GUILT AND SHAME AS AN ENIGMA IN MOTHERS WHO SUFFER FROM EATING DIFFICULTIES

- A hermeneutical study

by

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Guilt and shame as an enigma in mothers who suffer from eating difficulties – a hermeneutical study

ABSTRACT

Background: Some mental health problems can have a strong influence on the sense of guilt and shame. Eating difficulties (ED) such as anorexic, bulimic or binge behaviours are likely to be related to a guilty conscience and being ashamed oneself. About 90% of those who suffer from ED are females of childbearing age, and many are mothers. Only a small percentage of women who suffer from ED actually receive treatment, and guilt and shame can be one of the reasons for not seeking help. The direct or indirect impact on the mother child-relationship increases the need to focus on motherhood and individual daily life experiences of ED.

Aims and research questions: The overall aim of this thesis was to gain a deeper understanding of the phenomenon of guilt and shame by exploring mothers' experiences of suffering from ED (Paper I), women's experiences of ED in daily life (Papers II-III) and investigating mothers` experiences of guilt and shame related to motherhood (Paper IV). The specific aims were: to explore motherhood in the context of ED (Paper I); to explore women's bodily experiences of suffering from ED (Paper II); to explore the daily life experiences of women who suffer from ED (Paper III); and to illuminate and interpret guilt and shame as expressed by mothers with ED (Paper IV). The research questions were: What are mothers' daily life experiences when suffering from ED? (Paper I). How do women who suffer from ED experience the bodily aspects related of their condition? (Paper II).

What mental challenges related to daily life are experienced by women who suffer from ED? (Paper III). What is the meaning of guilt and shame experienced by mothers with ED? (Paper IV).

Methods: An explorative design with a hermeneutic approach was employed in this thesis. New understanding of the studied phenomena was developed through the dialogue between pre-understanding, previous research, the findings from the empirical sub-studies and theory related to the area under investigation. The four sub-studies are independent studies in their own right (Papers I-IV), as well as parts of the main study, since they form the pillars on which the hermeneutic circle is built. The dialogue between the parts and the whole began by reflecting with the participants. Eight mothers aged between 25 and 45 years participated in the study. They had children between the ages of three and 25 years. The first set of data was collected by means of seven focus group reflections (n=5) (Papers II-III). The focus groups were held within the context of a 15 session group art programme. The second set of data was collected by means of dialogues between the individual women and the author (n=8) (Papers I, IV). These meetings were held on two occasions with each participant.

Findings: The first paper revealed the main theme, 'Experiencing guilt as a mother in the context of ED', and two themes: 'Having a guilty conscience in relation to being a good enough mother' and 'Being preoccupied with not involving the children in the ED'. In the second paper the main theme was 'Powerful feelings of being trapped in and ashamed of one's own body' comprising two themes: 'The feeling of being trapped by overwhelming bodily sensations' and 'The feeling of being ashamed of one's own body'. The third paper revealed the main theme 'Balancing between mental vulnerability and strength' and three themes: 'Struggling with emotional ambivalence', 'Being cognitively aware of limitations' and 'Experiencing a sense of being lost and

frozen'. The fourth paper revealed the main theme 'Struggling in silence with guilt and shame as a mother living with ED and trying to keep it secret' and two themes: 'Feeling worried about failure and wanting to be successful' and 'Having condemning thoughts about one's own sense of responsibility'. The four sub-studies represented a new pre-understanding of the investigated area and a synthesis of them was developed. The new understanding was described as 'Guilt and shame as an enigma in mothers suffering from eating difficulties'.

Conclusion: Searching for new understanding about the enigma of guilt and shame in mothers suffering from ED led to a focus on the power of motherhood and the mothers' ability to suffer in silence. The desire to be a good mother and not transfer problems to the next generation seemed to intensify the sense of guilt and shame, as well as the will to keep the suffering associated with the mental health problem a secret. This was interpreted and understood as follows: Suffering from mental health problems in secret was found to intensify feelings of guilt and shame. Responsibility (guilt) and self-judgement (shame) have a powerful emotional and cognitive influence on important qualities of a woman's daily life and can lead to both strength and vulnerability.

Implications for mental health nurses are suggested. The conditions described in this study may cause mothers with ED to avoid seeking help. It is therefore necessary for the health services to offer mothers suffering from ED an environment in which they can articulate their problems. Improvement may be facilitated by means of emotional, cognitive and behavioural knowledge. By understanding the characteristics of a mother suffering from ED, mental health nurses will be able to identify such mothers. The knowledge that guilt and shame prevent mothers from verbalising their vulnerabilities will place mental health nurses in a better position to provide an environment for

articulation. This approach may help such mothers to make health promoting choices rather than searching for strategies to hide their problems under a veil of secrecy. Guilt and shame need to be focused upon and allowed space for articulation in the dialogue in order to help these women to express important everyday issues and problems in daily life when suffering from concealed health problems.

More research is needed on interventions that help to reveal guilt and shame and encourage the participants to open up and talk about the problems related to ED in the therapeutic situation. Further research should also focus on how to cope with motherhood in the context of ED as well as on how guilt and shame should be re-articulated so as to become understandable and thus be interpreted in ways that are recognisable to sufferers. The findings from this study concerning guilt and shame can be transferred to other areas related to persons suffering from mental health problems or to mothers with ED in the area of pre- and postnatal care and district health care.

Keywords: Art, content analysis, eating difficulties, guilt, hermeneutics, interviews, mental health nursing, mothers, shame.

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A body lies across the whole width of the canvas. Perfectly flat: feet stretches, arms against the body, face against the earth. Measuring up to the horizon. Man and landscape. Has there ever been such a gentle fall? He rests in peace in the warmth of the colour, in the dampness of the matter. Felled and confident. Confident in his fall.

Jeff Bertoncino

LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following papers, referred to in the text by their Roman numerals:

I Rørtveit, K., Åström S. & Severinsson E. (2009) Experiences of guilt as a mother in the context of eating difficulties. *Issues in Mental Health Nursing* **30**: 603-610.

II Rørtveit, K., Åström, S. & Severinsson E. (2009) The feeling of being trapped in and ashamed of one's own body: A qualitative study of women who suffer from eating difficulties. *International Journal of Mental Health Nursing* **18**: 91-99.

III Rørtveit, K., Vevatne, K. & Severinsson, E. (2009). Balancing between mental vulnerability and strength in daily life when suffering from eating difficulties. *Journal of Psychiatric and Mental Health Nursing* **16**: 317-325.

IV Rørtveit, K., Åström S. & Severinsson E. (2010) The meaning of guilt and shame – a qualitative study of mothers who suffer from eating difficulties. *International Journal of Mental Health Nursing* **19**: 231-239.

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The woman conceives. As a mother she is another person than the woman without child. She carries the fruit of the night nine months long in her body. Something grows. Something grows into her life that never again departs from it. She is a mother. She is and remains a mother even though her child dies, though all her children die. For at one time she carried the child under her heart. And it does not go out of her heart ever again.

Louise Bourgeois

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1 INTRODUCTION

It seems as if some problems are harder to grasp and some more necessary to conceal than others. In many ways they are a mystery – and the power that causes them to be borne in silence is difficult to understand – similar to an enigma.

This thesis was written for the PhD program in management at the department of Health studies, Faculty of Social Sciences, University of Stavanger. Although the public health perspective is included, the main focus is nursing science, as the author's core domain is mental health nursing (MHN). The decision about whether or not a health problem constitutes a public health problem is based on its degree of commonness (Severinsson 1995).

Eating difficulties (ED) such as bingeing, fasting and purging are common in society today: over the past 50 years ED has increased in developed countries (WHO 2004), and anorexia and obesity are among the three most common chronic problems in adolescent girls in the USA. Media attention has made ED more visible in western society, and one view of it involves the social, cultural and historical construction of women's bodies (Hardin 2003). As a consequence, women who suffer from ED feel ashamed when performing bingeing and compensatory behaviours and plan in great detail in order to keep the behaviour secret and avoid stigmatisation (Pettersen *et al.* 2008).

According to The Norwegian Board of Health Supervision (N.B.o.H. 2000), slenderness and a slim female body are not only ideals of beauty, but also communicate a hidden message of self-control and moral strength. The explanation for ED and self-starvation has changed over the years and one can find genetic, family and socio-cultural explanations in the literature (Nilsson 2007). The WHO has highlighted several important attitudinal and behavioural risk factors, such as

unhealthy dieting, excessive weight, shape and body dissatisfaction, family and social influences and the glamorisation of thinness in society and the mass-media as well as generic factors such as insecure attachment, physical abuse, bullying, low self-esteem and affective stress coping (WHO 2004). It is most important to be aware that only 30% with anorexia and fewer than 6% with bulimia are believed to actually receive treatment (N.B.o.H. 2000).

This thesis is a part of the work of the 'Women's Mental Health' research group at the University of Stavanger, Norway. The group focuses on the main phenomena: anxiety, depression, guilt and shame. Influenced by my clinical experience as a mental health nurse, I had a strong desire to investigate the sense of guilt and shame in mothers suffering from eating difficulties (ED) such as anorectic or bulimic behaviours. The research approach is hermeneutic (Gadamer 2004), thus the mothers are viewed as a whole that influences and is influenced by processes at different levels of their context. Parts of this influence consist of significant health aspects as well as important role qualities in daily life. In view of this fact it is essential to investigate and develop knowledge about human phenomena (guilt and shame) related to health problems (ED) in the context in which they occur (mothers with ED).

Health should be understood, not explained, and understanding is both emotional and cognitive (Lindström 2003). Mental health is a lifelong process that includes an individual's sense of harmony and balance, and leads to positive feelings such as self-worth and a strengthened identity. One approach to mental health and mental illness is to view them as end points of a continuum, moving through physical, personal, interpersonal and social levels throughout life. Mental illness can be characterised by a sense of distress and disharmony, such as feeling miserable and experiencing worries, fears and anxieties as well as by aspects that affect families, such as social withdrawal and inability to communicate coherently (Fontaine 2003). The focus on mothers in this

thesis acknowledges the claim that mental health may be influenced in vulnerable periods of the life-span by individual and family-related risk as well as by protective factors, even across generations (WHO 2004). Family-related aspects of mental health include being able to "balance between separateness and connection, the ability to be intimate, and the desire or willingness to help others in need" (Fontaine 2003, p. 5). One of the groups at highest risk of developing mental health problems are the children of parents who suffer from mental health illness and substance abuse (WHO 2004).

ED has many faces, and a variety of underlying factors have been described in the literature. Anorexia is defined as: "a serious illness often resulting in dangerous weight loss, in which a person, especially a girl or woman, does not eat, or eats too little, because they fear becoming fat", and bulimia as: "a mental illness in which someone eats in an uncontrolled way and in large amounts, then vomits to remove the food from their body" (Dictionary 2010). Common experiences at individual level have been revealed, such as powerful feelings of being fat, a desire to lose weight and body disturbances (N.B.o.H. 2000).

Lindström (2003) demonstrated that nursing is provided to patients with different needs in a continuum from problems, needs and demands to conditions that can be damaging to health. ED may vary in this continuum, as the patient experiences different levels of intensity in terms of her problems during different periods of life. However, in most of the literature, ED is treated as a diagnosis with three sub-diagnoses: anorexia, bulimia and non-specified eating disorders (N.B.o.H. 2000). The different diagnostic systems and the fact that persons suffering from ED tend to conceal their illness make epidemiological research difficult (Ekeroth 2005). Fairburn (2003) holds that ED is complex and involves a genetic predisposition and certain specific environmental risk factors. There are also prematurely high rates of unhealthy negative self-evaluation and parental problems (Fairburn *et al.* 1997). The fear of being too fat and losing control is

typically described by individuals suffering from ED as are mood, behavioural and psychological changes. The individual feels depressed and tends to withdraw socially and become preoccupied with food (Wilson *et al*. 2007). ED is linked to stress, control and relationships (Budd 2007) and Broussard (2005) reported that women with bulimia tend to isolate themselves, live in fear, feel as if their mind is at war and try to pacify the brain (Broussard 2005). Food 'addiction' and craving (*cf.* Rogers and Smit 2000) are examples of behaviours that may lead to actions (bingeing and purging) that trigger a guilty conscience as well as embarrassment on the part of the sufferer. Skårderud (2007a) described different 'concretised metaphors' that refer to the equivalence between the physical and psychic reality and illuminated the anorectic problem as a form of possession due to the interactions of body and mind (Skårderud 2007a).

The phenomena in this thesis were studied from a nursing perspective (Lindström 2003). Peplau (1991) and Fontaine (2003) stated that the interpersonal relationship is the basis of MHN. In the present work the nursing perspective was integrated throughout the study process, from the planning of the project to the dissertation, with special focus on the patient-nurse relationship and dialogue (Lassenius 2005, Lindström 2003). This approach is described as an empirical continuum by Lindström (2003). In the continuum, the nurse sensitively experiences different phenomena by seeing, hearing and feeling; the observations are interpreted into concepts that are linked to theoretical terms, which should be understood in the light of the theory they represent; a theory that is related to how the different concepts and phenomena are connected to each other. For instance when the nurse uses a theoretical concept in order to understand guilt and shame, it means that he/she gains new insight. Insight is a basis of the act of searching for understanding and moving in this empirical continuum requires reflection (Lindström 2003).

The nursing knowledge developed in this study focuses strongly on the mothers' own experiences and how they described their daily life as well as their feelings of guilt and shame in dialogue with the researcher. Knowledge of how mothers themselves experience motherhood when suffering from mental health problems is rare, despite the fact that it is vital for the development of evidence based treatment and adequate support.

1.1 Aims and research questions

The overall aim of this thesis was to gain a deeper understanding of the phenomena of guilt and shame, partly by exploring mothers' experiences of their ED and daily life (Papers II-III) and partly by investigating the mothers` experiences of guilt and shame related to motherhood (Papers I, IV). The specific aims were:

- To explore motherhood in the context of ED (Paper I).
- To explore women's bodily experiences of suffering from ED (Paper II).
- To explore the daily life experiences of women who suffer from ED (Paper III).
- To illuminate and interpret guilt and shame expressed by mothers with ED (Paper IV).

The research questions were:

- I: What are mothers' daily life experiences when suffering from ED? (Paper I).
- II: How do women who suffer from ED experience the bodily aspects related of their condition? (Paper II).
- III: What mental challenges related to daily life are experienced by women who suffer from ED? (Paper III).
- IV: What is the meaning of guilt and shame experienced by mothers with ED? (Paper IV).

1.2 Research design

An exploratory design was used in this thesis in order to highlight various ways in which the phenomena of guilt and shame can be manifested (Eriksson *et al.* 2007, Gadamer 2004, Polit and Beck 2004). The design is visualised in Figure I and has an inductive-deductive-abductive approach (Holm 2009, Eriksson and Lindstrom 1997). The hermeneutic research paradigm is based on Gadamer (2004) and comprises a dialogue about the mothers' lived experiences (motherhood, guilt and shame) in their own context (being a mother with ED) with the aim of developing new understanding. The type of knowledge sought is based on the researcher's pre-understanding in the area of MHN (Akerjordet 2009, Holm 2009). A genuine interest in identifying therapeutic strategies and interventions aimed at relieving guilt and shame in women with ED, in addition to new understanding, is developed as the dialogue enters the hermeneutic circle, dialectically moving between the empirical findings and theory, as well as between the parts and the whole (Gadamer 2004).

Four sub-studies (Papers I-IV) were conducted and constitute independent papers that formed the pillars on which the hermeneutic circle is built. These sub-studies move towards a synthesis that represents the whole. The dialogue began by reflecting together with the participants (n=8). A combination of focus groups (Papers II-III) and individual dialogues (Papers I, IV) illuminated various aspects of the research area (Schneider *et al.* 2007).

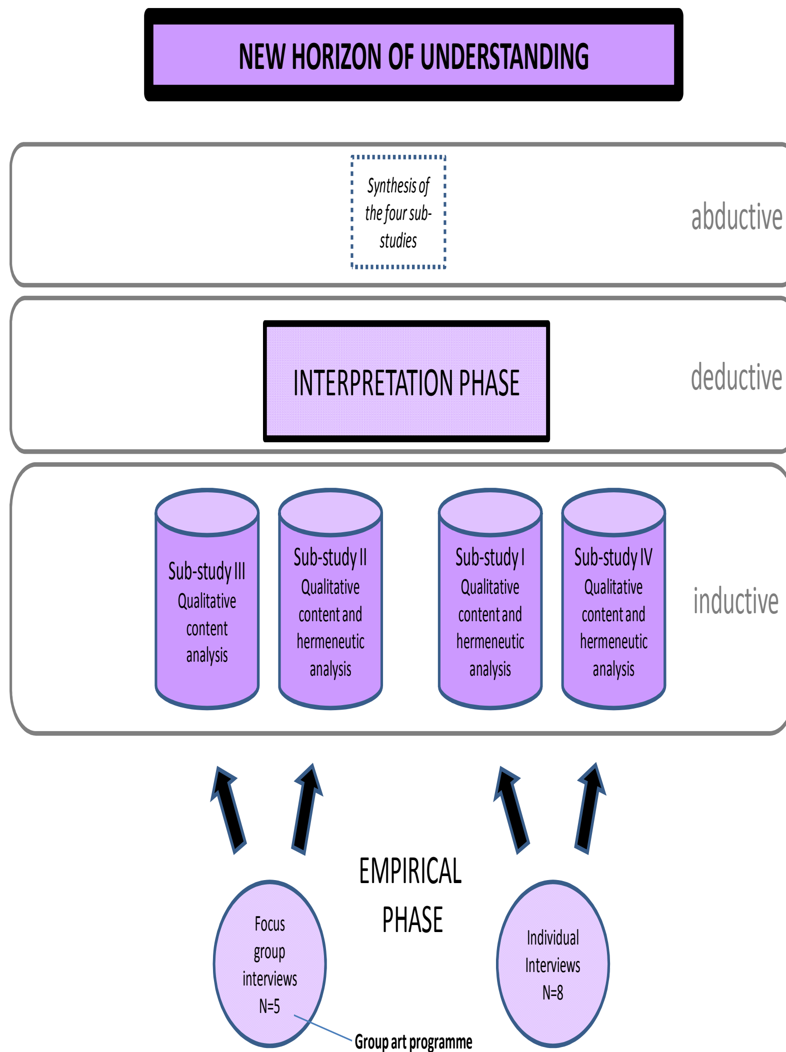
The first phase of the project involved an inductive approach (Holm 2009, Eriksson and Lindstrom 1997). As a researcher, I developed the research questions and thereafter designed a clinical programme on the basis of my previous knowledge of ED in mothers and its relation to guilt and shame, which was appropriate for an empirical explorative approach in this research area. The empirical data were analysed by

means of qualitative content analysis (Graneheim and Lundman 2004) and discussed with reference to the literature (Paper III). A hermeneutical approach (Gadamer 2004) was employed in sub-studies I, II and IV, which began with a qualitative content analysis (Graneheim and Lundman 2004). One goal was to illuminate the importance of the mothers' voices and experiences at an early stage of the analysis and give them an opportunity to influence the data during the whole process.

The second phase involved a deductive approach (Holm 2009, Eriksson and Lindstrom 1997) aimed at expanding knowledge that could serve as a foundation for the overall understanding of additional reflections in line with the research questions (Akerjordet 2009). Theories of guilt and shame, mental health nursing and hermeneutics were identified and explored in order to provide a framework for interpreting the empirical data pertaining to the mothers' experiences (Papers I-IV).

The third phase of the project involved an abductive approach (Holm 2009, Eriksson and Lindstrom 1997). A hermeneutical movement from the findings of the sub-studies (Papers I-IV) and identified theories led to a comprehensive understanding of the investigated area as presented in the summary of the thesis. This step also involved a meta-analysis of the studied phenomena.

Figure I: *Research design*



1.3 Structure of the thesis

This thesis is based on four original papers and a summary. First, the introduction, aims and research questions are presented as well as the structure of the thesis. The theoretical background describes guilt and shame, mothers with ED and mental health nursing. The methodology section presents the hermeneutical perspective, participants and clinical setting, data collection and analysis method, in addition to methodological and ethical considerations. An overview of the findings is followed by a discussion, comprehensive understanding, the contribution of this thesis to the clinical field and suggestions for further research.

2 THEORETICAL FRAMEWORK

The theoretical background of this thesis is based on the theory of guilt, shame and motherhood, as well as studies that relate them to ED. Theory of guilt and shame was used as the background for the interpretation of the investigated area, as well as for research that connects guilt and shame to ED. Thereafter, theories pertaining to motherhood will serve to illustrate the context of the investigated area, with special focus on mothers suffering from mental health problems and ED. The four sub studies (Papers I-IV) contain clinical implications. The theory of MHN with focus on communication is presented in order to serve as a framework for the clinical implications for nursing and the public health service.

2.1 Guilt, shame and ED as a dialectical process

> "… Throughout his life, man remains guilty in this sense… Man's existential guilt consists in his failing to carry out the mandate to fulfil all his possibilities" (Boss 1963).

In the present study, the phenomena of guilt and shame were studied in the form in which they were expressed through dialogue. Previous studies on guilt and shame served as a background for the discussion of the empirical findings in the inductive part in sub-studies I and IV (Papers I, IV). Theories of guilt and shame later served as a background for the hermeneutic interpretation of the findings in Papers I and IV. Most healthcare workers who work with ED are aware that women suffering from this condition have a strong sense of guilt and shame. However, those who are not familiar with ED are often curious about how guilt and shame are related to ED. Therefore, this section will begin with an overview of the similarities of and differences between

guilt and shame (Tangney and Dearing 2003), followed by some empirical studies that link guilt and shame to ED. Thereafter, theories of guilt and shame with special focus on emotions, thoughts and behaviours (Gilbert 2003, Tangney and Dearing 2003, Gilbert 2002) will be presented in order to give meaning to the concept used in this thesis.

Guilt and shame as twins

Experiences of guilt and shame are powerful and influence the most important areas of our lives. Guilt and shame are developed in early interpersonal relationships and have an impact on individual interpersonal behaviour throughout the lifespan. They are self-conscious, and moral emotions, which involve both evaluation of one self and one's moral behaviour (Tangney and Dearing 2003).

Guilt and shame are multifaceted experiences. The components focused upon in this thesis are categorised on emotional, cognitive and behavioural levels, indicating that guilt and shame comprise a complexity of feelings, cognitions and actions, which vary from person to person. In the present thesis, guilt and shame are not systematically divided; hence they occur as 'twins' often at the same time and triggered by the same events, in an individual manner. Although frequently mentioned together, these two phenomena need to be distinguished by clarifying their similarities and differences. Tangney and Dearing (2003) have presented an overview of these similarities and differences, see Table I.

Table I: Similarities of and differences between guilt and shame, from Tangney and Dearing (2003, p. 25).

FOCUS	**GUILT**	**SHAME**
Similarities of guilt and shame		
Emotions	Moral	Moral
Awareness	Self-conscious emotions	Self-conscious emotions
Valance	Negative	Negative
Attribution	Internal	Internal
Context	Interpersonal	Interpersonal
Events	Negative, similar to shame	Negative, similar to guilt
Differences between guilt and shame		
Evaluation	Focus on behaviour (what I *did*)	Focus on the self (on what *I* did)
Degree of distress	Less painful than shame	More painful than guilt
Self experience	Tension, regret, remorse	Shrinking, feeling worthless, small, powerless
Operation of self	Unified self intact	Split self: observing and observed
Impact on self	Self unimpaired by global devaluation	Self impaired by global devaluation
Concern about the other	One’s effect on others	Others’ evaluation on self
Counterfactual processes	Mentally undoing some aspect of behaviour	Mentally undoing some aspect of the self
Motivational features	Desire to confess, apologise, repair	Desire to hide, escape, strike back

Guilt and shame as integrated into patterns of ED

The fact that few of those who suffer from ED receive treatment (N.B.o.H. 2000) may be due to lack of individual motivation for change (*cf.* Geller 2006). This finding can also be understood as a result of the mechanisms of guilt and shame, which can prevent the individual from seeking help. An early study of American students (n=94) reported that women with ED experienced more guilt and shame in relation to eating than either normal or depressed women (Frank 1991b). It may seem as if guilt and shame are woven into experiences of ED and manifested through concrete bodily experiences such as eating and purging. Several researchers have focused on the relation between ED, guilt and shame, and some of these studies are presented in the following section.

In a German study, Grabhorn *et al.* (2005) revealed higher internalized shame scores in patients with anorexia and bulimia than those with anxiety and depression. They also found that, in patients with ED, performance-anxiety, perfectionism as well as low self esteem related to appearance were predictors of shame and argued that therapeutic strategies should focus on the affect of shame and social anxiety (Grabhorn *et al.* 2005).

A study of 97 Australian women with ED explored some affective processes with special focus on guilt and shame in relation to their ED behaviour. The study revealed that the severity of ED is related to "Shame and guilt in eating contexts and to shame about the body" (Burney and Irwin 2000, p. 58). The act of eating intensified the feeling of shame. Women with ED tended to condemn the disturbed eating behaviour (guilt) and their own inadequacy in this regard (shame). Hence, "eating-associated shame emerges as a substantially more important consideration than is eating-disordered guilt" (Burney and Irwin 2000, p. 58). These authors suggested more research on the role of the affects of guilt and shame in patients with ED.

Jambekar *et al.* (2003), who examined the relationship between shame and behavioural and attitudinal features of ED in men and women suffering from binge eating disorder, found that the level of shame seemed to be similar between genders and surprisingly not related to the degree of overweight or the frequency of bingeing. However, in men, shame was related to how dissatisfied they were with their bodies, while in women, it concerned worries about weight and dietary restraint. The latter finding was associated with femininity (eating small amounts or low calorie food intake) (Jambekar *et al.* 2003).

Swan and Andrews (2003) investigated ED, disclosure, depression and different shame aspects of ED in a group of women who had been treated for ED (n=68) and compared them to a non-clinical group (n=72). They found that, overall, the women with ED as well as those who had recovered scored higher across areas of shame than the control group. The investigated areas of shame included bodily characteristics, non-physical characteristics, general behaviour and eating behaviour. It is also interesting to note that 42% of the ED women reported non disclosure about themselves or their ED behaviour during treatment. These findings suggested that "non disclosure in treatment was most common around eating behaviour and other ED symptoms", and therapists need to directly address issues related to shame in therapy (Swan and Andrews 2003, p. 375).

Troop *et al.* (2008) measured anorexic and bulimic symptoms, depression and shame in women who had a history of ED (n=224) and revealed different types of shame related to various ED symptoms and that the severity of the ED was predicted by the shame level. The above findings were not affected by symptoms of depression and thus demonstrated that the level of external shame was related to anorectic severity (especially the degree of underweight), while internal shame was associated with bulimic severity (in particular over-concern with body weight and shape). External shame was linked with others perceiving the self as inferior, while internal shame was related to one's

inner feeling of shame. They also found that although women who were in remission from ED reported a lower degree of shame, they still exhibited a higher level of external shame compared to the non-clinical sample. The authors suggested that a high level of shame has an impact on the likelihood of seeking treatment as well as on the therapeutic relationship of those who attend treatment (Troop *et al.* 2008).

Goss and Allan (2009) reviewed research linking shame to ED and the possible role of shame and pride in the onset and maintenance of this condition. They discussed the clinical implications of their finding that experiences of shame vary. For instance, they suggested that being trained to recognise and manage shame and pride responses would be beneficial for clinicians. "An empathic, collaborative and empowering stance is likely to be crucial in treatment, as shame is likely to be triggered relatively easily, particularly at the beginning of therapy". Other implications may be to offer psychoeducation on the functional nature of ED or to try to improve the individual's social relationships by means of, for instance, group based approaches (Goss and Allan 2009, pp. 312-313).

Women with anorexia (n=13) were interviewed in a Norwegian qualitative study by Skårderud (2007c). Types and sub-types of shame were defined and related to the symptoms and meanings of anorexia. Two main types of shame were revealed; (1) globalized internal shame, which referred to a general sense of shame of being who one is; (2) focuses of shame, which were divided into several categories and sub-categories: feelings and cognitions (greed, envy, sadness, grandiosity, rage); failure to achieve, body shame (appearance, body function), self-control and self-destructive behaviour (self-control, self-mutilation, self-destruction), shame related to sexual abuse (being made to feel inferior, shame about not resisting) and, finally, shame about having an eating disorder (the problem of eating, the self-accusation of vanity, social stigma). The author also explored the feeling of pride as the opposite of shame. The categories were: self-control, being

extraordinary, appearance, rebellion and protest. A shame-shame cycle and a shame-pride cycle were presented and described as self-perpetuating mechanisms in anorexia. The author also illuminated 'silence' as a shame-expression that challenges the therapeutic relationship and health promoting dialogue; shame represents withdrawal, sabotages dialogue and has the potential to make the therapist feel "shut out" (p. 95). An implication for clinicians is to be aware of the deeper understanding of shame and its potential influence on the therapeutic relationship with the patient (Skårderud 2007c).

Guilt and shame as rich human emotions

The feelings of guilt and shame are "rich human emotions" serving important individual and relational functions (Tangney and Dearing 2003, p. 2). Guilt is defined as: "An emotional state produced by thoughts that we have not lived up to our ideal self and could have done otherwise" and shame as: "A painful emotion caused by a strong sense of guilt, embarrassment, unworthiness or disgrace" (Dictionary.com 2010). They are private, intimate and moral as well as guiding our behaviour and being "inextricably linked to the self in relationship with others" (Tangney and Dearing 2003, p. 2).

Guilt and shame are parts of a set of emotions (shame, embarrassment, pride and guilt) that can be referred to as secondary or higher-order and are developed later than primary emotions (anger, fear, sadness, joy). They start to unfold at about two years of age and depend on various competencies such as being able to recognise the self as an object for others. These self-conscious competencies can blend with and recruit negative primary emotions and reduce positive primary emotions (Gilbert 2002).

Zupancic and Kreidler (1999) suggested that a consequence of shame is the disablement and prevention of appropriate expressions of feelings in adulthood (Zupancic and Kreidler 1999). Guilt indicates anxiety; it is a reminder of a threat to the personality (Peplau 1991). According to

Lindström (2003), guilt is closely related to feelings of responsibility. Anxiety may often be a consequence of guilt and responsibility and can lead to a feeling of being limited, the most severe consequence of which may be a desire not to exist. Gilbert (2002) claimed that feelings of shame are rooted in a self-focusing system leading to defensive emotions, for instance anger, anxiety or concealment, while feelings of guilt are grounded in concern about the welfare of others (Gilbert 2002).

The emotional component also includes emotions developed when in a state of shame such as anxiety, anger or disgust with the self. Shame can be viewed as an affect associated with interruption or sudden loss of positive affects. The opposite of shame is often seen as pride, hence positive affects are inhibited when in a state of shame (Gilbert 2002).

Feelings of shame are more painful and harder to describe than feelings of guilt, and the sense of being physically small and inferior is commonly associated with shame. Experiences of having less control over situations involving shame than those involving guilt are common as is the feeling of being more observed by others and more concerned about their opinion of the self in shame-related reactions than in guilt-related reactions. Feelings of shame may generate a stronger desire to hide from others compared to guilt (Tangney and Dearing 2003).

Guilt and shame as awareness and self-conscious thoughts

The cognitive component of guilt and shame is social/external and includes automatic thoughts that others are looking down on oneself in a condemning and contemptuous way. The individual experiences an internal self-evaluative process comprising a global negative self-evaluation and, self-critical and self-attacking thoughts, which are essentially self-devaluating and internally shaming (Gilbert 2002). The core of shame is negative self-evaluation, an emotion associated with self-related cognitions that are based on negative characteristics. The affect of shame serves certain functions: amplifying awareness,

moderating intensity and protecting one's humanity (Zupancic and Kreidler 1999). Peplau (1991) claimed that guilt most often operates outside awareness. According to Tangney and Dearing (2003), awareness refers to self-conscious emotions related to both guilt and shame. From this perspective there is a close link to intrapersonal relationships, as guilt and shame affect self-esteem.

Guilt and shame are fundamentally tied to self perceptions (Tangney and Dearing 2003). The 'body shame' concept directs awareness to negative characteristics of the body's appearance and functions. Crossley (2006, p. 2) claimed that "In the face of transgression or error, the self turns toward the self – evaluating and rendering judgement". Our awareness of our body concerns how it is available to and externally perceived by other people; the body becomes an object as we adopt other people's perspectives towards ourselves (Crossley 2006). Internal and external shame and humiliation can be identified by developing self-awareness competencies and reflecting on the stigma of body shame (Gilbert 2002). However, Tangney and Dearing (2003) argued that shame results from self-relevant meanings attributed to an event and may occur before the development of self-conscious competencies.

Guilt and shame as motivators of different behaviours

The motivational and behavioural features of guilt comprise a desire to confess, apologise and repair. The motivational features of shame are rooted in devalued self and characterised by a desire to hide, escape and strike back (Tangney and Dearing 2003), leading to withdrawal and negative self-evaluation (Dickerson *et al.* 2004).

Shame may be viewed on a continuum from being a positive protector of one's humanity, which involves controlling one's behaviour and offering societal boundaries, to being extremely negative, destructive and debilitating, leading to low self-esteem, poor body image and insecurity. Tangney and Dearing (2003) claimed that the implications

of guilt and shame in terms of negative impacts on interpersonal behaviour are different: The feeling of shame is extremely painful and ugly, leading to negative interpersonal behaviour such as blaming others, bitterness and hostility. The feeling of guilt may lead to more beneficial interpersonal impacts such as empathy for others and acceptance of one's responsibility. These patterns have, according to Tangney and Dearing (2003, p.3), "the most direct applied implications – for parents, teachers, and clinicians alike".

Shame exerts an influence on interpersonal behaviour throughout the life span and is developed from early interpersonal experiences (Tangney and Dearing 2003). It can be viewed as an "affective-defensive response to the threat of, or actual experience of, social rejection or devaluation (loss of status) because one is (or has become) unattractive as a social agent" (Gilbert 2002, p. 7). Human beings are sensitive about how attractive they are to others and have competed against each other for millions of years, thus the power of attraction is important.

Shame leads to specific defensive behaviours such as a strong urge to avoid exposure, not to be seen, or to conceal. Gilbert (2003, p. 1205) claims that "the fear of shame and ridicule can be so strong that people will risk serious physical injury or even death to avoid it". When anger is elicited, the desire to gain revenge can be strong and focusing on the other as bad is referred to as humiliation (Gilbert 2002). However, there is little evidence for the assumption that the consequences of the painful feeling of shame make people avoid doing wrong things.

Moral behaviours have "been associated with the tendency to experience guilt but not shame" (Tangney and Dearing 2003, p. 216). From this perspective, shame is considered a function that was more relevant at an earlier stage of evolution in a less sophisticated and simpler human society, which is in accordance with the approach taken by Gilbert (2002). As moral emotions, guilt and shame guide moral

behaviour, although guilt is more likely do so than shame, as guilt fosters more constructive and responsible behaviour while the painful feeling of shame leads to self-destructive behaviour (Tangney and Dearing 2003).

Peplau (1991) claimed that guilt "may be observed in actions rather than in what is said" (p. 137). Revealing guilt feelings to others may lead to feelings of security. In contrast, the intense anxiety caused by guilt may lead to secrecy, which explains why the latter is a coping strategy (Peplau 1991).

2.2 Being a mother with ED

All the informants in the present study were mothers with ED (Papers I-IV). Previous studies on mothers suffering from ED were used as a background for discussion of the empirical findings in the inductive part of the present study (Papers I, IV). Most of the women who participated were positively surprised by the knowledge that they were not alone in being a mother with ED, as they believed that ED only concerned young girls. This also applies to a large number of healthcare workers who, according to Patel *et al.* (2002), are often not aware of the risk to the children of mothers with ED. This section illuminates a sample of empirical studies that links motherhood to ED in order to give meaning to the context of the information provided in the study (Patel *et al*. 2002).

The context of mothers with ED highlights on the public health perspective, as 90% of those who suffer from ED are women of childbearing age; it is estimated that ED affects women between the ages of 15 and 40 years (N.B.o.H. 2000). The gender aspect of the fasting, purging or overeating body illustrates the conflict between a "traditional female gender role of nurturer, mother and carer and the expectations placed upon a woman in a modern society" (Ogden 2003,

p. 211). However, ED has existed in many cultures for hundreds of years. For instance Frank (1991a) described 'the medieval holy women' as an example of disciplined bodies and attempted to understand their fasting, self-mortification practices and struggle to achieve autonomy in a patriarchal culture (Frank 1991a). The N.B.o.H. (2000) reported that ED is associated with body disturbance, an individual experience of being fat and a powerful desire to lose weight. A common feature is the persistent disturbed eating behaviour, aimed at controlling weight, which significantly oppress health and psychosocial functioning (Fairburn and Walsh 2002).

The increased risk of mental illness makes motherhood a vulnerable phase (Kersting *et al.* 2003), and for those who already suffer from mental health problems, the situation is even more difficult as the mother-child relationship has a variety of social and relational contexts that can challenge a woman. Parenting capacity may be affected by the mother's problem (Stein 2002, Stein *et al.* 1999) and a mother may sacrifice her own health for the sake of her children's well being (Ruddick 1989). The children, who often internalise their mothers' experiences, may be negatively affected by a mother's problems (Barnett *et al.* 2005, Stein 2002).

Kersting *et al.* (2003) claimed that outpatient psychotherapy for mothers is extremely necessary due to their anxiety about being separated from their children as a result of hospitalisation. A qualitative study investigating mothers with serious mental illness revealed the category 'keeping close' (Montgomery 2005), which described their efforts to have a meaningful relationship with their children in the context of illness and suffering.

It has been suggested that the children of women who suffer from ED are a risk group (Stein *et al.* 2006, Barnett *et al.* 2005). Barnett *et al.* (2005) hold that there is a trans-generational effect from parent to child, as children internalise their experiences, and described a project aimed at encouraging changes in ED behaviour. Women who suffer from ED are often reported to be perfectionist (Forbush *et al.* 2007, Halmi *et al.* 2000), and it can be assumed that perfectionism also has an influence on the desire to be a perfect mother. This might lead to repeated failure, thus increasing the gap between reality and the perfectionist ideal, and experiences of failure can be a risk factor in those with ED, as they maintain the condition (*cf.* Buhl 2002) and the ED circle (*cf.* Fairburn 2002).

ED is a common source of mental health problems in women of childbearing age (Patel *et al.* 2002), and two UK community case file audits estimated that approximately one third of the female clients attending outpatient ED services were either mothers or pregnant (Bryant-Waugh *et al.* 2007a). Studies have revealed that the changes associated with pregnancy and the postpartum period may be difficult for such women (Patel *et al.* 2002, Stein 2002, Stein and Fairburn 1996, Stein *et al.* 1994). Higher perfectionism scores (Forbush *et al.* 2007, Halmi *et al.* 2000) as well as living a double life (Pettersen *et al.* 2008) might also apply to motherhood and make daily life challenging. However, a Norwegian follow-up study on initially childless women (n=1.206) who became mothers had less eating problems, as well as reduced levels of alcohol use and impulsiveness, compared to those who were still childless, which indicates that motherhood has positive effects on ED. The authors suggested that these positive changes in the mothers' life situation, may have a beneficial influence on other areas (von Soest and Wichstrom 2008).

Patel *et al.* (2002) reviewed the literature on maternal ED. They identified and described five categories associated with ED transfer from mother to child: 1) a genetic influence (further research is required), 2) a direct influence on the children, by for example trying to influence them to be thinner, 3) an indirect influence that interferes with the sensitivity and responsiveness from mother to child due to the mother's preoccupation with the ED, or due to conflicts during meal times, 4) the influence of poor eating patterns, attitudes to body shape and role modelling of behaviour, and 5) the influence of generally dysfunctional family relationships. The study concluded that there is an increased risk of parenting difficulties in mothers who suffer from ED and that early intervention may prevent the transfer of the ED from mother to child.

A Chinese study on first time mothers (n=131) and bulimia and pregnancy-related factors concluded that the "transition to motherhood is a period of stress that may either precipitate or exacerbate disordered eating" (Lai *et al.* 2006, p. 303).

A Swedish study explored early adaptation to motherhood. A group of primiparous mothers with ED (n=41) and one control group (n=67) answered questionnaires and were interviewed about maternal adaptation and mental health problems. Practical adjustment and parenting problems in the first three months after delivery were reported by 90% of the mothers with ED compared to 13% in the control group. In response to the question about whether they enjoyed feeding the baby, half of the participants in the ED group stated 'a little or not at all' compared to one in the control group. They also reported worries related to motherhood: not having enough time for themselves; feeling disappointed; and not feeling happy or proud (Koubaa *et al.* 2008). The authors suggested that women with a history of ED should be screened and offered an intervention such as support programmes to

reduce stress or assess parenting skills. In their view such interventions may prevent mental health problems in the children.

Stein *et al.* (1994) observed mothers with (n=34) and without (n=24) ED and their 12-14 month old children during mealtimes and play in their home. First time pregnant mothers were chosen in order to develop new knowledge about the initial experience of raising and feeding a one year old child. The findings revealed that the mothers with ED were more intrusive and less facilitating during mealtimes and play and also expressed more negative emotions in relation to mealtimes, although this did not apply to play. Mothers with ED had more conflicts with their children during mealtimes and the children were less cheerful at meals and play. The children of mothers with ED tended to weigh less than those of the controls, and two independent and inverse factors were related to the infants' weight: the amount of mealtime conflict between mother and child and the extent of the mother's concern about her own shape. The authors also stressed the finding that good interaction between mothers with ED and their child revealed an important area of similarity with the control group (Stein *et al*. 1994).

In a prospective study of a general population of first time pregnant women, Stein and Fairburn (1996) measured clinical features of ED and mood in pregnancy and the postpartum period and found great changes in eating behaviour and attitudes. The most striking finding was an increase in ED problems between late pregnancy and three months postpartum, with a small number developing severe ED during the postnatal period. The study indicates that there is an increase in ED problems after childbirth. "Many women found this disturbing and would have welcomed education or advice about how to deal with the changes in eating, weight and shape that arise as a result of pregnancy".

The authors claimed that such interventions would reduce the potential risk of developing ED (Stein and Fairburn 1996 p. 324).

In a follow-up study, Stein *et al.* (2006) compared mothers with ED (n=33) and mothers without ED (n=23) by assessing children's, mothers' and fathers' psychopathology and by observing the mother-child interaction. The children were aged 10 years. They found that the children of mothers with ED were more likely than the control group to score higher ED problems, to exhibit dietary restraint and place too much importance on ideas about weight and shape. Their scores were comparable to food avoidance emotional disorder and selective eating problems. The authors suggested two possible mechanisms as an explanation for the findings: 1) the duration of mothers' ED problems, and 2) the amount of mother and child-conflict at mealtimes when the child was five years old. When these two factors are strong or of long duration, the mother's ED has a direct influence on the child and increases the risk of the child adopting the mother's ED behaviour and attitude. The authors also pointed out the possible genetic influence and the fact that this issue was beyond the scope of their study (Stein *et al.* 2006).

Barnett *et al.* (2005) took a preventive perspective and argued for an intervention for mothers with ED in order to reduce the risk of their children developing similar problems. Although the sample was small (n=8), they concluded that "While actively focusing on the mother/child relationship, the benefits of the group spilled over and enabled the mothers to examine their own issues, with the resulting advantage of reducing the damage to both mother and child" (Barnett *et al.* 2005 p. 210).

In an intervention specially designed to meet the needs of mothers with ED, Bryant-Waugh *et al.* (2007a) identified themes that are considered important for such mothers and health care workers to address. Ten main themes described the concerns of mothers who suffer from ED: passing on traits, food preparation and provision, interactions around food and mealtimes, mothers' food intake, self care, self identity and parental expectations, impact on the general parent-child relationship, need for control, the group experience as well as practicalities and format. Various aspects of the motherhood role, such as mealtime interactions, food preparation and the potential influence of own eating behaviour on the children, were highlighted as difficult. They also revealed concerns related to a broader aspect of their parenthood, which were associated with lower self-esteem compared to controls and indicated that these mothers need to be offered a group intervention incorporating both general parenting skills and more specific ED topics. The study emphasised the importance of offering them support "in an environment that they would feel able to attend" (Bryant-Waugh *et al.* 2007a, p. 355).

In a follow-up study, Bryant-Waugh *et al.* (2007b) reported a preliminary evaluation of an eight session group intervention for mothers suffering from ED. The intervention was designed on the basis of the results from an earlier study, targeting women with children under the age of five. Eight sessions were held with a structural focus on 'Interactions around food and mealtimes', 'Food preparation and provision', 'Mothers' intake', 'Self care', 'Self identity and expectations of the role of parent', 'Need for control', 'Impact on the general parent-child relationship', and 'Group debrief session' (pp. 442-444). The intervention was evaluated in terms of feasibility, acceptability and the potential to lead to meaningful changes. The participants assessed the intervention format as well as the eight sessions as useful and valid. They reported, for example, that forming a group of mothers in the same situation made it comfortable to raise

personal issues. It was helpful to know that they were not alone with their problems. Obtaining practical suggestions and advice from others was very useful and individualised homework tasks were preferred. However, some of the mothers reported that talking about the ED problems was difficult and they suggested the formation of groups for women with similar conditions such as bingeing-purging or anorectic behaviours should be formed. Many of the participants were driven by a desire to succeed and worried about how the ED would affect their children. Overall, the authors found the intervention beneficial; "In terms of potential for clinical effectiveness, we found a suggestion that parenting concerns might be reduced and that mood might be enhanced through group participation" (Bryant-Waugh *et al.* 2007b, p. 446).

2.3 Mental Health Nursing

> *…nursing is to refine and nourish; this concerns the body, soul and spirit. To refine may for instance mean to help a patient to free herself from harmful experiences or shame and feelings of guilt by helping her to express herself to one who is willing to listen and contain* (translated from the Norwegian) (Lindström 2003, p. 96).

The nursing perspective presented in this thesis provides a theoretical background for the implications for practice that emerged as a result of this study (Papers I-IV). The main focus of MHN is practical and theoretical, with the aim of helping patients who suffer from mental health problems as well as their families. Nurses continuously try to understand the patient and his/her situation, want him/her to suffer as little as possible and deal with or overcome the difficulties by means of various interventions. One goal can be to help the patient to disclose concealed problems and define goals such as making meaningful life changes. As a result of intimate contact with patients and their

problems, nurses are close to the patients' experiences. According to Lindström (2003), the basic act of nursing is based on professional nursing, playing and teaching. The principal acts of nursing are cleaning and nourishing, which involves the body, soul and spirit. Cleaning may, for instance, mean listening to and containing a patient's negative experiences (Lindström 2003). One concrete example of core nursing actions in MHN is leading the patient to a greater level of awareness. By helping the patient towards such a state, he/she is empowered to dare to listen to his/her inner self. This is achieved by means of a nurse who listens, clarifies, confronts, interprets and teaches. By, for instance, observing or listening to what the patient may not dare to see or hear, the nurse can create an opportunity for the patient to dare to listen to him/herslf and thereby, perhaps, achieve insight. The core of MHN is love, responsibility and mercy. The presented perspective mirrors the inner core of the nursing domain. A playful and engaged attitude on the part of the nurse involves the ability to unite the fantasy and the reality in the situation, thereby creating and identifying in an abstract way (Lindström 2003). Mind and body are viewed as a single unity, and what happens in the parts affects the whole in the context of the total organism (Hall and Lindzey 1978). In MHN one should be continuously aware of the overall premise of the holistic approach: that the whole is superior to the parts (Lindström 2003).

Akerjordet and Severinsson (2004) argued that in order to be sensitive to and understand clients' inner need and despair and at the same time maintain self-awareness, it is important for mental health nurses to be emotional intelligent, which is characterised by the relationship with the patient, the substance of supervision, motivation and responsibility.

Nursing, sharing knowledge and communication

Lindström (2003) highlighted teaching as a commonly used example of the act of nursing. Teaching, or sharing knowledge and experiences, is a human process that involves a cognitive dimension that is difficult to

replicate, and sharing tacit knowledge is the sharing of personal beliefs about a situation (Engström 2003). Different backgrounds, perspectives and motivation demand that the individuals involved share emotions, feelings and mental models to create mutual trust. A mentoring dyad is a typical arena in which individuals can share tacit knowledge and establish a context characterised by care and trust by means of important face-to-face interaction and conversation (Engström 2003). MHN may benefit from mentors' activity and roles such as supporting, encouraging, guiding, advising, reflecting and educating (Clutterbuck 2004). These actions may help the patient be aware, as described by Lindström (2003). The mentorship role focuses on the mentor as a companion who helps the groups to deal with different issues such as sharing knowledge, which is a "uniquely human process involving a cognitive dimension that is difficult to replicate" (Engström 2003, p. 37). This process is a learning alliance, where both parties acquire the same amount of insight, focusing on helping the learner to achieve independence and self-reliance (Clutterbuck 2004). In society today it has been argued that the real source of competitive advantage is knowledge (Drucker 1998), which is also a key concept in the area of mentorship. Traditionally, the concept of tacit knowledge has been important in the area of MHN. The role of this form of knowledge has also been of importance in the area of mentorship, and Engström (2003) described it as a kind of knowledge that is "tied to the senses, skills in body movement, individual perception, physical experiences, and intuition" (p. 36), which is difficult to describe to others.

Nursing, play and art

Lindström (2003) often mentioned the act of playing as an example of central actions in MHN. Creating art is an example of a way to stimulate fantasy and create something new and may even be an aesthetic expression that communicates inner or outer experiences. Employing art as a means of communication and expression can be useful in several areas of nursing. Wikström (2000) concluded that a

visual art programme designed to communicate with elderly subjects in order to build upon their knowledge and personal experience could also be used in nursing management (Wikstrom 2000). Visual art may also be employed successfully in qualitative research to learn more about the participants. Edvard Munch's famous painting 'The Scream' is an example of a work of art being used by others to strengthen an expression. One may find this piece of art reworked in several ways all over the world as well as by patients who are attempting to express themselves, for instance their anxiety.

Art therapy is a therapeutic act that involves and integrates art and therapy as well as the act of playing. In the therapy, creating a picture is intended to develop and deepen the nurse-patient relationship as well as making is visible for both parties in the communication process. Expressions in the form of art do not disappear, hence it is possible to relate them to a verbalised theme. They mirror a process and creating them stimulates creative skills, which may activate the communication. The art work remains when verbal language is insufficient, and difficult experiences, thoughts and feelings can be expressed through visual metaphors (Minde 2000). Communication, meaning, thoughts and feelings associated with the work of art are important. Art is about using symbols and metaphors, which puts the client in a position to reflect on what has been created as well as on feelings or thoughts that may arise when looking at the works of art.

3 METHODOLOGICAL FRAMEWORK

This thesis explores and interprets experiences of guilt and shame within the context of the daily life of mothers who suffer from ED. The following section describes the methodological framework used in the study. The hermeneutical approach will first be outlined, thereafter the participants and clinical setting, the data collection and analysis methods as well as methodological and ethical considerations.

3.1 A hermeneutical approach

Employing the hermeneutical approach

A hermeneutical approach (Gadamer 2004) was used, as this method helps the researcher to gain a deeper understanding of human suffering. In the present thesis, this approach facilitated our understanding of guilt and shame and associated experiences as well as the reality, thus creating a picture of the mothers with ED, their vulnerability and strength. The hermeneutical perspective employed was derived from the inductive-deductive-abductive approach (*cf.* Eriksson and Lindstrom 1997), see Figure I. The meaning of the phenomena of guilt and shame was interpreted by me as a researcher, in accordance with my pre-understanding of the world and how it relates to the context of the investigated area (*cf.* Polit and Beck 2004). The context was mothers suffering from ED, who were patients in a University Hospital on the West Coast of Norway. In order to deepen and expand the understanding of guilt and shame, the hermeneutic circle was employed, and every aspect of the phenomena was considered as a part (*cf.* Gadamer 2004).

The interpretation and publishing of the four sub-studies (Papers I-IV) took place within a relatively short period of time (Papers I-III were

published in 2009, while Paper IV was accepted for publication in January 2010). The movement between the conclusion of one paper and the start of the next forced me into a circle of concentrating on understanding each part separately, always bearing in mind that they represented an image of a greater picture. The parts were dependent on each other as they developed into a synthesis of the new understanding, resulting in a dialogue between the different sub-studies (Paper I-IV) and the four research questions.

Consideration of the parts may, in some cases lead to the impression of being reductive in relation to the data. For instance, the separation of bodily experiences (Paper II) and mental experiences (Paper III) could give rise to such thoughts. However, this is a way of highlighting dimensions in the data and putting them into a position that allows them to be dived into meaningful pathways with a clear direction, thus giving meaning to the whole. The findings provided understanding, by means of careful carrying out the analysis and interpretation of the results (*cf.* Holm 2009).

Understanding is basic in hermeneutical thinking, and language is the medium (Gadamer 2004). Within hermeneutics, dialogue may lead to new understanding when the horizons of the participants meet that of the researcher, i.e. the fusion of horizons. According to Gadamer (2004), a genuine conversation is one we fall into or become involved in, it has a spirit of its own and no one knows what will emerge from it. Unspoken language may hide unarticulated pain, thoughts and actions or concealed bodily sensations, as described in sub-study II (Paper II).

In this thesis, the dialogue contained in sub-studies II and III (Papers II-III) was conducted within the framework of art exercises. Such a framework highlights an element of play, and Gadamer (2004) claimed that the act of playing is performed for the sake of recreation. It is the experience of the piece of art that is important, not aesthetic consciousness. Expressing symbols by means of art may reveal

experiences of the un-reflected body and can be useful in several areas, such as articulating issues related to body functioning; illness, fears and concerns; exploring alternative views of illness; investigating body image; and expanding the concept of self in the world and relationships (Malchiodi 2003) (Papers II-III).

Metaphors may be central and provide a key to understanding. Using metaphors in an attempt to understand the world and the self (*cf.* Lakoff and Johnson 1980) may contribute alternative models for understanding human experiences such as bodily sensations (Paper II). A metaphor describes a subject as being or equal to an object in some way without using the words 'like' or 'as' (Dictionary 2010). Metaphors are usually a part of imaginary thinking – something more extraordinary than ordinary. They are parts of daily life, not only in language, but also in thoughts and actions – our normal conceptual thinking and behaviour are fundamentally metaphorical by nature. The way we think, what we experience and what we do every day is, to a large degree, metaphorical. This is usually outside our awareness, and one way of finding the metaphors is by searching for them in our language (Lakoff and Johnson 1980).

Using metaphors may make conversation easier and in this thesis the mothers' art work was present in the dialogue, as it had the potential to help them open up and express their inner thoughts (Papers II-III). In hermeneutics, the researcher's task is to endow wordless language with words by means of text and capture the unspoken meaning in appropriate language (Nåden 2000). Hence, it is important for the researcher to bear in mind that the meaning shall be interpreted in its context (Gadamer 2004).

Pre-understanding

The nursing tradition is my speciality, and after several years of clinical work, I have become pragmatic, searching for practical solutions and theoretical knowledge, thus aware of the fact that patients' problems

are parts of a larger, private context. Therefore, I believe that different solutions can be found when the patients' experiences merge with of research, and thereby strengthening nursing practice.

The scholar's language, understanding and previously established pre-understanding are important aspects in hermeneutics. Moreover, Gadamer (2004) argued that pre-understanding is something that gives us access to the world, understanding is interpretation and interpretation is an absolute form of understanding.

It is important to emphasise the researcher's pre-understanding when starting a hermeneutical project. With regard to the present thesis, my pre-understanding was coloured by several years of working as a registered psychiatric nurse and supervisor in several mental health care settings – for instance, as a group leader in art therapy programmes for out-patients with mental health problems, and in cognitive behavioural therapy for out-patients suffering from ED. My experience of art therapy groups inspired me to create a programme aimed at communicating through a focus group oriented activity (*cf.* Colucci 2007) (Papers II-III). The idea was to conduct group dialogues within the framework of an art therapy programme. I believe that the process of communicating through art facilitates access to more in-depth descriptions, which have the potential to contribute deeper knowledge of the investigated area. However, I attempted to bear in mind that my pre-understanding could lead me astray as a researcher and that such programmes might hinder dialogue. The data were therefore in addition collected from individual dialogues (Papers I, IV).

One important part of pre-understanding is the formulation of the research question. When I entered the research field, clinical encounters led to my interest in mothers with ED. I came into contact with mothers who tried to conceal excessive food shopping, who had a strong propensity for bingeing and purging and who hid their ED-related problems from their close family members. These meetings would later

inform and inspire the research questions developed in the present study as I began to wonder what their daily lives were like outside of the clinical setting, in their life-world (Papers I-IV).

During the analysis, the dialogue formed an important part of the pre-understanding, which illuminated the mothers' vulnerabilities as well as their strength (Paper III). This sub-study reveals the obvious balance between strength and vulnerability and highlights the sense of strength more than the other three sub-studies (Papers I, II, IV), which provide a more accurate description of the experiences of the mothers who participated in the studies. Mothers with ED are both strong and vulnerable (Paper III).

Gadamer (2004) claimed that the author's pre-understanding is always taking shape. The process underlying the studies comprises a circle of meditating, searching for new understanding and using it as a pre-understanding for the next interpretation – as described in the hermeneutic circle (Gadamer 2004). In the present thesis, the four papers illustrate the process of understanding and pre-understanding.

Engaging in a dialogue with the participants, both in the focus groups (Papers II-III) and in the individual interviews (Papers I, IV), implied that, as a researcher, I listened carefully and was able to understand the women's words. In this phase the researcher must be aware that his/her pre-understanding may influence the dialogue (Holm 2009). For instance, the overall aim of this thesis mirrors my pre-understanding before the start of the project, namely that mothers with ED experience feelings of guilt and shame related to their condition. This phase highlights what I believe is one of the main weaknesses of the programme. It was vital that I did not attempt to force guilt and shame on these mothers but remained open in the dialogue about these concepts. As a researcher, I had to take care when I introduced guilt and shame into the dialogue, especially in sub-study IV (Paper IV), where these concepts constituted the explicit focus. I tried to adopt an

attitude that treated guilt and shame as general human experiences that are likely to reflect and relate to different contexts of our lives. At the same time, I constantly tried to validate the meaning of the individual expressions articulated by the mothers.

As described above, the process from the beginning to the end of this thesis was dynamic, where the parts gave meaning to the whole, and the whole gave meaning to the parts, thus allowing it to be seen as part of a greater picture. The four sub-studies (Papers I-IV) endow the synthesizes with meaning to the synthesis. In the process, the chaos and structure, as well as the clinical understanding and theoretical knowledge, have dialectically moved into a centre where the synthesis of each sub-study has been formed and completed at the end of the project. Hence, the project itself gives new meaning to the area of guilt and shame related to mental health problems and motherhood. The data have to be understood, and "in order to develop an interpretative synthesis (…) new understanding must be based on earlier theory and research" (Holm 2009, p. 35).

The organisation of the data was guided by the overall aim of this thesis and research questions (Papers I-IV). Paper I illuminates challenges in a mother's life, due to living with ED and raising children. It contributes new understanding of the quality of the lives of mothers with ED, their guilty conscience related to being good enough and their preoccupation with not involving the children in the ED. The paper creates the first pillar of knowledge for the rest of the study, providing relevant answers to the question: Why explore guilt and shame in mothers with ED?

Thereafter, Papers II and III explore the mothers' daily life experiences, but without considering the context of motherhood. The powerful feelings of being trapped and ashamed of one's own body (Paper II) and the balance between mental vulnerability and strength (Paper III) generated an understanding of how these mothers are challenged by

their suffering body in daily life, thus helping the reader to understand their mental battle.

The final sub-study (Paper IV) moved more deeply into the hermeneutic circle, using the previous papers (Papers I-III) as well as earlier studies and theory to investigate the data on guilt and shame expressed by the mothers. As the aim was to interpret guilt and shame, the study searched for descriptions and meaning of the mothers' experiences related to the ED and being a mother, which revealed their experiences of struggling in silence, worrying and wanting to be successful, as well as thinking negatively about their own responsibility (Paper IV).

When the four sub-studies (Papers I-IV) had been developed, a synthesis of the main findings was made. At that point I was convinced that the findings reflected different images of the mothers' experiences (see chapter 6.).

3.2 Participants and clinical setting

In late 2005, a letter containing information about the study and a request for informants was sent to all therapists in a University Hospital on the West Coast of Norway, three communities and a Centre for Eating Disorders. Participants were to be recruited for a 15 session group programme with focus on ED, daily life, guilt and shame and being a mother. Inclusion criteria were mothers suffering from ED who did not have major problems in the areas of drugs, disability or co-morbidity such as psychosis or other serious mental illness. There was no age limit for the participants or their children.

Six mothers joined the programme, although one withdrew before I started audio-taping the focus-group sessions (Papers II-III). However, she agreed to join the individual meetings (Papers I, IV). The sessions

took place in spring 2006 at the Outpatient Unit, which offers a group treatment programme for patients with different diagnoses, including ED. The integrated programme was based on cognitive as well as art therapy conversations. Both group leaders were registered psychiatric nurses, specially trained to work with patients with ED, by means of art therapy and cognitive treatment.

A total of eight mothers participated as informants in the sub-studies of thesis (Table II). They were aged between 25 and 45 years, had one to three children, whose ages ranged from three to 25 years. First, the group programme was performed, which contained focus group reflections (Papers II-III). Five mothers participated in this step. Then, two individual dialogues between the eight mothers and the researcher were conducted (Papers I, IV).

Sub-studies II-III (Papers II-III)
In spring 2006, seven focus group interviews were carried out in a group programme with five mothers suffering from ED at the Outpatient Unit of the University Hospital. The meetings were attended by three to five women; however, all participants joined the discussion of the different focuses because they were introduced in more than one session. The five participants had ED symptoms, which varied from severe binge eating, purging, and fasting to body dissatisfaction. One participant had almost overcome her ED, one was hospitalised for 3 days due to depression during the study period, four were out-patients and one was an in-patient. Since the start of their ED (10 – 14 years) only one participant had been symptom free (while pregnant).

Sub-studies I and VI (Papers I, IV)
Two individual interviews were conducted with eight mothers with ED from June to November 2006, at the Outpatient Unit of the University Hospital. Of the eight mothers who participated, one was an in-patient and seven were out-patients. Although two had almost recovered from their ED, they had all experienced long-term suffering; major eating-

problems, bingeing, purging, weight problems and body-shape concerns.

Table II: *Overview of the mothers who participated in the four sub-studies (Papers I-IV). Mothers from Papers II and III are presented in bold text.*

Mother	Age	EDduration	BMI	Children	Children's age
1	**48**	**12 years**	**14.9**	**3**	**25, 22, 18**
2	44	30 years	18.5	3	23, 20, 11
3	**42**	**10 years**	**33.1**	**2**	**13,17**
4	36	*	*	2	7,4
5	**32**	**10 years**	**24**	**2**	**11, 4**
6	**29**	**14 years**	**18.9**	**2**	**9.3**
7	**28**	**11 years**	**20**	**2**	**10, 8**
8	23	*	15.8	1	3

* = unknown

3.3 Data collection methods

The following section describes the data collection methods used for this thesis under the following headings: overview of the data collection, focus group dialogues and individual dialogues.

Overview of the data collection

As described earlier, the data collection was performed by interviewing mothers within the framework of a pre-designed group art programme

(Papers II, III) and individual dialogues (Papers I, IV). Qualitative data collection methods based on small samples, various forms of content analysis and unstructured interviews were used (Brink and Wood 1998). The data collection for this thesis was carried out in the following steps:

1) The mothers were informed about the study and described their ED and demographics.

2) Qualitative data were collected in group sessions (Appendix I) performed as focus group interviews. The dialogues were audio-taped and transcribed verbatim by the researcher. Five mothers participated in a 15 session programme and three to five took part on each occasion. Seven of these sessions were audio-taped.

3) Two individual interviews were conducted with eight participants focusing on ED and daily life experiences (both interviews), motherhood (first interview) and guilt and shame (second interview). The interviews were audio-taped and transcribed verbatim by the researcher.

4) The data included photos of art produced during the art sessions (Chapter 6.).

Focus group dialogues in a programme (Papers II-III)
This section will describe the focus group format used for data collection for the two sub-studies (Papers II, III).

There has been a growing interest in and recognition of focus group discussion as a valuable qualitative data collection method (Colucci 2007). The focus group as used in the sub-studies in this thesis (Papers II-III) is a technique “that collects data through group interaction on a topic determined by the researcher”, where the researcher’s interest provides the focus and the data come from the group interaction (p. 6)

(Morgan 1997). The formats of focus groups vary and are decided by the researcher, in accordance with the specific aims of the study. Morgan (1997) stated that more creative uses and formats for such groups remain to be discovered.

When the research area involves patients, as in the present thesis, the participants have an ethical and moral responsibility to each other, about which they are informed at the start of the meeting. For the group art programme employed in sub-studies II and III (Papers II-III), this information was provided at the start of the first session. The participants' reliance on the researcher and the interaction within the focus groups may be argued to have a direct impact on its strength or weakness (Morgan 1997). As the group in the present sub-studies (Papers II-III) met several times, the participants and researchers became familiar with each other and the interaction took place in a safe milieu. For instance, there was no conflict between the participants but a friendly and confirmatory attitude, sometimes engaged and sometimes empathetic. Overall, the sessions were characterised by interactions that were coloured by the mothers' shared experiences, which seemed to enhance their knowledge and lead to a deeper understanding of the themes discussed (*cf.* Morgan 1997).

A Registered Psychiatric Nurse and I acted as moderators, while I also functioned as the researcher. We introduced the topics to the group, invited the participants into the discussion and relied on the group interaction to provide the data. In order to achieve good quality data, the moderator must find appropriate ways of approaching the participants. Colucci (2007) argued that using activity-oriented questions in focus group discussions may encourage answers and give rise to discussions. This may be particularly beneficial for participants who are less likely to respond immediately, are reflective, need extra time to think and prefer to present ideas in the form of pictures when talking about sensitive or threatening topics. Drawing a picture of, for instance, a behaviour, idea or attitude and thereafter describing it to the

group is one example of the projective activity-oriented techniques described by Colucci (2007). The participants can also be asked to reflect on daydreams and fantasies related to a topic. These exercises accomplish their purpose when the moderator invites the participants to describe their answers in depth, to provide more details, to apply them to a real situation and express agreement or lack of agreement with other participants' feedback. Due to creative and complex answers, the interpretation and analysis of projective questions may be challenging (Colucci 2007).

In the present study, a pre-designed group art programme (Appendix I) was conducted as a means of collecting data and using activity-oriented techniques. The group art programme aimed at stimulating deeper verbal reflections as described by Colucci (2007) and its structure was planned in advance and evaluated by the leaders immediately after each session. The nurse leaders' interaction in the groups was based on communication with a clinical purpose related to the participants' dialogue. The goal of the art expression was to obtain data enriched by metaphorical and verbal reflections through focus group discussions (Papers II-III). The therapeutic consideration was that this setting might stimulate the women's sense of self-efficacy as well as social contacts during their recovery process (*cf.* Nilsson 2007) and encourage them to express previously non-articulated aspects of their lives (*cf.* Colucci 2007).

All themes were introduced by the nurse leaders, followed by warm up exercises, and the discussion took place at the end of the sessions. At the start of the programme, some basic psycho-education was presented to the participants on the benefits of the cognitive model of ED with focus on regular meal times (*cf.* Fairburn 2002). When the art exercise was held, the women were encouraged to concentrate and work in silence. The themes were discussed by the participants before and after the activities. Each session comprised an introduction, general conversation, an art activity and deep verbal reflection. This schedule

was flexible and sometimes the sessions took on a different form (for instance devoting less time than planned to art activity and more to reflections). However, the start and end of each session was always kept within the time frame. During the meetings, the participants became more and more familiar with each other and shared experiences, knowledge and a deeper understanding of themselves. I audio-taped and transcribed sessions 9 to 15.

Individual interviews (Papers I, IV)
Individual interviews allowed closer communication between interviewer and informant (Morgan 1997). They also offered the advantage of gaining a deeper understanding of a person's opinions and experiences. In the present study, individual interviews provided more information on the topic and more details about the mothers (*cf.* Morgan 1997).

Eight mothers were interviewed on the topics of guilt and shame, being a mother and their daily lives (Papers I, IV). This step was intended to ensure that their individual voices could be heard. The dialogue took place in accordance with Gadamer (2004). As I was looking for new understanding of being a mother suffering from ED through dialogue, I sought to engage in a genuine conversation with the mothers in order to comprehend and accept their points of view. Gadamer (2004) stated that in such dialogues it is what the particular individual says that should be understood, not the individual him/herself. The dialogue in sub-study I (Paper I) focused on the following:

- Suffering from ED in the context of pregnancy, the postpartum period and being a mother.
- Reflections about the influence of ED on motherhood and vice versa; and

- What the children know and may have observed of the mother's ED as well as how they should be informed about ED in general and their mother's ED in particular.

In the interviews for sub-study IV, the dialogue was based on the following open question (Paper IV):

- Please reflect on the feelings of guilt and shame and how they are related to your ED and being a mother. Please describe some personal experiences of guilt and shame.

The conversations lasted from 30 to 60 minutes and were audio-taped and transcribed by me.

3.4 Data analysis methods

This section describes how the data were organized, structured and given meaning. Qualitative data comprise transcribed text in the form of loosely structured narrative materials collected in the dialogue between the researcher and the informant. The analysis process aims at organising, structuring and identifying experiences in the research data. Important themes are searched for from the outset of the data collection starts (Polit and Beck 2004).

Qualitative content analysis: Papers I-IV
A qualitative content analysis in several steps (Graneheim and Lundman 2004) was used as a basis for organising the data in all four sub-studies (Papers I-IV). The transcribed text was read several times in order to gain a deep understanding and comprehend essential features. The first step of the analysis included identifying themes as well as gaining "an understanding of the meaning by listening to the tapes and reading the text as a whole" (Holm 2009, p. 44). The

interviews were then structured and themes and sub-themes identified. During the analysis the researcher searched for similarities and differences in the text. In the interpretative process that balanced between the parts and the whole, the similarities and differences were linked to sub-themes, themes and a main-theme. Thereafter the themes were validated and the interpreted data discussed by the authors and the research group with focus on how to understand and discover their meaning (Holm 2009, Graneheim and Lundman 2004). The content was grouped into meaning units, condensed meaning units, sub-themes and themes. All four sub-studies (Papers I-IV) ended with one main theme, which was relevant to the research questions used in the studies.

Hermeneutic interpretation: Papers I, II and IV

After performing the qualitative content analysis (Graneheim and Lundman 2004), a hermeneutic approach (Gadamer 2004) was employed for Papers I, II and IV. This section is illuminated by the thorough description provided above of the movement of the thesis in the hermeneutic circle. According to Gadamer (2004 p. 306), interpretation is "the explicit form of understanding" and in the hermeneutic tradition "understanding is always interpretation" in the hermeneutic tradition. The interpretation is inspired by the interpreter. All sub-studies (Papers I-IV) were placed in the hermeneutic circle as described previously, and their position demonstrates how the analysis of the findings of one study inspired the next, as each study presented individual results. In this process, the sub-studies (Papers I-IV) were parts of the whole and influenced each other in order the development of new understanding as described in the hermeneutic circle (Gadamer 2004). A deeper understanding of the meaning of guilt and shame was developed in parallel with the work conducted in the four sub-studies (Papers I-V). For instance, in the first study (Paper I), the interviews focused on the mothers' daily lives with ED and being a mother. In the second and third sub-studies (Papers II-III), the data from the focus groups were analysed and the findings divided into a bodily (Paper II)

and mental level (Paper III). The developed themes were regularly discussed by the authors and presented at the research group meetings in order to ensure reflexive feedback and validity of the interpreted themes.

The analysis of this thesis and its four sub-studies may be summarised as follows:

1) I transcribed the interviews verbatim and saved them in the three separated data-maps with the following domains: (1) 'Focus groups', seven sessions (Papers II-III), (2) 'Motherhood', eight interviews (Paper I), and (3) 'Guilt and shame', eight interviews (Paper IV). In this phase I entered the researcher's role and abandoned that of clinician and moderator. By transcribing the interviews while listening to them, I achieved an overview of as well as distance to the informant. By changing roles I asked the text other questions to than those of a clinician and thereby discovered new areas on which to concentrate. For instance, as a clinician I had not paid attention to the interesting and rich descriptions concerning the bodily areas, which in the following steps were illuminated and analysed in Paper II.

2) In this phase I worked with the domains separately. The transcribed text was read and re-read in order to grasp its meaning, always bearing the research questions in mind. I started organising the text, which was marked with various colours to indicate different themes and wrote code words in the margins. For instance, the challenges related to feelings, thoughts and existential matters were organised under a theme which was later interpreted as of mental challenges in Paper III.

3) Text marked with the same colour was moved from its original context and grouped. Bit by bit the text was considered as a whole, thus one sub-study gave meaning to the next. For

instance, all text that related to being a mother was organised and analysed as a whole (Paper I) following the analysis procedure mentioned above (*cf.* Graneheim and Lundman 2004). Meaning units related to being a mother with ED were thereafter divided and organised into sub-themes. Meaningful descriptions were identified, and sometimes I was surprised by the rich descriptions of, for instance, being pregnant and the post-partum period. These were a result of a question aimed at making the mothers reflect on motherhood, which I believed would lead to brief answers (Paper I).

4) At this point the analysis started again, searching for a deeper understanding of, for instance, guilt and shame (Paper IV) and dividing the meaning units into different sub-themes, such as having a guilty conscience about the children.

5) The text of the different main themes was organised into one main theme, two to three themes and two to four sub-themes.

6) The text in step five was organised into a table, which initially comprised meaning units and condensed meaning units (*cf.* Graneheim and Lundman 2004) and was read by all the authors (S. Å.: Papers I, II, IV; K.V.: Paper III, E.S.: in Papers I-IV, K.R. in Papers I-IV). This phase involved reading, comparing and validating the abstraction process from the condensed meaning units to the main theme.

7) The final phase comprised the adjustment of the analysis. The meaning units were omitted, but examples of citations from the mothers were provided. The abstraction and themes were validated by involving the research groups and asking them to provide feedback on the interpretation in order to validate the results. Papers II and III were validated by the Women's Mental Health research group at the University of Stavanger. Papers I and IV were validated by the research group at the Centre for

Women's, Family and Child Health at Vestfold University College.

The phases described above included the hermeneutic process as described earlier. For instance, the themes were analysed in accordance with the research question in order to derive meaning from the investigated areas. The sub-themes were interpreted as parts of the whole, and the meaning units constituted examples that gave substance to the main theme, demonstrating that the thesis and sub-studies were based on the empirical continuum (*cf.* Lindström 2003). The authors' pre-understanding was continuously discussed at research seminars.

3.5 Methodological considerations

The qualitative explorative method was used to study and increase knowledge of the investigated area. One advantage of this approach is the close contact between the researcher and the mothers (*cf.* Severinsson 1995). Qualitative work may not always be dependent on a correctly followed method or set of rules, and it is important for the researcher to continually test his/her prejudices (Gadamer 2004). New dimensions of a phenomenon should be demonstrated to have validity and trustworthiness, and there are various concepts available for this purposes (Denzin and Lincoln 2000). According to Polit and Beck (2004), it is important to attend to both the 'art' and the 'science' when thinking about the criteria for interpreting and describing qualitative studies. The most common criteria of trustworthiness in a qualitative study were outlined by Lincoln and Guba (1985): credibility, dependability, confirmability and transferability.

Credibility refers to the truth of and confidence in the data and interpretation, which involves carrying out and describing the study in such a way as to enhance the believability of the findings for external

readers (Lincoln and Guba 1985, Whittemore *et al.* 2001). In the case of the four sub-studies (Papers I-IV), it was most important for the authors to demonstrate the validity by remaining close to the mothers' own voices and discussing the interpretation in the research groups involved. This ensured confidence in the truth of the study. The interpretation was performed in several steps, by reading and re-reading the text in order to remain as close as possible to the mothers' expressions while still allowing the authors' interpretation to be creative, built on pre-understanding an intuitive grasp of the meaning. The researchers' own perspectives and motives were described in the sub-studies.

Dependability refers to the data's stability over time, i.e. whether the findings would be repeated with the same participants and context (Lincoln and Guba 1985). The *dependability* of the four sub-studies (Papers I-IV) was ensured by being in dialogue with the participants on several occasions. However, more research could be performed in this area using other designs to compare the congruence in the mothers' expressions in the focus groups interviews and individual dialogues (Paper III). This would allow evaluation of the importance of expressing feelings of shame (Paper II), as well as the congruence between the mothers' and the children's experiences (Papers I & IV).

Confirmability refers to the neutrality of the data and allows agreement to be reached between two or more people about their relevance and meaning (Lincoln and Guba 1985). The meaning and relevance of the four sub-studies were discussed between the authors and subsequently in the research groups.

Transferability refers to the idea that the findings from the data can be transferred to other settings (Lincoln and Guba 1985). Findings from

this qualitative study are, however, unlikely to be generalised due to various limitations. For example, the small number of participants, the fact that the women were from the same culture and recruited from a small area of Norway and that they were undergoing treatment, which indicated that they might have had other motives for participation than individuals not undergoing treatment. Although these limitations are obvious, the rich descriptions have the potential to be recognised by other mothers with concealed health problems or health care professionals working with such women. If the results are presented to other groups, it should be left to the group members to decide on the possibility of transferability. Transferability depends on the reader's view, whether the he/she recognise the descriptions and themes as a result of his her own experiences and thus considers the data to be accurate.

3.6 Ethical considerations

Ethical issues were considered throughout the research process. The World Medical Association (WMA 2008) and Ethical Guidelines for Nursing Research in the Nordic countries (Guidelines 2003) were followed in order to ensure that the research adhered to current ethical principles. The anonymity of the data material was assured by coding the transcriptions by letters from A to H. Any names mentioned in the interviews were rendered anonymous. The data material was locked in a safe during the study period, and any material that could be identified will be destroyed on conclusion of the project, in accordance with the guidelines of the Norwegian Social Science Data Service.

The WMA developed the Declaration of Helsinki as "a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data" (WMA 2008). I adhered to the recommendation by Hummelvoll (2008) that

ethical considerations should be taken into account when conducting research on persons with mental health problems. Thus good ethical practice was ensured, and I as a researcher dealt with issues questions of the informants' autonomy, beneficence, non-maleficence and justice (Hummelvoll *et al.* 2010). The authors are ethically obliged to make the results available to the public and to declare any conflicts of interest (WMA 2008). The four sub-studies (Papers I-IV) in the present thesis were published in international journals on mental health nursing with a peer review system, and there were no conflicts of interest.

According to the WMA (2008), one ethical research principle is that "the research protocol must be submitted for consideration, comment, guidance and approval to a research ethics committee before the study begins". This study was approved by the Regional Ethics Committee of Norway (no. 192.05) and the Norwegian Social Science Data Service (no. 13387). Permission was granted by a University Hospital on the West Coast of Norway prior to the start of the studies. No significant changes were made to the protocol during the research period.

According to the WMA (2008), the participants must be informed about the research such as the aim of the study, methods to be employed and any other relevant aspects. This step acknowledges the participants' autonomy (Hummelvoll *et al.* 2010). Information about the right to refuse to participate in the study, the right to withdraw at any time and that withdrawal would have no consequences for future treatment was provided by me as a researcher. The participants provided their informed consent in writing. They were informed about the aim, methods and data collection procedure, as well as the fact that the sessions and interviews would be audio-taped, transcribed verbatim and only available to the researcher. They were assured that the transcriptions would be rendered anonymous and that it would not be possible to identify them.

The participants' health, dignity, integrity, privacy and the confidentiality of personal information were considered throughout the studies (WMA 2008). During the data collection period, the participants were encouraged to make contact with their individual therapist if necessary, due to the fact that the research focus could make them more vulnerable. For instance, one of the informants agreed to participate in the focus group sessions, but withdrew prior to the start due to feeling unwell among others with the same problems. However, she attended in the individual interviews. Another, who was an in-patient, was reminded that she was free to withdraw if participating in the group upset her. However, such information can indicate to vulnerable participants that they are not valuable, thus it is essential for the researchers to not only be accepting of and tolerant towards expressions of vulnerability, but also to ensure that these participants feel that they have something to contribute.

There is a latent ethical dilemma in dialogues that seek deep knowledge about difficult themes, as talking about suffering may increase pain and talking about one's senses of shame may lead to more shame. Therefore the language must find a balance between openness and a confirming and respectful manner. The aim of the dialogue is, as Gadamer (2004) stated not to get inside another person and relive his/her experiences, but to gain an understanding of the investigated area.

The planning and organisation of the study were performed by nurses with both a clinical and a scientific background, and the participants were followed up by their therapists outside the actual Outpatient Unit. This ensured an ethical and safe framework in relation to the participants' health. The design of this study highlights the participants' experiences, which ensures that the users' voices are heard in the research field in addition to the suggested clinical implications.

Overall, this study follows the basic ethical principles contained in the ethical guidelines for nursing research in the Nordic countries (Guidelines 2003); the principle of autonomy, of doing good, not doing harm and justice.

4 FINDINGS

In this chapter, the findings from the four sub-studies (Papers I-IV) are presented and related to aims. The findings constitute the basis for the interpretative hermeneutic synthesis.

4.1 Paper I: Experiences of guilt as a mother in the context of eating difficulties

The aim of this sub-study (Paper I) was to explore motherhood in the context of ED. One main theme and two themes emerged. The main theme: *Experiencing guilt as a mother in the context of eating difficulties* comprised two themes and four sub-themes. The main theme described difficulties associated with guilt, which were related to different areas of motherhood: pregnancy, the postpartum period, acting as a role model and children's need for information related to ED.

The first theme 'Having a guilty conscience in relation to being a good enough mother' revealed worries about not being adequate as a mother and feelings associated with guilt and fear. This theme comprised two sub-themes. The first, 'Devaluing oneself as a mother', was characterised by fear of not investing enough energy in the mother-child relationship and feeling bad about living a double life. Concerns that their problems had influenced the mother-child relationship and worries that the children would become aware of it were also described. The mothers wanted to be perfect, felt uncertain about the expectations on a mother and worried about being judged by others as not good enough. Feelings of guilt about not engaging in what they perceived as

a good mother-child relationship were triggered when the mothers were tired, irritated and unhappy.

The sub-theme 'Experiencing becoming a mother as a vulnerable period' comprised rich reflections about pregnancy and the post partum period, which they appeared to find a pleasant subject to reflect on. They remembered it as being one of the best times of their lives as well as the most vulnerable due to the ED. Positive experiences were: being indifferent to the ED, having a break from the ED and feeling proud of oneself. Negative experiences were: losing or gaining too much weight, being surprised by becoming pregnant due to periods of amenorrhea, self induced purging and feeling ashamed of being big. During pregnancy, ED-behaviour led to concern about the baby, and coping strategies were mentioned (abstaining from weighing oneself and taking more exercise instead of dieting). Some relapsed in the postpartum period, and two tried to seek help when the ED-related problems reappeared. However, the attempt to obtain help was unsuccessful for the two women who employed this strategy.

The theme 'Being preoccupied about not involving the children in the ED' focused on reflections about the children, worries about involving them in the ED, not knowing what information to give them and avoiding transferring the problems to them. Talking about this issue was reported as difficult but important. They described insecurity about how to act in relation to the children's meals and body shape. This theme comprised two sub-themes. 'Worrying about the influence of ED on the children', was grounded in fear of transferring responsibility, guilt or the ED itself and made the mothers try to conceal their condition. Daily meals were difficult and challenging, and they reported being anxious and irritable when eating, which was hard to cope with when the children were around. The question about whether or not to inform the children about the ED evoked different responses. They provided their children with information due to a desire to minimise the negative effect on them, while withholding information

was not recommended by one mother who had waited too long to tell her children. She advised her peers to be more open about their problems. Being aware of the children's level of knowledge as well as when and how to inform them was difficult for all the women and a subject of great interest to them. Explaining that the problems had nothing to do with the children was important. However, the idea of talking to the children about the ED made them feel uncomfortable. Providing information would oblige the mother to change their ED behaviour. It was suggested that information should be provided on the children's level in a concrete, open, honest and caring way and that they should be prepared for questions. Those who had informed their children felt good about it, believing that had they not done so, the children would sense that something was wrong, which would make them suspicious and unsecure. Those who concealed information worried that it would negatively affect the children and argued that it was better to wait until they were mature enough to deal with such information. Lying about the concealed bingeing and purging felt bad.

The sub-theme 'Feeling incompetent to deal with issues connected to the children's body shape' was reported as challenging due to the fact that they identified themselves with the child. This was exemplified by being preoccupied with checking a daughter's body shape and whether she had lost weight. Other examples were a sense of having low credibility in the area of supervising a child's weight problem and feeling uncomfortable due to being dishonest about food and meals for fear that it would confuse the children.

4.2 Paper II: The feeling of being trapped in and ashamed of one's own body: A qualitative study of women who suffer from eating difficulties

The aim of this sub-study (Paper II) was to explore women's bodily experiences of suffering from ED. The study revealed the main theme *Powerful feelings of being trapped in and ashamed of one's own body*, which comprised two themes. The main theme provided insight into the overwhelming physical manifestation of ED: a desire to be thin and obsessively devaluing one's own body. The findings are illustrated by two themes and five sub-themes.

The first theme, 'Feeling of being trapped by powerful physical sensations', reflected the inner struggle related to the three sub-themes: Experiencing physical sensations, Being physically devoted to the ED and Bodily suffering as a consequence of the ED. The sub-theme, 'Experiencing physical sensations' was described as exaggerated bodily reactions when gaining weight or feeling sated, exemplified by a feeling of bodily change when gaining a few grams, a strong obsession with weight and shape, or considering the body too big to pass through a door. The women described being obliged to diet in order to feel empty and thin. The sub-theme 'Being physically devoted to the ED' concerned being physically addicted to bingeing and purging, similar to drug addiction or obsessions. Examples of this were gearing oneself up for a kick when planning to binge eat and extreme anxiety or panic as a consequence of being interrupted when bingeing or purging. The power of these feelings was described in the group while, in contrast, pleasant feelings such as relief, peace and becoming 'high' were the outcome of stress reducing reactions such as bingeing.

The sub-theme ‘Bodily suffering as a consequence of the ED’ described the negative physical sides of the ED as well as its power. The group discussions on this theme were engaged, lively and supportive. Examples of suffering were: constantly trying to ignore the feeling of hunger; awareness of the damage to the body as a result of reduced food intake; the struggle to adhere to a diet; exhaustion due to poor physical condition; the focus on appearance; and isolation as a result of the sense of looking disgusting.

The theme ‘Feeling of being ashamed of one’s own body’ comprised an evaluation of the body. This theme was frequently reflected on and coloured by feelings of shame and attempts to conceal the ED. The sub-theme ‘Feeling of being judged by others’ was familiar to and engaged all the participants. It comprised descriptions of feeling watched by others, being judged because of their body size, fearing that they were not thin enough and feeling unwell among others. Comparing themselves with and being envious of others was also described, as was fear of being judged by the other group members.

The sub-theme ‘Hiding and lying to conceal the ED actions’ described strategies for deceiving their families and how it kept most of them busy and exhausted. These strategies were aimed at preventing family members from becoming aware of food-shopping, bingeing, purging, and dieting, all of which were planned and carried out in secret.

4.3 Paper III: Balancing between mental vulnerability and strength in daily life when suffering from eating difficulties

The aim of this sub-study (Paper III) was to explore the daily life experiences of women who suffer from ED. The study revealed one main theme and three themes. The main theme, *Balancing between mental vulnerability and strength*, revealed the participants’

experiences of emotional, cognitive and existential challenges and represented a dynamic process involving an attempt to maintain balance. Emotional chaos made them vulnerable, while awareness of the limitations imposed by the ED prompted them to seek a balance, which demanded strength as well as an existential longing for something else. The main theme was illustrated by three themes and five women participated.

The theme, ‘Struggling with emotional ambivalence’ described feelings of being empty, depression, sorrow, anxiety and resignation as well as repressed anger, the struggle to conceal feelings, overwhelming emotions. Working with and against the ED, fluctuating motivation and lack of energy were exhausting. Their own weight demands led to feelings of ambivalence that occupied them and restricted their emotional life. Motivation and feelings about the body or eating behaviour fluctuated from day to day, from healthy thoughts to being occupied by planning how to accomplish bingeing. from being obsessed about weight and shape to worrying about eating behaviour. Feelings had to be dealt with, and improvement in the ED could lead to a sense of not coping adequately with emotions. Experiencing an emotional conflict between the inside and outside led to an inability to express the true self.

The theme, ‘Being cognitively aware of limitations’, revealed that the women were cognitively aware of their situation. The excessive focus on ED in their lives involving food, meals, weight and shape as well as their external appearance and mental struggle was considered limiting. Feelings, thoughts and behaviour connected to the ED were labelled as ‘sick’ or ‘crazy’ and indicated a fear of losing control. The ED was considered an obsession that had to be kept secret. Achieving balance was aimed at concealing their problems. Such awareness also represented strength, as it helped them to experience a normal life. They reflected on themselves as two parts: an outside and an inside. The latter held extremely strong feelings where binge eating, purging

and restricted food intake compensated for the inability to express them. This provided a means of appearing indifferent and keeping up a façade where nobody noticed the problems and there was no risk of being unmasked. A good façade concealed the problems. Dieting and purging would gain them an ideal and slim body. The perfect mask was likely to be a direct contrast to their experiences of a disgusting interior.

The theme 'Experiencing an existential sense of being lost and frozen' was characterised by helplessness, hopelessness and despair. They had longed for something different for several years. The attractive exterior concealed overwhelming feelings. However, some participants were confused about who they were, as being divided was normal for them. The mask concealed the mental struggle and hid their overwhelming interior, while at the same time presenting an attractive exterior and the happy sides of themselves. They wanted to live a normal daily life where nobody noticed their problems. One clay figure made in an art session was associated with being alienated from one's own family, which was a strategy for coping with the ED. At the same time, they reflected on their anxiety about getting well, as the desire to be thin conflicted with overcoming the ED.

4.4 Paper IV: The meaning of guilt and shame – a qualitative study of mothers who suffer from eating difficulties

The aim of this sub-study (Paper IV) was to illuminate and interpret guilt and shame as expressed by mothers with ED. The study revealed one main theme and two sub-themes. The main theme, *Struggling in silence with guilt and shame as a mother living with ED and trying to keep it secret*, comprised rich and meaningful descriptions of guilt and shame and was interpreted as secret experiences endured in silence. Guilt and shame in different situations were described and divided into an emotional and a cognitive level. Four sub-themes emerged. Guilt and shame appeared to be important factors that influence and were influenced by the role of motherhood.

The theme, 'Feeling worried about failure and wanting to be successful', comprised the emotional level and involved feelings of guilt about forsaking the children and feeling ashamed. It reflected a desire to be successful as a contrast to the sense of failure and encompassed two sub-themes. The sub-theme 'Experiencing powerful feelings of guilt about the children' described the mothers' overwhelming fear of influencing the children, causing them to develop ED or blame themselves for their mother's illness. The desire to be a good mother was integrated into the reflections and they felt responsible for ensuring that their children's childhood was not dominated by the ED.

The sub-theme, 'Feeling ashamed of oneself' was characterised by words such as bodily hate, disgust and humiliation. They felt ashamed about not eating normally and feeling overweight. They described feelings of shame and guilt about not recovering and being limited by

the ED. Shame was regarded as a direct consequence of the ED. Feelings of guilt and shame were intertwined and increased bodily reactions such as the painful feeling of humiliation, having a guilty conscience and shame. For instance, being discovered overeating led to feelings of panic due to shame.

The theme, ‘Having condemning thoughts about one’s own sense of responsibility’, viewed guilt and shame from a reflective perspective of self-judgement. It represented the cognitive level and was dominated by thoughts of responsibility and self-judgement. The sub-theme ‘Blaming oneself for having problems and for burdening the children’ comprised responsible reflections on having ED and its influence on the children. They also judged their bodily appearance and behaviour. This sub-theme was characterised by strong moral reflections about responsibility for developing the ED, for not taking sufficient action to change their life situation, worries about transferring the problems to their children or that the latter sensed their mother’s struggle or destructive actions. Their anxiety about the family being a potential victim of the ED was always strong, and the fear of hospitalisation increased the feeling of guilt.

The sub-theme ‘Judging one’s own body in daily life’ was dominated by reflections on behaviour that was intended to conceal the ED, for instance, restricted food intake or pretending to eat more than they did. They were afraid of being criticised by others, for example when a family member discovered them hiding food, they felt as if they had committed a crime or experienced shame at the idea that their child might mention their purging to others. They reflected on the taboo associated with being overweight triggered by the media and today’s culture. Normal situations were often vulnerable (for instance meal times) and led to a feeling of being misunderstood, loneliness and even more guilt and shame. One mother had been urged to breast-feed and had to avoid some types of food to manage it, which triggered a relapse

of severe ED. The performance of ED behaviour such as purging or merely being fat triggered shame and guilt.

5 DISCUSSION

The overall aim of this thesis was to gain a deeper understanding of the phenomena of guilt and shame, partly by exploring mothers` experiences of their ED and daily lives (Papers II-III) and partly by investigating their sense of guilt and shame related to motherhood (Papers I, IV). The main findings illuminated the powerful challenges of daily life experiences of mothers who were balancing between the role of motherhood (Paper I), bodily sensations (Paper II), mental challenges (Paper III) as well as guilt and shame (Paper IV). In the four sub-studies, the different perspectives of such experiences were explored and this section presents a discussion of the findings. The specific aims are presented in each paper under Findings. The following four headings are in accordance with the four research questions addressed in the sub-studies (Papers I-IV), and will guide this discussion.

5.1 What are mothers' daily life experiences when suffering from eating difficulties?

Mothers' daily life experiences when suffering from ED are characterised by guilt. The influence of the ED on motherhood is strong, leading to feelings and thoughts of guilt; having a guilty conscience in relation to not being a good enough mother; and being preoccupied with not involving the children in the ED (Paper I).

A guilty conscience in relation to not being a good enough mother when suffering from ED seems to demonstrate the mothers' urge to balance the problems and yet protect the children (Paper I). A woman's health problems and underlying feelings of guilt may increase due to

motherhood and the desire to be a good mother. Ruddic (1989) described mothering as a bitter task if a mother is helpless to prevent social evils from affecting her children and if she does not have a realistic language with which to outline her maternal responsibilities, as speaking about mothering is problematic. Such challenges may also be a result of a mother's health problems, and her desire to be a good mother may be hindered by efforts to protect the children from problems (Paper I). The need to focus on experiences during pregnancy, postpartum and on motherhood in general, both retrospectively and in the present life situation, is highlighted. This may give rise to an opportunity to reflect on motherhood by, for instance, bringing experiences of the pregnancy and post-partum period into the discourse (Paper I).

Mothers' guilt in the context of ED is characterised by devaluing themselves as mothers and judging their mothering abilities. Worries about transferring problems to the children may increase feelings of guilt as well as fear of exposing them to the ED. Lacking energy, being too tired and spending too little time with the children may have a negative impact on the mother-child-relationship (Paper I). This is supported by Patel *et al.* (2002), who described the direct and indirect influence of mothers with ED on the children and how role modelling and discordant family relationships may have an impact. However, women with ED are often reported to be perfectionist and self-judgmental (Forbush *et al.* 2007, Halmi *et al.* 2000), to live a double life (Pettersen *et al.* 2008) and to place excessive demands on themselves. This is supported by Bryant-Waugh *et al.* (2007b, p. 447), who described mothers with ED as driven by a strong desire "to do the best for their children" because they worried that their "difficulties, low mood and lack of self-confidence or self-esteem" would have an impact on their children. Mothers with ED may in many cases manage well (Stein 2002), and the will to conceal the ED (Paper III) might be driven by a wish to live a normal life. The mothers who struggle in silence

with their ED and try to keep it secret (Paper IV) may actually represent those mothers who manage well.

Guilt in the context of ED and motherhood may be strongly related to the process of becoming a mother (Paper I). Talking about the experiences of pregnancy and the post-partum period may be a way of bringing the ordinary and extraordinary events of motherhood into the dialogue as described by Ruddick (1989). When mothers reveal rich and varying descriptions of this period, they highlight the variety experienced at this stage of their lives (Paper I). Earlier studies have demonstrated how ED may be precipitated or exacerbated during the process of becoming a mother (Lai *et al.* 2006). Problems immediately after delivery can be associated with stress when feeding the child, worries, disappointment and feelings of failure (Koubaa *et al.* 2008). Stein and Fairburn (1996) found that ED symptoms may increase in the postpartum period and recommended providing educational support on how to deal with eating, weight and body shape changes after pregnancy. However, mothers may have positive experiences of pregnancy (Paper I), as supported by the findings from von Soest and Wichstrøm (2008), who found that ED-related problems may actually decrease in mothers compared to those who remain childless. The variety of mothers' experiences of the ED is important and indicates that community health care workers should be alert and proactive in meetings with pregnant woman. An enquiring attitude targeting meal times and nurturing in pregnancy may provide an opportunity for those who need education and advice to open up a hidden area (Paper I).

Guilt in mothers with ED is also associated with a preoccupation about not involving the children, which demonstrates a mother's intuitive concern about the influence of the ED on her offspring (Paper I). The worry about transferring ED from mother to child is actually based on reality and supported by studies by Stein *et al.* (2006; 1994), which demonstrated that children of mothers with ED can be affected by the mothers' problems. Moreover, Bryant-Waugh *et al.* (2007a) revealed

that mothers with ED felt a need for control when feeding the children and were uncertain about what the children should eat, as they had difficulties managing their own food intake. Conflict at mealtimes may be due to the mothers' ED and can interfere with the mothering role (Stein *et al.* 1999). This is supported in Paper I, which demonstrates how the mothers experienced anxiety and irritability at mealtimes and that the meal may be associated with treatment rather than with a natural activity. Stein *et al.* (1999) found that conflicts were less likely if the mothers disregarded their own concerns. Eating routines may also have a positive effect on the ED due to being forced to adhere to regular mealtimes (Paper I). The concern about transferring the ED from mother to child also involves providing information to the children about the ED, which may be seen as a double-edged sword; on the one hand information can be positive and relieve the children's potential negative feelings as well as preventing lies and providing opportunities for explanations. On the other, it can lead to worry about how and when to inform, whether it can have negative effects on the children or cause them to copy the mother's ED-behaviour. However, information places the mother in a position in which she feels obliged to change. The children may actually find it difficult to understand the power of the ED. If choosing to withhold information, one has to be prepared for questions. Answers about the ED should involve the following: the information must be understandable, adequate and not exaggerated; encompass expressions of love for the children; and avoid introducing the idea that they might develop ED or other problems themselves (Paper I). This theme also illuminates the cognitive awareness experienced by women with ED (Paper III) and their cognitive sense of responsibility (Paper IV).

Feelings of guilt may result in a sense of incompetence in relation to dealing with issues connected to the children' the children's body shape (Paper I). A consequence of a mother's ED may actually be a wish for their children to be thin (Patel *et al.* 2002). This finding, combined with

the underreported rate of ED described by the Norwegian Board of Health (2000) has an implication for MHN practice to ensure that sufferers do not feel ignored when seeking help. Identifying women with a history of ED is important in community health in order to offer support or education, especially if they feel incompetent to deal with their children's diet and body shape. Groups provided in community health care settings may help mothers and also minimise the damage to children if they actively target mother-child relationships (Barnett *et al.* 2005) or challenges related to motherhood and ED (Bryant-Waugh *et al.* 2007a, Bryant-Waugh *et al.* 2007b).

5.2 How do women who suffer from eating difficulties experience the bodily aspects related to their condition?

Women who suffer from ED experience the bodily aspects related to their condition as powerful feelings of being trapped in and ashamed of their own body, which demonstrates that ED has a major impact on women's lives. They may feel trapped by overwhelming physical sensations characterised by exaggerated yet concrete feelings of being full, empty, thin or losing weight (Paper II). This is in accordance with Skårderud (2007a), who revealed concrete feelings of actually taking up too much space and described how our body is a metaphorical, concrete physical reality; the body's here-and-now nature and individual body and mind interactions make these perceptions very difficult to negotiate.

Bodily sensations are also associated with being physically devoted to the ED; i.e. extremely strong ED behaviours such as cravings, desires or addictions (Paper II). This is supported by Rogers and Smit (2000), who argued that there are similarities between the pattern of these

habits and drug abuse, hence they should be understood in terms of the cognitive influence of eating. Another way of understanding the desire for bingeing and purging is described by Nordbø *et al.* (2006) in relation to losing weight: an inner drive, a rush or sense of power that makes the anorectic behaviour influence the woman to feel good about herself (Nordbø *et al*. 2006).

Bodily suffering in ED is experienced as exhausting due to inner conflicts and the fear of failure when dieting (Paper II). Negative self-evaluation is determined by body shape and weight, which is supported by Wilson *et al.* (2007), who also claimed that semi-starvation leads to depression and social withdrawal. Broussard (2005) described the conflicting thoughts and obsessions as an ongoing war with one's mind, leading to isolation and fear of weight gain.

Powerful bodily feelings related to the ED are characterised by being ashamed of one's own body (Paper II), which may also be viewed in the light of the strong experiences of guilt and shame and their meanings (Paper IV). Tangney and Dearing (2003) described shame as having a negative influence on the self, a painful and ugly feeling. It is associated with strong concerns about being judged by others (Paper II) and indicates a wish to look like and be admired by others, as supported by Broussard (2005), or to become different or change as described by Nordbø *et al.* (2006). Powerful bodily feelings are characterised by concerns about being physically devalued by others or that the body is too fat, which evokes negative feelings when among others. The ED represents the prospect of a better appearance, such as being thin (Paper II). This is supported by Hardin *et al.* (2003), who argued that the discursive media system associated with ED and self starvation has become normalised, as has the desire to become thin or even anorectic. However, Broussard (2005) found that bingeing and purging were considered abnormal and likely to be judged by others, in addition to

being carried out in secret, which led to isolation. These descriptions may also be viewed in the light of Tangney and Dearing (2003), who outlined the painful feeling of shame and its negative effect on the individual.

The feeling of being ashamed of the body leads to hiding and lying to conceal ED-actions. Organising and structuring the day has a function in normal family life such as coping with meals and masking fasting, bingeing and purging (Paper II). This strategy also enables control and security as described by Nordbø *et al.* (2006) and can be understood as a means of achieving mastery and connection as a basic process underlying the anomalous eating behaviour (*cf.* Budd 2007). Shame leads to a negative evaluation of the self and causes the woman to hide, escape or strike back (Tangney and Dearing 2003). Daily life is controlled in a way that represses the feeling of shame, for instance, by avoiding discovery when binging and purging (Paper II).

5.3 What mental challenges related to daily life are experienced by women who suffer from eating difficulties?

Mental challenges related to daily life when suffering from ED are characterised by balancing between mental vulnerability and strength and associated with emotional pressure, cognitive chaos and an existential attempt to maintain a sense of balance (Paper III). The struggle with emotional ambivalence is linked to vulnerable, chaotic and exhausting feelings, which often reflect incongruence. Feelings may change from one minute to the next and result in an inability to express them as well as lack of predictability (Paper III). This is supported by Nordbø *et al.* (2006), who argued that inability to express emotions may be associated with avoiding negative experiences, which

can maintain the ED. Previous knowledge supports the fact that people with ED have difficulties in affect-regulation or affect-toleration (Buhl 2002); they may lack control over, try to repress, forget or avoid affects through their ED behaviour (starving, purging, bingeing) (Skarderud *et al.* 2004). The ED behaviour can be seen as an inability to translate these impulses into a verbal language, thus making it painful to endure difficult feelings such as emptiness and loss (Buhl 2002). Feelings of depression, sorrow and anxiety as well as repressed anger or emptiness commonly represent mental vulnerability (Paper III).

Mental challenges related to the ED are also characterised by cognitive awareness that ED limits daily life (Paper III). An overview and control of the situation as well as a realistic picture of daily life may be maintained by such awareness. Control helps the women to cope; a strong and independent exterior does not reveal the emotional chaos (Paper III). This is supported by The Norwegian Board of Health (2000), which claims that an attractive and slender body sends a hidden message of control and strength. Awareness of one's appearance and the struggle to improve the aesthetic exterior may relate to perfectionism as described by Nilsson (2007). The feeling of having an unattractive body reflects a wish to be someone else as outlined by Skårderud *et al.* (2004). However, the over-evaluation of the focus on the exterior may maintain the negative thoughts and ED, as described by Fairburn and Harrison (2003). The awareness may also make women label their own thoughts as 'sick' due to shame about the ED actions and their inability to live a normal life (Paper III). Skårderud (2007) suggested that shame maintains or aggravates the ED due to the shame-shame circle: shame leads to more shame. The awareness may, however, actually represent a link with normal life, and the will to conceal the ED represents a wish to be a resourceful person (Paper III).

Mental challenges related to daily life when suffering from ED also involve existential experiences of being lost and frozen. These experiences reflect a wish for other ways of living. Suffering from ED

for many years leads to feelings of helplessness, hopelessness and despair. A desire for slenderness or thinness competes with a wish for change. Together, these experiences represent a longing for an existence without the ED, hence the urge to be slim. The sense of being lost is characterised by an existential longing for something else (Paper III). The isolation experienced in daily life and within one's own family is an example and may be interpreted as a metaphor for a prison as described by Geller (2006). Being isolated in daily life and in the family, the sense of not being understood and feeling confused in terms of understanding oneself are harmful beliefs about oneself, relationships and the ED in a cycle of self-perpetuation, where the ED is viewed as a prison. The feeling of isolation and exclusion is supported by studies on parents of children suffering from ED (Hillege *et al.* 2006). However, those who suffer from ED are likely to think that they could not survive without it, thus this condition constitutes an existential challenge that supports a discursive analysis of the construct of 'anorexia' (Paper III). The media, clinics and popular literature construct the category 'anorexia' based on how it becomes visible in thinking, perceiving and acting (Hardin 2003). This is exemplified by daily activities such as meal times, as experienced by mothers with ED (Paper I). The existential challenge may be greater when the women in question have to fulfil important roles such as motherhood as it puts the children at risk of developing ED behaviour (Barnett *et al.* 2005). Carrying on daily life requires strength.

5.4 What is the meaning of guilt and shame experienced by mothers with eating difficulties?

The meaning of guilt and shame for mothers with ED is characterised by a silent struggle and trying to keep it secret (Paper IV). Mothers with ED described their guilty conscience in relation to being a good

mother as maintaining a balance between their problems and protecting their children from being affected (Paper I). Guilt and shame have different nuances in a person's daily life and may contribute to powerful experiences due to mental suffering, such as ED. Feelings of guilt were related to the children and feelings of shame about oneself as a mother; thoughts of guilt and shame including blaming oneself, worrying about the impact on the children and judging one's body. The meaning of guilt and shame may be different at emotional and cognitive levels (Paper IV).

Guilt and shame at an emotional level in mothers suffering from ED are characterised by a feeling of failure and wanting to be successful. At this level, their meaning includes the mother's guilt about the children, shame about herself and a desire to succeed (Paper IV). The feeling of being ashamed of oneself can lead to defensive emotions such as anger, anxiety or concealment as described by Gilbert (2003). The emotional level is associated with powerful feelings of guilt about the children, such as great fear of affecting them due to their own ED problems (Paper IV). Previous research has demonstrated that ED-related problems can have a negative impact on parenting capacity and hence the children's development (Stein 2002). Tangney and Dearing (2003) argued that the way in which shame is handled by parents is important due to the negative consequences and potential direct impact it may have on the relationship with their children, i.e. withdrawal, denial, anger and lack of empathy. They suggested that recognising and acknowledging shame may be helpful in preventing shame-related problems (Tangney and Dearing 2003). The meaning of guilt and shame at the emotional level also includes feelings of being ashamed of oneself, which indicates how shame is associated with physical behaviour when suffering from ED (Paper IV). This is supported by the way in which Gilbert (2003) related shame to anger, concealment and anxiety and accords with Pettersen *et al.* (2008), who revealed that women with ED experience strong shame when bingeing and purging

and plan in great detail in order to conceal their behaviour and avoid stigmatisation. The emotional reactions associated with guilt and shame may be self-hate, feeling disgusting and vulnerable, as ED behaviour generates humiliation and anger towards oneself (Paper IV). This accords with the overwhelming feelings of being trapped in and ashamed of one's own body (Paper II). Shame of being judged by others, a desire for thinness and an obsession with devaluing oneself and ones' body may be a result of the perpetuation of the judgement of others (Paper IV)

The meaning of guilt and shame at the cognitive level in mothers suffering from ED is characterised by condemning thoughts about their own sense of responsibility. This level is associated with thoughts about being responsible for one's own situation, having ED, self-judgment of the body and placing responsibility on the children (Paper IV). The self-critical thoughts that devalue and embarrass are a part of the internal component of shame as described by Gilbert (2002). A potential positive function of shame may be to allow constructive thoughts in terms of self-evaluation (Paper IV). However, evaluations generated by experiences of shame are negative by nature, and the painful feeling does not automatically prevent people from doing wrong things (Tangney and Dearing 2003, Gilbert 2002). The cognitive level includes blaming oneself for having problems and for burdening the children (Paper IV). Guilt and shame are self-conscious emotions (Tangney and Dearing 2003), and the social/external cognitive shame-component includes thoughts about others looking down on the self (Gilbert 2002). A behavioural component may be a strong urge to avoid exposure and to conceal. The question of whether or not the body is attractive or acceptable is derived from a socially constructed body as described by Gilbert (2007). Being an acceptable and good mother is a deep desire and, if not successful, the self-blame becomes overpowering (Paper IV). As a moral emotion, shame has an important guiding function, and a heightened state of self-awareness makes

people more likely to experience shame (Tangney and Dearing 2003). Blaming oneself for burdening the children is associated with worries about being a poor role model (Paper IV). The WHO (2004) stated that family-related risk and protective factors may have a strong influence on mental health in vulnerable life-periods and across generations. Parents who suffer from mental illness or substance misuse represent the highest risk of their children developing mental health problems (WHO 2004). The impact of ED on the close family may be strong and 'inherited' at different levels through the social milieu, such as influencing one's own children's attitude concerning body, shape or food (*cf.* Lai *et al.* 2006, Patel *et al.* 2002, Stein 2002, Stein and Fairburn 1996, Stein *et al.* 1994). It seems reasonable to assume that motherhood exacerbates feelings of guilt when failure occurs; the mothers feel responsible for providing a safe milieu for their children, and the present study revealed an awareness of the potential negative influence of ED on their children (Paper IV).

The cognitive level is also associated with self-judgement of one's own body and its appearance. Concealed problems are continuously at risk of being unmasked in daily life. In the present study, pretending and concealing were closely related to bodily actions and appearance (Paper IV). This is supported by Burney and Irwin (2000), who described ED behaviour as shame-triggering. Concrete situations such as meal times feel false. The level of self-judgement increases when thinking about such behaviour as well as about potential criticism from others. This level of self-judgement is associated with the body and its appearance, as even thinking about oneself as fat or about ED behaviour is associated with failure (Paper IV). This is in accordance with Crossley (2006), who suggested that we are influenced by others' perspectives of ourselves and our body. The awareness of one's own body as an 'object' arises in 'normal' events and situations due to being misunderstood by others. The 'body shame' concept highlights negative experiences related to the body's appearance and functions.

Shame may be seen as an affective-defensive response to social rejection, devaluation or unattractiveness (Gilbert 2002). The power of attraction is important.

6 COMPREHENSIVE UNDERSTANDING OF THE IMAGES AS METAPHORS

The overall aim of this thesis was to gain a deeper understanding of the phenomena of guilt and shame in the context of ED. A comprehensive understanding of the findings was achieved, based on a synthesis of the main findings from the four sub-studies (Papers I-IV). The comprehensive understanding was labelled *Guilt and shame as an enigma in mothers suffering from eating difficulties* and characterises the main findings.

An abductive interpretation was performed from the inductive via the deductive stage, which was guided by the key meanings derived from the reflections on the masks that took place in the focus groups. In the abductive stage (*cf.* Eriksson and Lindstrom 1997), I gave the masks and figures a meaning. In the deductive stage, I related this meaning to theory (Table III), which gave meaning to the findings that emerged in the inductive stage. I was guided by three reflections: guilt as an image of an existential challenge; shame as an image of a bodily analysis; and motherhood as an image of a part of a whole. Key words from the mothers' reflections on the art pieces in the dialogue were used to guide the comprehensive understanding.

The theories led to a comprehensive understanding of the meaning of the dialogue inherent in the masks and symbolic figures. There were different explanations and understandings. The key concepts from the reflections on the clay figures guided my deeper understanding, and the main theories used for the interpretation were those on guilt and shame (Tangney and Dearing 2003) and suffering (Lassenius 2005). At the existential level, theory on the meaning of will (Frankl 1994), play (Gadamer 2004), guilt (Tangney and Dearing 2003) ice world and

suffering (Lassenius 2005) was used. At the symbolic level, theory on symbols (Jung 1991), shame (Tangney and Dearing 2003) and on the metaphorical body (Skårderud 2007a) was employed. On the holistic level, theory on holism (Lindström 2003), mother (Jung 1991) and on parenting (Tangney and Dearing 2003) was applied. In the abductive stage, the comprehensive understanding was considered in the light of images of masks and figures created in the groups, which are described and explained as metaphors mirroring the new understanding that I achieved as a researcher. The enigma of guilt and shame in mothers suffering from ED was viewed from the perspective of the three approaches that were described, explained and understood in relation to the images presented below. The new understanding was viewed in the context of ED and draws parallels to Papers I-IV; the understanding of guilt draws parallels to Papers I-IV; the understanding of shame draws parallels to Papers II-III; and the understanding of motherhood draws parallels to Papers I, III and IV. The following images were presented:

- A mask as an existential hiding place for secrets – a dialogue about guilt.
- A figure as a symbol of an imprisoning shelter – a dialogue about shame.
- A figure as a significant part of a whole – a dialogue about motherhood.

The art pieces were made by the participants in sub-studies II and III (Papers II-III). They are presented in this section and complemented by a comment from a mother (M) when reflecting on the piece of art in a dialogue with the researcher (R). The comments are derived from a dialogue in the group where themes were reflected and re-reflected upon. The images and citations that follow mirror three themes that expressed reflections and self-descriptions. Masks made from plaster illustrate how the process of play and reflections may allow access to strengths and vulnerabilities of an existential nature. Figures described as bodies were made of clay and illustrate how the reflexive body may

provide an analytical interpretation of symbols and metaphors. Clay figures described as a symbol of oneself illustrate how motherhood was seen as part of a whole.

Table III: Overview of the process of comprehensive understanding: Guilt and shame as an enigma in mothers suffering from eating difficulties

Abductive stage Metaphorical images	A mask as an existential hiding place for mental secrets – a dialogue about guilt.	A body as a symbolic shelter – a dialogue about shame.	A mother as a significant part of a whole – a dialogue about motherhood.
Deductive stage Core concepts, theories	1) Guilt, 7) Meaning, 5) Play, 4) Ice world, 4) Suffering	1) Shame, 6) Metaphorical body, 2) Symbols	1) Parenting, 1) Mother, 3) Holism
Inductive stage Empirical main themes	Experiencing guilt as a mother in the context of ED (Paper I) Powerful feelings of being trapped in and ashamed of one's own body (Paper II) Balancing between mental vulnerability and strength (Paper III) Struggling in silence with guilt and shame as a mother living with ED and trying to keep it secret (Paper IV)		
Inductive stage Empirical sub-themes	Having a guilty conscience in relation to being a good enough mother (Paper I) Being preoccupied with not involving the children in the ED (Paper I) Being physically devoted to the ED (Paper II) Experiencing bodily sensations (Paper II) Bodily suffering as a consequence of the ED (Paper II) Experiencing an existential sense of being lost and frozen (Paper III) Being cognitively aware of limitations (Paper III) Struggling with emotional balance (Paper III) Feeling worried about failure and wanting to be successful (Paper IV) Having condemning thoughts about one's own sense of responsibility (Paper IV)		

1) Tangney & Dearing (2003), 2) Jung (1991), 3) Lindström (2003), 4) Lassenius (2005), 5) Gadamer (2004), 6) Skårderud (2007), 7) Frankl (1994)

6.1 A mask as an existential hiding place for mental secrets – a dialogue about guilt

This section describes a mask as a means of achieving deeper understanding through play. An existential understanding of guilt that challenges the mothers in the form of dilemmas was focused upon. The images refer to Papers I-IV. The masks will be described and explained as an existential hiding place for mental secrets.

The meanings inherent in the masks evoke existential dilemmas, which are visualised and described in two domains: (1) The enigma of a mask as a façade for the inner world; and (2) The meaning of a mask in terms of concealing emotions.

The enigma of a mask as a façade for the inner world

The dialogue below describes a mask that conceals; it is used for protection and as a hiding place; it is responsible for supporting the façade; and prevents others from noticing the negative sides. The enigma of this mask is understood as a dialogue about whether it gives a false image of, reveals or hides an inner world.

R: *Why the hand?*
M 1: *Because it hides…* (silence). *It's often like that; I conceal everything all the time. It's also as if I am always in a good mood.*
(…)
You must always maintain the façade. So that nobody will notice. Nobody should notice the mood swings, although they are present all the time.

The mask is associated with a sense of power that provides an existential meaning. The metaphor of the mask as a façade mirrors will power: the will to appear strong despite vulnerability and personal failures. Guilt generally arises from feelings of failure (Tangney and Dearing 2003). These feelings are likely to emerge from a set of beliefs related to moral standards, which people associate with judgemental behaviour. The degree to which people transgress and experience guilt varies, as do the situations in which they experience guilt. An important issue is that the degree to which people are willing or able to acknowledge their transgressions varies from one individual to another (Tangney and Dearing 2003).

The vulnerabilities and strengths may be an existential struggle when suffering from ED as described in Paper III. The awareness of guilt leads to self-observation of our characteristics, cravings and actions. Guilt is a nagging feeling, resulting in preoccupation with thinking about and wishing to undo a certain behaviour (Tangney and Dearing 2003). However, guilt is typically related to a particular behaviour, which can be distinguished from the person's core identity and is therefore less painful than shame. The sense of tension, remorse and regret involved in guilt makes it easier to handle than shame (Tangney and Dearing 2003).

Frankl (1994) claimed that the will to find meaning is the central motivation in human beings and draws a parallel to self-actualisation theory, which holds that human beings have to commit to an important task in order to achieve self-actualisation. The above dialogue led to a search for the meaning of hiding behind a mask. The mothers in this study tended to feel guilty and blame themselves for their problems, and uncovering the problems triggered a feeling of failure. Being uncovered leads to additional feelings of shame and a guilty conscience, hence, maintaining the façade required strength. Maintaining the façade with the help of the mask was understood as a way to hide themselves and their problems. A mask also helped to protect the mothers from feelings evoked by the critical eyes of others. One meaning of the mask is as a means of locking the problems in, or creating a room for silence where the problems cannot be reached. Concealing may be a lifelong process and lead to stagnation. This understanding reveals how living with ED is a struggle to keep an emotional balance (Paper III). The existential experience of living with ED over time is associated with a feeling of being lost and frozen in the problems (Paper III). One meaning of revealing different masks through play may be to validate both the strong and the vulnerable sides of oneself and to give them a face in a secure setting.

The existential guilt represented in this image is associated with experiences at different mental levels as well as feelings and thoughts about responsibility. Tangney and Dearing (2003) revealed that a person's set of values reflects the moral standard and should be separated from his/her proneness to experience guilt, which relates to the affective predisposition. The latter is an emotional style associated with a tendency to experience guilt as a response to failure or transgression (Tangney and Dearing 2003).

The masks illuminate the will to conceal weakness from and project strength to the social context, for instance one's own family, children or husband. Daily life is ambiguous and, in the context of mask-making and play, the participants are given an opportunity to present their different faces without having to feel guilty about it. When performed within an existential context, it may provide an opportunity to reveal different existential dilemmas. Masks can create as well as inhibit, they can make the person behind them disappear in a crowd or give him/her a special character, or the power of the symbol that they represent (Cooper 1978). A mask provides us with a tool for concealing what we do not want others to observe.

Thus, the act of art itself may be viewed in the light of an existential setting. The existential act of art performance mirrors the concept of play. Gadamer (2004) claimed that the concept of play has a major role in aesthetics and that speaking about play when referring to art is associated with the act of playing, or "the mode of being of the work of art itself" (p. 102). Play contains its own seriousness, and only when the player loses him/herself in play is its purpose fulfilled (Gadamer 2004). This leads us to an understanding of play, which is important at the existential level: "it is not aesthetic consciousness but the experience of art and thus the question of the mode of being of the work of art that must be the object of our examination" (p. 103). The

work of art, Gadamer (2004) claimed, has its true being in becoming an experience and changing the people who experience it.

The meaning of a mask for concealing emotions

The following metaphor describes a dialogue that illuminates the feeling of leading a double life. This mask represents control and describes incongruence in the way one actually feels and acts out the feelings. The enigma of this mask is understood as a dialogue about whether the feeling of living a double life increases or decreases the worry about what will happen if one loses control. Therefore silence has become a solution and feelings are kept secret. The secret is hidden behind a mask; this mask is literally unable to speak, as the lips are sewn together.

> *I feel as if I'm leading a double life. I think that if I suddenly became angry I would be afraid that so much would come out that I would become sort of crazy. There are so many things that want to come out. I'm afraid of losing all control.*
> *(…)*
> *I'm very angry, hence I can't… It's like this: I can carry it for weeks or even months, and then suddenly one day… It's almost*

> *as if I cannot speak because so many things are going around in my head.*

The understanding on an existential level illuminates how the mothers are forced by urges and drawn towards a meaning (*cf.* Frankl 1994). As illuminated in Paper II, the physical power of the ED and the need for overeating and purging is compared with drug addiction. Acting out the physical urges is embarrassing and nourishes the feeling of guilt. This understanding reveals that the intensity of the guilt feelings moves back and forth on a continuum in line with different episodes in the mother's daily life as described in Papers I and IV.

Grasping the meaning always leads to choices and is related to a special person in a special context (Frankl 1994). Papers I and IV demonstrate that the overall existential meaning for the participants in this thesis is being good enough as a mother and protecting the children from their suffering. The concealed problems were kept secret (Papers I, IV). This explains why it is difficult to make meaningful changes when trapped in the power of ED (Papers II-III).

The dialogue above can also be understood in terms of 'secrets' and 'the ice-world' (Lassenius 2005). Secrets are memories that one prefers to conceal from other people. Some secrets are too burdensome to carry alone, and it may be necessary for the individual to be open about them. Secrecy leads a person into existential loneliness and can hinder health promotion. This can be associated with frozen suffering or an ice-world as described by Lasssenius (2005). Life in the ice-world freezes over time. Suffering can also make a person lonely by forcing the individual into isolation. However this does not mean that he/she wishes to surrender to isolation.

A long lasting state of mental ill-health has great power over the person and influences the dynamic human being. It may lead to a feeling of being imprisoned in suffering. When there is no way out of this condition, the mental state moves towards a longing for change or freedom. A movement from the stagnation of the ice-world and suffering starts from the care provided by another person. Suffering is confirmed by human relationships (Lassenius 2005). Suffering in silence is malignant and the struggle involved can lead to oppressive and stagnant states. The opposite of the ice-world is the positive world of spirit that inspires the individual towards personal becoming and being (Lassenius 2005).

In the abductive approach, the comprehensive understanding views the masks as necessary, both as a form of play and reality that challenges the self due to dilemmas resulting from existential guilt. In the act of playing, the masks represent ways of living out one's strong and weak sides and trying out the difficult feeling of guilt. In the real world, masks represent protection, concealment and changes. By means of a mask, difficult feelings, vulnerabilities and suffering may remain undisclosed, concealed and unarticulated. Unarticulated mental suffering is likely to have strong components of self-blaming guilt and self devaluing shame, both of which increase the silence. Lindström (2003) suggested that there is a time limit for how long a person can cope with being alone in the battle of suffering. When this limit is reached, a masked resignation or destructive action will be the response to an intense longing to escape from suffering.

In this section, some of the reflections on the masks made in the art programme raised the interpretation of the theme of guilt to an existential level. At this stage the interpretation was developed from a deductive approach, mainly by means of theories from Tangney and

Dearing (2003) and Lassenius (2005), after which an existential interpretation took place (Gadamer 2004, Frankl 1994).

6.2 A figure as a symbol of an imprisoning shelter – a dialogue about shame

The second image in this abductive stage is viewed from the perspective of a symbolic analysis. The clay figures were described and commented on in the group dialogue. From the analytic perspective, I decided to analyse shame by means of bodily expressions in clay figures. The images are related to Papers II, where they are explained and understood as bodily shame. The section will continue by describing clay figures of motherhood.

Different understandings are latent in this material. The symbols support the articulation of the interpreted meanings. The clay figures seemed to facilitate an understanding of bodily shame and are visualised and interpreted in two domains: (1) The stomach as a shelter for pain; and (2) The enigma of the ED – as a malign tumour.

The stomach as a shelter for pain

The image below depicts a figure with a metaphorical stomach: The stomach is constantly growing, while the small holes symbolises pain.

> M2: *Especially that one* (the figure). *It sort of grows and grows and grows… and those holes in the tummy symbolise how painful my stomach is all the time. How acid things are.* (…). *I think it represents my present state very well. In fact it includes a feeling of pain in the stomach.*
> (…)
> *It's locked in the stomach. And it is the stomach that causes me trouble when I eat. It* (the stomach) *increases the hunger – and it is disgusting afterwards. It's there* (in the stomach) *all the bad feelings related to the ED reside.*

The pain is described as constant; the stomach feels hungry and it contains all the negative feelings related to the ED. This clay figure metaphor can be analysed on the basis of the stomach as a shelter for pain.

First, it is important to illuminate the perspective of the symbolic interpretation. According to Jung (1991), the symbol represents the psyche and has the capacity to indicate the future direction of a

person's whole life. A symbol can be analysed from two sides: the first is retrospective and guided by instincts, while the second is prospective and guided by ultimate human goals (Jung 1991). A symbol represents an attempt to satisfy frustrated impulses as well as being an archetypical embodiment (Hall and Lindzey 1978).

The figure above may be interpreted as a symbol of the body in the form of a shelter. A shelter is a protection from blame, a dwelling place or a home that is considered a refuge (Dictionary.com 2010). The overwhelming feelings presented by means of the figure are concrete and manifest themselves through the body such as a sense of disgust due to one's appearance and ED-related behaviour, which may be a way of presenting shame. The pain described above is associated with words such as troubled, acid and disgust. Tangney and Dearing (2003) characterised shame as an "extremely painful and ugly feeling" (p. 3), which actually poses a tremendous threat to the self. The feeling of shame is capable of making people blame and damn themselves as flawed or useless (Tangney and Dearing 2003). This raises the question of whether it is a physical experience and whether the dialogue above actually describes a physical feeling of shame.

The image may be interpreted in the light of the research by Skårderud (2007a, b), as it demonstrates an expression of concrete bodily senses. When the senses have no reference, the individual evaluates them silently. They are extraneous and private, and likely to be kept secret. Skårderud (2007b) argued that emotions may induce bodily sensations, and that "the human body is unavoidably metaphorical" (p. 249). However, the author stressed that bodily symbols in anorexia are ambiguous in nature and argued that metaphors for the body are numerous; they should be symbolically open, as they may have different meanings (Skårderud 2007b).

Feelings of being trapped by overwhelming physical sensations when having ED (Paper II) include exaggerated bodily sensations, a physical devotion to the ED and physical suffering as a consequence of the ED. Paper II revealed experiences of bodily pain, sheltering powerful sensations at the same time as a strong feeling of shame. Some pains are obviously observed by the outer world, others are concealed, unseen and even unarticulated (Paper III). Concealed pain in the context of ED seems likely to be kept in secret, even from the closest family members and for a long time (Paper II). Such bodily sensations have few references, other than concrete physical feelings of being or having something abnormal.

In the abductive stage, the comprehensive understanding of the clay figures represents the body as a tool for reflecting on symbols related to important topics. The description of a symbol in the form of a body provides us with a tool for revealing unconscious issues. The concealed bodily problems seemed to increase shame. The bodily metaphors indicate that shame may be so strong that one can physically feel it. However, Skårderud (2007b) pointed out the risk of being reductionist if one claims to know what ED problems ‘are about’ on a general level and provided an example from the history of anorexia, where there have been numerous attempts to describe possible meanings of the symbol of a slender body. This highlights the importance of always remaining true to the user’s voice and the dialogue.

The enigma of the ED – as a malign tumour

The clay figure below symbolises a tumour and describes the idea of ED as a ‘physical thing’. This metaphor depicts the ED as a tumour located in the stomach that is growing and malign, hurts constantly and is experienced as something that eats one up from the inside and will not disappear:

> M 2: *It* (the figure) *is like a growing tumour that developed in the stomach. It's a feeling I have all the time, and I have pain in my stomach. I actually don't know how to express it more accurately* (…).
> R: *Is the tumour in the stomach a symbol of your ED?*
> M 2: *Yes it is. It is eating me up from the inside. And it has manifested itself as a painful lump in the stomach that I can't escape from no matter what I do.*

Paper II reveals how the physical experience of ED is something that controls the body, and the idea of the ED as a metaphorical malign tumour reflects the power of such feelings. The dialogue above may be interpreted as a battle against the disease. Wiklund (2000, p. 70) described a battle in the body when freeing oneself from a disease and finding the way towards wholeness. It is similar to a struggle against an evil enemy and requires that one sacrifices parts of the body. The meaning of this process is to seek balance and re-create one's whole, and several battles take place in the body as the human being searches for his/her own unity and wholeness.

Women who suffer from ED describe powerful bodily feelings and sensations. Feelings of being trapped in one's own body as well as being ashamed of it are strong, and it is likely that the silence makes the negative experiences, i.e. the bodily suffering, physical devotion and

the bodily sensations, more powerful (Paper II). Tangney and Dearing (2003) claimed that shame involves a global evaluation of the self. The feeling of shame is a problematic emotion that is extremely difficult to relieve. Shame is associated with, for instance, poor interpersonal skills or feelings of anger and hostility. Shame reflects who people are as individuals. There are few reparative solutions to shame, and an attempt to deflect the feeling of shame by withdrawal, escape or shifting the blame to others is common. In general, shame is more painful than guilt.

Formulating and creating symbols that involve the body as a metaphor is one activity-oriented method in focus groups (*cf.* Colucci 2007) used on vulnerable areas that may illuminate important and valuable reflections. In this section, some of the figures made in the art programme raise the interpretation of the themes of shame, motherhood and the ED to an analytical level and demonstrate how dialogues through art may inspire the use of analytic and symbolic ideas. By creating a piece of art, one may gain access to the unconscious and achieve a new understanding from experiences of conflicts.

The visualised metaphors can be seen when words disappear (Minde 2000). The clay figures illuminated suffering, which may be interpreted as shame. Paper II revealed that shame was associated with bodily senses. It seems as if the extraordinary pattern of shame takes place, implants and actually nourishes itself in the bodies of those who suffer from ED, which, among other things, may prevent these women from valuing themselves as mothers (Paper IV).

The comprehensive understanding was developed from a deductive approach, mainly by means of theories from Skårderud (2007), Tangney and Dearing (2003) and Wiklund (2000), from the perspective

of analytical interpretation (Jung 1991). An abductive interpretation was performed, guided by the key discourses from the reflections on the figures made in the art programme. The figures facilitated the creation of analytical symbols interpreted as metaphors.

6.3 A figure as a significant part of a whole – a dialogue about motherhood

The third image in this abductive stage concerns a holistic perspective of a mother as it occurs in this thesis: a view that considers that one part influences other parts of a context or the whole (Lindström 2003). Two clay figures are presented and will be described, explained and understood in the light of two domains: (1) The enigma of a mother as a symbol of care and (2) Motherhood as part of a family. They were made in the art programme and reflected on in the dialogue about mothers. In the abductive stage they were analysed in the light of the whole. The images are especially relevant to Papers I, III and IV.

The enigma of a mother as a symbol of care

The clay figure below depicts a woman carrying a child – immediately projecting a typical mother and child image. It therefore surprised me that this mother stated that the whole figure was herself. The enigma represents a dialogue about whether she feels like the weak or the strong one.

(M 3): *I'm mostly the one inside, I guess…* (…). *Many who look at me are talking, and they think that I'm tough and all that, which I am not at all. But very few know that.*

This metaphor reveals an image of a mother who needs to be taken care of. When the mother states that she is mostly the one inside, it becomes clear that she is probably both of them - that this is not an image of a mother and child, but of a mother who is both weak and strong.

In the light of holism, Lindström (2003) claimed that the whole is always superior to the parts and that each individual follows his/her own set of laws. A deeper understanding involves aspects of feelings and cognitions in their own context. In this section, motherhood is understood in the light of the holistic perspective: feelings, cognitions and context are important elements for understanding a mother with ED. The symbol of a mother is female strength, the origin, shelter and protector of all life (Cooper 1978). The archetypical mother (Jung 1991) is a superior protector who cares for and loves her children endlessly. The image of motherhood is based on love and responsibility

for the child. The existential meaning of motherhood is maternal care for her children. However, this image has no place for a mother who is small and in need of protection. If a mother has the power to choose, she will opt for good health for the sake of her children. If she feels unable to fulfil this task, a guilty conscience may become overwhelming as described in Papers I and IV.

A mother wants the best for her children, and the context that surrounds the ED makes her judge herself as a mother, which leads to guilt (Paper I). She struggles in silence with guilt and shame, while living with ED and trying to keep it secret (Paper IV). Health influences motherhood and motherhood influences health in the vulnerable periods of life (Papers I, IV). According to Frankl (1994), a human being has the freedom to act in ways that provide meaning, which may lead to the person experiencing goodness, truth or love of a person. If one has the power and courage to live through pain, suffering may take on meaning. Love and conscience are intuitive and have one extraordinary goal. The differences between them are that love targets opportunities and conscience targets needs and demands (Frankl 1994). Motherhood involves both love and conscience.

Motherhood as part of a family

The clay figure below was created by a mother who felt like a different and odd part of the family due to her ED problems. She had her place in the family, but still felt like an outsider. The rest of the family was functional and lived their lives, while she struggled with the ED.

(M 2): *It might be my husband and my three children, and me being like* (the damaged ball)*... It might be my family members who are nice and me who is like that one* (the damaged ball).

It is natural to interpret motherhood in the context of parenting. Tangney and Dearing (2003) claimed that motherhood is parenting, and parenting is the primary source of love and nurturance in the children's lives; it is the source of the greatest love for the children, and the mother's wish is to give the best the world has to offer. Parenting involves self-evaluation: parents often question their abilities and judge themselves, and their shame can arise from different sources. The feeling of being a bad parent will in most cases lead to a sense of guilt and shame. Tangney and Dearing (2003, p. 186) claimed that the link between shame and anger is especially important in parenting as "shame has its most corrosive effect when hidden and denied". Revealing shame through words may hinder withdrawal, denial or anger. Words are tools for bringing sensations to a cognitive level and allow the use of rational functions such as reasoning, judgment and the search for justice. Articulation may be opened up by using different forms of expression.

The fundamental goal of parenting is to promote happiness, joy and feelings of security and to shield the children from distress and pain. At

the same time, parents want to influence their children to be sensitive and responsive, to develop a clear sense of right and wrong and to become part of society with an awareness of the concerns of and responsibility to others. Parents serve as primary disciplinary figures for their children. They teach their children morality and to be good and caring as well as influencing them to be happy, well-adjusted people with a solid sense of self-esteem (Tangney and Dearing 2003). How a mother performs parenting is influenced by her own individual history.

This thesis has described the mother who is assaulted by suffering and who balances between love and conscience as well as between caring and feelings of responsibility (Papers I, IV). When a mother is betrayed by her health, it potentially leads to closed rooms, open only to her. Guilt feelings on account of the children are dominant in the mother's suffering (Papers I, IV). The act of motherhood is likely to be observed by the outer world; failures may become visible, criticised and lead to the individual feeling devalued, and the attempt to balance between vulnerability and strength (Paper III) may be difficult.

A mother's struggle to keep silent about her vulnerability in daily life may be interpreted as a way to protect her children from being influenced by her problems (Paper IV). These experiences may fundamentally challenge a mother. When a mother suffers from mental problems such as ED, she is forced to balance her vulnerability and strength; the emotional pressure, cognitive chaos and existential attempt to maintain a sense of balance become a feature of daily life (Paper III). She has to deal with affect-regulation or affect-toleration (*cf.* Buhl 2002) in order to gain control over affects and manage affect controlling behaviour such as starving, purging and bingeing in secret in an effort to spare the children.

Travelbee (1971) claimed that “no human beings can be repeatedly exposed to illness, suffering and death without being changed as a result of these encounters” (Travelbee 1971, p. 40). The silence and concealment of guilt may feed the suffering and secrecy as well as imprisoning and tying up the person. Mothers with ED have a strong wish to be a successful mother (Paper IV) and have a guilty conscience on account of their children due to not feeling good enough as a mother (Paper I). They worry about failure and struggle in silence with guilt and shame in attempt to conceal their problems (Paper IV).

This thesis has revealed that existential health influences the way a mother judges herself as a parent (Papers I, IV); a mother’s daily life is affected by an ED that may be exaggerated by contexts such as family life or being a mother. An attempt to balance may be hidden in an outer appearance or mask, but trying to project strength is challenging (Paper III). The ED problems are difficult for the involved person to resolve, while the ambivalence towards change is an obstacle, as is the feeling of being unable to escape from the destructive sense of shame.

7 CLINICAL IMPLICATIONS

The four empirical studies provides evidence of the importance of health care workers having knowledge about the powerful mental challenges (Paper III) and bodily sensations (Paper II) experienced by women with ED. Such knowledge would enable them to identify mothers with ED as well as make them aware of the fact that the various aspects of guilt and shame lead to the under-reporting of problems associated with ED (Papers I, IV). Communication is also important, and encouraging the women to verbally express their problems can help them to cope with their lives (Papers II, III). Group interventions are suggested in Papers I and IV and can be used for various purposes in MHN.

Nurses are in a position to help patients, but appropriate help requires a relationship where the nurse communicates care, knowledge and trust. As demonstrated by the present thesis, ED is generally endured in silence. Together with feelings of shame, this may counteract the dialogue in the therapeutic process. The nurse's emotional intelligence is extremely important for the development of the therapeutic relationship; the nurse must be sensitive to the patients' needs while at the same time maintaining self-awareness (*cf.* Akerjordet and Severinsson 2004).

The dialogue with the patient is one of the most important tools in MHN, and nurses develop their communication skills by means of different techniques. Those used for the dialogue in the focus groups described in this thesis (Papers II, III) were based on cognitive reflection techniques combined with art therapy. In this approach, symbols and metaphors are created by the participants and later used

for focused reflection. Such techniques may help the nurse to lead the patient to greater awareness, which is a core action of MHN (*cf.* Lindström 2003). In MHN, the language of art can be used for the purpose of helping the patient to gain a deeper insight into his/her problems. The dialogue may be facilitated by a hint derived from art.

The thesis demonstrates that the use of play and art may provide people in crisis with an opportunity to go beyond their boundaries. The act of being creative and artistic can provide relief and insight. In the creative process, the patient is active and physically engaged, spontaneous and self-motivated due to being occupied by the exercise. The act of creating is central, and the patient becomes a creator of personal expressions in the form of clay figures and masks, which have their own meanings, yet can be interpreted in an abstract way. Art may provide a means of expressing un-verbalised, difficult and sometimes forgotten memories. Through the images, these memories become visible and can be spoken about. As a result of this process, the most fundamental thoughts and feelings may be expressed in images rather than words. Using art as a means of communication accords with the theory that considers the act of play as central to MHN (*cf.* Lindström 2003). Art and play may have important purposes: exploring, expressing and articulating issues related to bodily functioning, body image, illness, feelings of fear and concern associated with the illness, alternative views about illness, as well as expanding the concept of self in the world and in relationships (*cf.* Malchiodi 2003). Art expression provides an opportunity to go beyond boundaries, gain meaning, develop insight and ease pain. The process involves self-engagement, and the patient has an opportunity to be active, physically engaged, spontaneous and self-motivated. This process provides treatment by allowing the patient to work on non-articulated, difficult, concealed, problematic or forgotten memories, and the discourse may be steered on to new pathways.

Treatment and support by means of group programmes are recommended in Papers II and III. Several complex minds cross-feed each other in group therapeutic settings and, as mentioned above, the group dynamics require different nursing skills. The individual ED related problems pose various challenges, and groups may be more difficult to manage than one-to-one settings, due to the power of various processes such as seduction, destruction and abuse. It is therefore essential to be aware that groups may have a negative effect on the therapeutic intervention. However, in general, group approaches offer a positive milieu, which provides an opportunity for the participants to obtain support and learn from or be motivated by each other (*cf.* Karterud 1999), thereby helping the patient by means of nursing, playing and teaching (*cf.* Lindström 2003).

Situations described in this study may lead to avoidance of help seeking, due to the desire to keep ED-related problems as private secrets. Nurses should be able to identify mothers with such problems, be aware that guilt and shame may hinder them from verbalising their vulnerabilities and offer them an environment for articulation. The opportunity to verbalise emotional and cognitive knowledge and behaviour is important. This understanding may help both the nurses and the patients to identify problem-solving actions and help mothers to find strategies to tackle their problems in secret. Guilt and shame should be focused on in the dialogue and allowed room for articulation in order to help mothers suffering from ED to express important issues and roles in their daily lives.

8 CONCLUSION

In conclusion, this thesis has demonstrated how guilt and shame can be viewed as a burdensome and challenging private secret, which leads the sufferer to resort to silence and results in difficulties in daily life. The power of guilt and shame was viewed *as an enigma that seeks understanding through a dialectical process*, as opposed to absolute answers. Searching for an answer to the enigma of guilt and shame in mothers suffering from ED led to a focus on the power of motherhood and the mothers' ability to suffer in silence. Mothers with ED struggle as a result of their battle to be good enough mothers and cope with the ambiguous challenges of daily life, at the same time as they try to do their best to cope with their own situation; they balance on a wire. Becoming a mother opens up new dimensions and may increase feelings of guilt and shame.

The findings from this study concerning *guilt and shame* can be transferred to other areas related to persons suffering from mental health problems or to mothers with ED in the area of pre- and postnatal care and district health care. Nurses should be aware of the power of guilt and shame and support and find strategies to help the mothers to cope with and discover solutions to the problems in their daily lives. The mothers should receive support adapted to their experiences of their home situation.

The thesis demonstrates that a *guilty conscience and shame* are coloured by feelings, thoughts and actions. They are also influenced by roles, and those that involve the most responsibility have the potential to evoke the strongest sense of guilt. Behaviour is judged by one's sense of guilt and shame, thus these senses are very valuable in terms of moral and behavioural guidance. The thesis suggests that guilt may

guide while shame may hinder appropriate behaviour. Guilt and shame are inherited in human beings, but also influenced by predisposition and environment and guide us in our relationships from early childhood to death. The intensity influences the impact; when the feelings of guilt and shame are strong, they may constitute a hindrance; however, when the feeling of guilt is not overwhelming, it can guide a person to make creative and positive choices. Some guilt can be easily verbalised and a dialogue is likely to provide direction and motivate positive changes in life. Other feelings of guilt are difficult to talk about and may lead to an increased sense of shame.

The thesis demonstrates *a desire to do well as a mother*. The idea of transferring problems to the younger generation seemed to intensify the sense of guilt and shame and made the women keep the ED a secret. This was interpreted and understood as follows: Suffering from ED as a mother is associated with secrets and intense feelings of guilt and shame. The sense of responsibility (guilt) and self-judgement (shame) have powerful emotional and cognitive influences on important aspects (motherhood) of a woman's daily life.

Further research should focus on *guilt and shame in mother-child relationships in the light of ED* or other specific difficulties that influence and make motherhood vulnerable, with the aim of developing adequate treatment and support programmes. Interviews with adult children of mothers with ED could have complemented the results of the present study, while interviews with nurses might have provided important information about how to handle mother-child relationships when working with mothers with ED. The art programme used for the data collection could also be evaluated and employed as a clinical tool. Such a programme could also form the basis for interventions for mothers suffering from guilt and shame related to other health problems.

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Stavanger University Hospital, Clinic of Psychiatry supported the project; special thanks to the leaders at Gruppepoliklinikken who made it possible to organise and start out the project, and the leaders at Stavanger DPS, Lassahagen who made it possible to finish the writing of the project. Thank you for being leaders who show such great interest and engagement in nursing research!

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Professor and supervisor Elisabeth Severinsson, Faculty of Health Sciences, Vestfold University College and Department of Research, Stavanger University Hospital, has been my constructive and inspiring academic supervisor, - I am extremely grateful to you, your insight and to your wisdom within mental health nursing. Thank you!

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The research groups at the University of Stavanger and the Vestfold University College has given me valuable comments and feedbacks. The fellow PhD students Anne Lise Holm at Stord/Haugesund University College, Nina Elisabeth Blegen at the Vestfold University College and Marit Alstveit at the University of Stavanger; you have been inspiring and great help! Also thanks to the research nurses at the Stavanger University Hospital who have been supportive and encouraging from the early start: Ingelin Testad, Inge Joa, Kirsten Lode and Ingrid Leiknes. I am also sincerely grateful to Britt Sætre Hansen for your support, energy and knowledge! You have become my creative research-friend and I am deeply grateful.

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My wonderful friends and family: thank you for supporting me! I am most grateful for data-help and help in organising my daily life! Thanks to my lovely parents who always believe in me and help me whenever I need it. And, - your perspectives within nursing and creative work has been most valuable, thank you!

Finally, my husband Einar and children Jenny and Edvard. You are simply the loveliest! You encourage my dreams, provide humour and joy and force me into a wonderful and creative daily life. Thank you!

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Appendix A:

Paper I

Rørtveit, K. ; Åstrøm, S. ; Severinsson, E. (2009): Experiences of guilt as a mother in the context of eating difficulties. *Issues in Mental Health Nursing*, 30(2009), 603-610.

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Appendix B:

Paper II

Rørtveit, K. ; Åstrøm, S. ; Severinsson, E. (2009): The Feeling of being trapped in and ashamed of one's own body: A qualitative study of women who suffer from eating difficulties. *International Journal of Mental Health Nursing*, 18(2009), 91-99.

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Appendix C:

Paper III

Rørtveit, K. ; Vevatne, K. ; Severinsson, E. (2009): Balancing between mental vulnerability and strength in daily life when suffering from eating difficulties. *Journal of Psychiatric and Mental Health Nursing*, 16(2009), 317-325.

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Appendix D:

Paper IV

Rørtveit, K. ; Åström, S. ; Severinsson, E. (2010): The Meaning of guilt and shame - a qualitative study of mothers who suffer from eating difficulties. *International Journal of Mental Health Nursing*, 19(2010), 231-239.

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Appendix E:

Letter to therapists

Fra: Rørtveit Kristine
Sendt: 13. desember 2005 12:54
Til:

Til behandlere, psykologer, psykiatrisk sykepleiere, allmennpraktikere, xx Kommune.

Jeg skal i forbindelse med mitt doktorgradsprosjekt starte en gruppe med kunstterapi for **mødre som lider av en bulimi spiseforstyrrelse**. I forbindelse med det trenger jeg 8 informanter/deltakere til gruppen som planlegges å starte i februar 2006 på xxx. Jeg ønsker å komme i kontakt med informanter gjennom primærleger og andre som er knyttet til den aktuelle gruppen. Forespørselen er også sendt ut til behandlere i psykiatrisk klinikk, samt senter for spiseforstyrrelse. Jeg er svært takknemlig dersom dere videreformidler kontakten ved å sende denne informasjonen til primærleger, psykologer, og psykiatriske sykepleiere.
For ytterligere informasjon om prosjektet kontakt meg per mail, eller teleforn xxx.

Mvh
Kristine Rørtveit
psyk.spl./stipendiat

Appendix F:

Information to participants

Kristine Rørtveit 090106
xxx

Forespørsel om å delta i forskningsprosjekt

I forbindelse med min doktorgradsavhandling skal jeg gjøre en studie som omhandler mødre som lider av bulimi spiseforstyrrelse, deres forhold til skam og skyld, med kunstterapi som middel. Jeg ønsker 8 deltakere til studien. *Det kreves ingen erfaring eller kunnskap om kunst som uttrykk for å delta i gruppen.*

Målet med studien: å få økt kunnskap om skyld og skam, økt forståelse for mødre som har en spiseforstyrrelse, og økt fokus på kunstterapiens betydning som uttrykk.
Inklusjonskriterier: at deltakerne har barn (barnas alder har ingen betydning), har en bulimi spiseforstyrrelse, og ikke er ikke sterkt belastet med annen somatisk sykdom, stort rusbruk, eller psykisk utviklingshemming. Jeg vil derfor invitere deg til å delta. Deltakelse i prosjektet er frivillig.

Dersom du sier ja til å delta inviteres du til å delta i en behandlingsgruppe ledet av kunstterapeut eller annen terapeut som har erfaring med kreativ tilnærming. Gruppene vil vare i 2 timer en gang i uken. Det vil være 16 gruppemøter. Behandlingen vil finne sted på (xxx). Før gruppene starter vil jeg kalle deg inn til en samtale der jeg informerer ytterligere, og du blir vist rundt. Jeg vil være deltakene observatør i gruppen, og vil delta i alle gruppemøtene. Jeg vil bruke samtaler, mine observasjoner og foto av kunsten du lager som del av datasamling til min doktoravhandling. Dataene som brukes anonymiseres i avhandlingen. Omtrent midt i opplegget avtaler vi en time der jeg intervjuer det om forhold omkring det å være mor. Etter at de 16 gruppesamlingene er avsluttet avtaler vi en time der jeg intervjuer deg om hvordan du opplevde det å bruke kunstterapi som uttrykksform. Intervjuene tas opp på bånd, og vil bli brukt som data for mitt doktorgradsprosjekt.

Vi avtaler sammen om jeg skal skrive rapporter i sykehusets elektroniske journalsystem dersom det er noe som er aktuelle for behandler å vite. Du skal gå i din vanlige behandling under denne tiden.

Studien planlegges å starte i februar 2006 og avsluttes mai/juni 2006. Gruppene vil foregå onsdager kl 1300 – 1500 i (xxx) sine lokaler. Det er viktig at du møter til alle timene dersom du takker ja til tilbudet. Du kan når som helst trekke deg fra studien. Dersom du takker nei til å delta i undersøkelsen, vil det ikke ha noen betydning for deg i videre behandling eller sykehusopplegg.

Med hilsen

Kristine Rørtveit
Stipendiat/psyk.spl.

Appendix G:

Approval from The West Norway Regional Committee for Medical Research Ethics

UNIVERSITETET I BERGEN
Det medisinske fakultet
Harald Hårfagresgt. 1,
Postboks 7800, 5020 BERGEN
Tlf: 55 58 20 84/86
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http://www.etikkom.no/REK/

Regional komité for
medisinsk forskningsetikk
Vest-Norge (REK Vest)

Bergen, 14.11.05
Sak nr.: 05/9371
dok. 3

Stipendiat Kristine Rørtveit
Helse Stavanger HF
Armauer Hansens vei 20
4068 STAVANGER

Ad prosjekt: Opplevelse av skam og skyld hos mødre som lider av en spiseforstyrrelse – pasientens og kunstterapeutens perspektiv (192.05)

Det vises til ditt svarbrev datert 01.11.05.

REK Vest v/leder har vurdert saken. En har ikke flere merknader og studien er endelig klarert fra denne komité sin side.

Vi ønsker deg lykke til med gjennomføringen og minner om at komiteen setter pris på en sluttrapport, eventuelt en kopi av trykt publikasjon når studien er fullført.

Vennlig hilsen

Arnold Berstad
leder

Arne Salbu
sekretær

Appendix H:

Receipt from The Norwegian Social Science Data Services

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Kristine Rørtveit
Gruppepoliklinikk I
Spesialavdeling for voksne
Psykiatrisk klinikk
Postboks 1163
4068 STAVANGER

2 (1)

Vår dato: 28.11.2005 Vår ref: 200501568 SS /RH Deres dato: Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 23.09.2005. Meldingen gjelder prosjekt:

13387	*Opplevelse av skyld og skam hos modre som lider av spiseforstyrrelse - pasientens og kunstterapeutens perspektiv*
Behandlingsansvarlig	*Helse Stavanger HF, ved institusjonens øverste leder*
Daglig ansvarlig	*Kristine Rørtveit*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

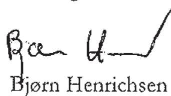
Personvernombudets vurdering forutsetter at prosjektet gjennomføres slik det er beskrevet i vedlagt prosjektvurdering. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/register/

Personvernombudet vil ved prosjektets avslutning, 30.12.2006, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen



Bjørn Henrichsen

Synnøve Serigstad

Kontaktperson: Synnøve Serigstad tlf: 55 58 35 42

Prosjektvurdering

Daglig ansvarlig

Kristine Rørtveit
Gruppepoliklinikk I
Spesialavdeling for voksne
Psykiatrisk klinikk
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4068 STAVANGER

13387 **Opplevelse av skyld og skam hos mødre som lider av spiseforstyrrelse - pasientens og kunstterapeutens perspektiv**

Formålet med prosjektet er å dokumentere og få økt kunnskap om spiseforstyrrelse som lidelse, kunstterapi som tilnærming, og skam og skyld som fenomen.

Utvalget består av 12-16 kvinner som har født egne barn og lider av bulimi, samt kunstterapeuter og behandlere. Førstegangskontakt med pasientene opprettes av pasientenes behandlere, prosjektleder oppretter selv førstegangskontakt med behandlerne. Det gis skriftlig og muntlig informasjon, og det innhentes skriftlig samtykke. Personvernombudet forutsetter at følgende opplysninger tilføyes deltakerinformasjonen:
- At prosjektet er tilrådd av Personvernombudet for forskning ved Norsk samfunnsvitenskapelig datatjeneste og av Regional komité for medisinsk forskningsetikk.
- At prosjektet er planlagt avsluttet i 2009, men at datamaterialet anonymiseres ved utgangen av 2006.

Data samles inn via intervju, observasjoner og fotografi av bilder som lages i billedterapitimene. Det registreres opplysninger om hvordan det er å ha en spiseforstyrrelse, hvordan livet som mor er påvirket av det å ha en spiseforstyrrelse, og hvordan det oppleves å kunne bruke bilde som tilnærming i behandling. Det vil kunne bli registrert opplysninger om barna. Kvinnenes navn registrerer navn, og dette er direkte personidentifiserende opplysninger. Disse opplysningene erstattes med et referansenummer som viser til en navneliste som oppbevares atskilt fra det øvrige datamaterialet.

Opplysningene er sensitive, da de omhandler kvinnenes helse, jf. personopplysningslovens § 2, punkt 8 c.

Datamaterialet oppbevares og bearbeides på pc tilhørende Helse Stavanger i nettverk tilknyttet Internett, isolert privat pc og i manuelt arkiv/papir. Det tas digitale bilder, og intervjuene tas opp på lydbånd.

Ved prosjektslutt 20.12.2009 skal datamaterialet anonymiseres. For at datamaterialet skal være anonymt må navnelisten slettes, lydopptak makuleres og bildeopptak slettes. I tillegg må samtykkeslipper makuleres. Opplysninger som er relevante for pasientenes behandling kan etter deres ønske overføres til journal.

Prosjektet er tilrådd av Regional komité for medisinsk forskningsetikk.

Appendix I:

Group Art Programme

Structure and content of a 15 session programme by RPN Elin Furubotn and Kristine Rørtveit.
Weekly meetings, each session of a two-hour duration: About 30 minutes for introduction and conversation, 40 minutes for art exercise, 50 minutes for reflection.

Session	**Phase**	**Focus**	**Aim**	**Exercise**
1-2	Safety	Information and introduction. Resources, interests and positive skills. Introduce aspects of own ED to the group. Psycho-education about regular eating and cognitive model of ED.	To feel welcome. To overcome the aversion to the other participants. To create a safe atmosphere. To activate each participant's resources. To increase basic knowledge about ED.	Short psycho-education for the group. Art exercise: Paint a tree with your left hand and make it as ugly you can. Let a pencil move on paper without lifting it up, while you listen to music for a brief moment. Look at the sketch and see if you can find a pattern or symbol that can express one of your resources. Look at the tree you painted. Paint a new tree in a way that symbolises yourself.
3-7	Working phase	Individual ED related problems.	To externalize the ED. To prepare for a deeper reflection on one self and individual reflection on the ED.	Write a letter with focus on positive and negative sides of the ED. Make a symbol of your ED in clay. Make a symbol of yourself in clay.
8-9	Working phase	Suffering from ED: How is your daily life?	To express feelings and thoughts verbally or through symbols. To reflect upon own ED.	Introduction to cognitive distractions. Mindfulness exercise. Make a mask that looks aggressive!
10-11	Working phase	Guilt and shame	To reflect on and express experiences of guilt and shame.	Mindfulness exercise. Make a mask that expresses how you feel today.
12-13	Working phase	Motherhood	To express experiences of being a mother.	Choose a form of expression: clay-modelling, painting/drawing, making a mask.
14-15	Ending phase	The future. What have you learned? How is you ED how do you want it to be in the future?	To be ready to leave the group.	Look at all the things you have made. Is there anything that you would like to change or finish? Use first 30 minutes to finish the work, and the rest of the time for verbal reflection.

Appendix J: Overview of research questions, findings, and conclusions of the four sub-studies

Overview of the research question, findings and conclusions of the four sub-studies

Paper	I	II	III	IV
Research question	What are mother's daily life experiences when suffering from ED?	How do women who suffer from ED experience the bodily aspects related to their condition?	What mental challenges related to daily life experiences are experienced by women who suffer from ED?	What is the meaning of guilt and shame experienced by mothers with ED?
Main-theme	Experiencing guilt as a mother in the context of eating difficulties	Powerful feelings of being trapped in and ashamed of one's own body	Balancing between mental vulnerability and strength	Struggling in silence with guilt and shame as a mother living with ED and trying to keep it secret
Theme I	Having a guilty conscience in relation to being a good enough mother	The feeling of being trapped by overwhelming physical sensations	Struggling with emotional ambivalence	Feeling worried about failure and wanting to be successful
Theme II	Being preoccupied about not involving the children in the eating difficulties	The feelings of being ashamed of one's own body	Being cognitively aware of limitations	Having condemningly thoughts about one's own sense of responsibility
Theme III			Experiencing an existential sense of being lost and frozen	
Conclusion	The study illuminated the importance of identifying mothers with ED and offering them treatment and or support.	Bodily experiences were reported as strong. One clinical implication for nurses is to acknowledge this fact and make it possible for these women to articulate their difficulties, especially those connected to the feelings of being trapped and ashamed. Support groups focusing on these themes could be one way of assisting women and easing some of the negative feelings associated with ED.	The mental challenges were strong and affected the participant's lives. One clinical implication for psychiatric nurses is to acknowledge the strength of emotional, cognitive and existential challenges and make it possible for patients to articulate their exhaustion in spite of their outward appearance of strength.	Feelings and awareness of guilt and shame are strong; they vary between individuals and may be intensified in mothers who suffer from ED. It is important for mental health nurses to help mothers with ED articulate such feelings in order to promote health.