding to the two subscales for anxiety and depression. Only one item, "I can sit at ease and feel relaxed", loaded on both factors. This was also found in some previous studies [88, 156]. The factor analysis of PHQ-9 gave one factor including all items. Also, a factor analysis combining all items from PHQ-9 and HADS-D was carried out in which two factors were extracted. The items in HADS-D only loaded on one factors while the first two items in PHQ-9 loaded on both

factor 1 and 2 (table 4). These two items comprise the core symptoms of depression which seems to be covered by both scales. The results from this combined factor analysis shows that PHQ-9 and HADS-D to some extent measures different aspects of depression.

The internal consistencies found in study II were in concordance with previous studies [87, 158, 167]. Cronbach's  $\alpha$  of HADS and it subscales HADS-D and HADS-A was 0.90, 0.87 and 0.84 respectively. PHQ-9 had a Cronbach's  $\alpha$  of 0.91.

### Paper III - Patients' beliefs about causes of depression

This paper comprised the same population as in paper I but included only those who responded to the open-ended question "what do you consider is the cause of your depression" (N=303). Of these patients, 73 % were women, they had a mean age of 44 years, and about 50 % were on sick leave. The majority, 82 % were on AD.

From the content analysis of the patients' answers, 16 separate categories emerged. Since the patients wrote short and clear descriptions of their beliefs, these categories were all very close to the text. The categories were organized under themes explaining the general topics brought up among these patients. The three themes found in this study were current life stressors, past life events and constitution.

Table 5 shows the categories and themes, specified with frequencies and exemplified with patients' citations. In this study there were generally few gender and age differences. In accordance with previous findings the patients in our study often mentioned several etiological beliefs [135, 146].

As seen in table 5 current life stressors in different aspects were mentioned by about two thirds of the patients. Work related stress was very common (33.3 %) and also family related problems (24.1 %). The fact that current stressors were perceived as important reasons for developing depression is supported by several studies [142, 146, 152, 178]. Theme 2 included past life events where death of a relative or a friend was the most common category followed by separations which most often was a divorce.

**Table 5**. The frequency of mentioned categories and themes with examples of answers on each category to the question "What do you consider is the cause of your depression?" Themes are in bold, categories in non-bold. The category personality is defined by four sub-categories. N=303.

Causes	% (n)	Examples of answers given by the patients
Theme 1 Current life stressors	68.6 % (208)	
Work situation	33.3 % (101)	"Stress, threats and violence at work" (older woman)
Family situation	24.1 % (73)	"Single with four children" (middle aged woman)
Somatic illness	11.9 % (36)	"Herniated disc, pain" (older man)
Unemployment	7.3 % (22)	"Unemployment after having worked for the same company in 30 years" (older man)
Loneliness	5.9 % (18)	"Prolonged tediousness and loneliness" (younger man)
Bad economy	3.0 % (9)	"That my family have had a problems economically the last year" (middle aged woman)
Non specified stress	13.5 % (41)	"Stress, a lot of pressure from many directions" (middle aged woman)
Theme 2 Past life events	32.3 % (98)	
Death of relative or friend	9.9 % (30)	"After the death of my husband 3 years ago" (older woman)
Broken relations	8.9 % (27)	"A previous difficult divorce" (middle aged woman)
Childhood	6.6 % (20)	"An almost non-existent love in my childhood" (young woman)
Traumatic events	5.0 % (15)	"Got attacked by four men" (middle aged man)
Reproduction	4.0 % (12)	"Crisis after pregnancy and delivery" (young woman)
Non specified life events	4.3 % (13)	"Different events, different experiences" (young woman)
Theme 3 Constitutional	35.3 % (107)	
Personality	31.4 % (95)	
Ambitious	17.8 % (54)	"Too high ambitions, difficult to set limits, does not see when it gets too much" (middle aged man)
Sensitive	5.3 % (16)	"Think that I'm essentially a very sensitive person. Worry too much" (younger woman)
Depressed disposition	4.0 % (12)	"Asthenic disposition, melancholic disposition" (older woman)
Non specified personality	4.3 % (13)	"Much lies in my personality" (middle aged woman)
Biological/heredity	3.6 % (11)	"I think it's partly genetic" (young woman)
Season	2.0 % (6)	"The darkness during winter" (young woman)
Do not know	5,0 % (15)	

An important finding of this study was that only 3.6 % of the patients stated a biological explanation to their depression. This is far less than could be expected among professionals. A considerable amount of the patients mentioned their own personality as a cause of their depression (31.4 %).

In the study we found descriptions of three kinds of personalities: sensitive, ambitious and depressive. The depressive personality could have been sorted under the same sub-category as sensitive but was described differently. The sensitive personality was described as sensitivity to reaction of external stressors, while the depressive personality was described as though the depression was a part of their personality no matter what, a pessimistic view on things. The depressive personality hence tends to be a more biological explanation, as though the patient was born with it.

In previous research about personality a five factor description has been suggested [179]. In this "big five", the personality facets are: neuroticism, extraversion, openness, agreeableness and conscientiousness. Theories about personality were not taken into consideration when analyzing answers from the patients in paper III. However, in retrospective, comparing our results to the personalities described in "big five" is interesting. Both the personality we called sensitive and depressive is comparable with neuroticism, while the personality with high demands and ambitiousness corresponds to the conscientiousness facet. In previous studies, neuroticism has shown to be a risk factor for MD [14, 15]. In a North American study it was found that a higher neuroticism among women also played an important role in the relationship to MD, and also that patients with traits of neuroticism were higher consumers of mental health care [180, 181].

When investigating if any of the believed causes for depression were associated with improvement at the follow-up after six weeks, the only cause that correlated with a positive outcome was previous separations. Separations correlated with both remission and response; r=0.17 (p=0.003) and r=0.24 (p<0.001) respectively. Comparing the patients who were responders to non-responders, separations were three times more common among the responders (18 vs. 6 %, p=0.003). Among patients with HADS-D≥10 the category separation correlated even more with remission r=0.29 (p=0.002) and improvement r=0.23 (p=0.02). Hence, the prognosis of depression caused by a previous divorce or separation from partner seems to be good.

### Paper IV- Patients' beliefs about improving factors

In this paper, exploring previously depressed patients' beliefs about factors for improvement, the characteristics of the population were similar to those in paper I and III. Fourteen separate categories and four themes were found when analyzing the patients' answers. These are all shown in table 6 with their respective frequencies.

Similar to the finding in paper III, the patients had several beliefs of what had made them better and there were few gender and age differences. Multiple explanations for improvement given by patients have also been found in a previous study [145].

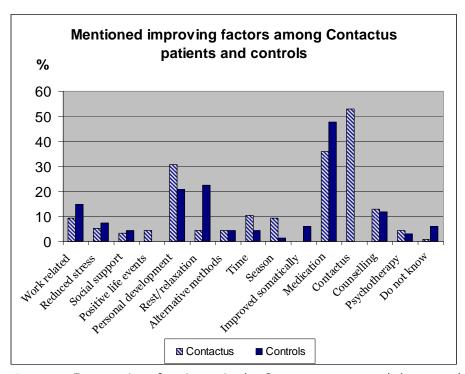
As seen in table 6, the patients were generally positive to the professional help they had received. Seventy two percent of the patients mentioned some aspect of help given by their health care providers as having contributed to their improvement. The most frequently given answers were the Contactus program and pharmacotherapy. Believing that AD are helpful is supported by some previous studies [142, 145, 151]. However, in most studies patients are found to prefer psychotherapy instead if AD [133, 139-144]. Also, when patients were asked for the most important factor for improvement, a previous study found that only 11 % mentioned AD [129].

From the patients' answers, the Contactus program was clearly an important improvement factor. Among the Contactus patients more than half (53 %) stated that the Contactus program was a reason for their improvement. Examples of what these patients wrote generally involved the benefit of meeting and sharing experiences with others in the same situation and receiving knowledge by lectures. Knowing that there are effective treatments available seemed important to the patients, and was described as giving hope in that their condition did not have to last forever. Often the patients mentioned both the educational part and the group sessions. Patients who were clinically depressed (HADS-D≥11) at baseline mentioned the Contactus program more often than those patients who were already in remission at baseline (63.5 % vs. 39.6 %, p=0.02).

**Table 6.** Percentage and the number of patients who mentioned an improvement factor that belonged to the given category or theme. All categories are exemplified with a citation given by the patients. N=184.

Improving factors	% (n)	Examples of answers given by the patients
Theme 1 External factors	22.8 % (42)	
Work related	11.4 % (21)	"One part is probably because I got relocated at work" (middle aged woman)
Reduction of stress non-specified	6.0 % (11)	"No stress, no demands-pressure" (middle aged woman)
Social support	3.8 % (7)	"Support from relatives and friends" (young woman)
Positive life events	2.7 % (5)	"I have recently had a child and things have not revolved around me as much" (young woman)
Theme 2 Self management	39.7 %(73)	
Personal development	27.2 % (50)	"I listen more to myself and do not accept too much work" (young man)
Rest/relaxation	10.9 % (20)	"Have slowed down and not stressed around" (young man)
Alternative methods	4.3 % (8)	"I've paid attention to nutrition and exercise" (young man)
Theme 3 Passing spontaneously	15.2 % (28)	
Time	8.2 % (15)	"I believe time, at least partly, heals" (middle aged woman)
Season	6.5 % (12)	"Lighter outside, happy when spring" (young woman)
Improved somatically	2.2 % (4)	"My gastric ulcer has healed" (older woman)
Theme 4 Professional help	71.7 % (132)	
The Contactus program (N=117)	53.0 % (62)	"By talking to others who have the same problem" (younger man)
Antidepressants (AD)	40.2 % (74)	"I think it's about 90 % due to the medication (citalopram)" (middle aged woman)
Supportive counseling	12.5 % (23)	"Have talked to a good counselor" (middle aged woman)
Psychotherapy	3.8 % (7)	"I'm in cognitive psychotherapy (very good)" (older man)
Do not know	2.7 % (5)	

There were few significant differences when comparing the frequencies of improvement factors given by the participants in the Contactus group compared to the control group which were treated as usual. As figure 3 depicts, there were some tendencies but only the categories "rest and relaxation" and "improving somatically" differed significantly between the groups. Among the controls, having mentioned "rest and relaxation" was negatively correlated to response according to HADS-D (r=-0.25, p<0.05) while mentioning professional help correlated positively with remission (r=0.27, p<0.05).



**Figure 3**. Frequencies of patients, in the Contactus group and the control group respectively, mentioning the different categories of reasons for their improvement.

Although the two groups mentioned similar improvement factors, the results from study IV indicated that patients' beliefs are modifiable. This was assumed since the believed causes of depression, found in paper III, correlated with the beliefs about improvement factors among the controls but not among the Contactus patients. Briefly, among the controls, believing that the depression was caused by current stressors was correlated with

beliefs in external factors for the improvement (r=0.26, p<0.05) and believing that the depression was due to their own constitution was correlated with beliefs in professional help (r=0.33, p<0.01).

# CONCLUSIONS

- The Contactus program in addition to treatment as usual contributed to improved outcome with about twice as high response and remission rates among patients participating in the Contactus program as compared to controls. Subjects in this group also felt subjectively better to a much higher extent and had a higher increase in functioning than the controls.
- Patients' beliefs about the cause of their depression seldom involved biological explanations. Most patients believed in current stress such as stress at work and in their family as causes of their depression.
- Beliefs about the reason for improvement at follow-up clearly showed that the patients attributed their improvement to professional help such as antidepressants and the Contactus program.
- Both HADS and PHQ-9 had high internal consistencies and stable factor structures. However, they show diversity in their severity ratings and cut-offs and to some extent they seemed to recognize different patients as depressed.
- The most reasonable cut-off in HADS-D when screening for depression is ≥8. In PHQ-9 the recommended cut-off ≥10 might be too generous.
- Finally, results from this thesis show that patient education and group counseling were both appreciated and improved treatment outcome. Intervention such as Contactus would have a benefit as a supplement to the usual treatment in primary care. Patients' participation in the decisions regarding treatment should always be strived for. Increasing patients' knowledge about depression might facilitate their involvement in the care, increase compliance and improve outcome. Self-rating scales are valuable in detecting depression (and anxiety) but must be followed by a clinical interview to establish the diagnosis and treatment options.

## **CLINICAL IMPLICATIONS**

Depression is a disorder that causes considerable suffering to the patient and to his or her family, and leads to a decreased quality of life. As regards the care of depressed patients in the society, there is still a large need to recognize these patients and offer them the proper treatment. In PC the diversity of patients seeking help ranges from patients needing simple health controls to patients with serious illnesses. Depression is very common among the patients in PC but is often unrecognized.

The comorbidity of depression with other mental disorders and physical symptoms is high. Depression can be hidden behind other symptoms. Screening with self-rating scales among patients with a higher risk of depression is emphasized, such as patients with frequent health care visits, patients with pain or other chronic illnesses, and also patients with unexplainable symptoms. Even though self-rating scales are helpful in the clinical practice, a score indicating depression must always be followed up with a clinical assessment to determine the right diagnosis. In other words, the self-rating scales cannot replace a clinical interview but they facilitate the recognition of these cases.

Comparisons of different self-rating scales are important in order to facilitate the choice of which scale to use. The self-rating scales HADS and PHQ-9 are both valuable instruments to recognize depressed patients in PC. HADS has the advantage of screening both for anxiety and depression and is by far a more validated instrument. Also, it might be more suitable among patients with somatic symptoms. PHQ-9 has the advantage of including all criteria of depression according to DSM-IV. Both scales can, when used repeatedly, monitor the course and treatment outcome.

There are effective treatments of depression which make about 70 % of the patients better. However, further improvements in the treatment and care of depression are possible. In Swedish PC the treatment offered to patients with depression is usually AD and supportive counseling either by a GP, a nurse or a counselor. Very few patients receive CBT, mostly because of a lack of trained professionals. In this thesis an intervention called the Contactus program was evaluated and showed to have a high impact on treatment outcome as compared to patients treated as usual. In this program the patients were provided with more knowledge by a series of lectures about their disorder and were also given an opportunity to meet other patients to share common experiences with. The program was shown to be highly appreciated by the patients. We suggest a program such as Contactus to be

implemented in the care of depressed patients in PC and possibly also in psychiatric outpatient settings.

Health care and treatment should as far as possible be carried out in consent with the patient, which is also stated in the Swedish law of health care. For this to be possible, we have to find out what the patients themselves believe and prefer. In this thesis it was found that very few of the patients stated biological reasons for their depression which is a contrast the general beliefs among clinicians and researcher. To achieve sufficient outcome and better treatment compliance, depressed patients need to be provided with knowledge about their disorder, its connection to physical symptoms and the effects and side-effects of treatment — besides adequate AD in reasonable dosages and follow-ups. This should be offered to them either individually or in group settings, with the advantage of group-support and the probably higher cost-effectiveness.

### **FUTURE RESEARCH**

Much is still unknown about several aspects of depression. From the results in this thesis there is clearly a need to further investigate treatment strategies including patient education and group counseling. Research on complex interventions is difficult to interpret fully since there might be several different active ingredients involved in the given intervention, which have influence on outcome, and other ingredients with less influence on the outcome. It would be interesting to know the effectiveness of each of the patient education and group counseling methods separately.

There are many self-rating scales and several studies evaluating these. However, there is still a lot unknown about which scale to choose and in which population. Today, if used, the choice of self-rating scales is often based on local traditions. More studies are needed, comparing several common self-rating scales to each other and to a gold standard interview, preferably in large PC populations. It would also be interesting to investigate if specific self-rating scales are more suitable for patients with specific characteristics, with minor or major depression or with simultaneous symptoms such as anxiety and pain.

Patients' beliefs about the cause and treatment of depression have shown to be important for treatment outcome, compliance and coping strategies. It would be of interest to further investigate the effect of patient education on these beliefs. Previous research has shown that low treatment compliance is a problem among depressed patients. Future research about the relationship between patients' beliefs and compliance is needed, and also whether providing patients with information about their disorder and the treatment could influence the compliance.

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