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# **Toward an Understanding of Abuse in Health Care**

**– A Female Patient Perspective**

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*“if you really want to know what’s going on,  
you have to feel it; you have to be affected by it;  
you have to let it move you”*

*Phyllis Noerager Stern (In: Glaserian Grounded Theory, 2009)*



# ABSTRACT

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**Background.** High numbers of incidents of abuse in health care (AHC) have been reported by patients in Sweden. In questionnaire studies (n=9600), every fifth Swedish woman and every tenth Swedish man reported any lifetime experience of AHC, and a majority reported suffering from their experiences. Female patients with experiences of AHC described them as experiences of *being nullified*, and male patients as experiences of *being mentally pinioned*. Little is known about why AHC occurs and how it can prevail in a health care system that aims to relieve patients' suffering.

**Aim.** The overall aim of the thesis was to bring understanding to what AHC is and to start exploring what contributes to its occurrence, focusing on a female patient perspective.

**Methods.** In study I, a concept analysis of AHC was conducted based on the concept's appearance in scientific literature and through case studies. Also, AHC was demarcated against the related concepts *patient dissatisfaction*, *medical error*, and *personal identity threat*, in order to analyze differences and similarities with these concepts. For studies II and III the Transgressions of Ethical Principles in Health Care Questionnaire (TEP) was developed to measure to what extent female patients remain silent toward the health care system after having experienced abusive or wrongful ethical transgressions in the Swedish health care system. It was hypothesized that to a high degree female patients remain silent toward the health care system after such experiences, and this lack of feedback may in turn contribute to the hampering of structural change toward better encounters. The questionnaire was answered by female patients recruited at a women's clinic in the south of Sweden (n=530). Study IV built on a constructed grounded theory design and included informants who reported experiences of AHC in TEP (n=12). The interviews focused on the informants' stories of what contributed to their experiences of AHC.

**Results.** Based on the concept analysis, AHC was described as patients' subjective experiences in health care of encounters devoid of care, in which they experienced suffering and loss of their human value. Study II showed that a majority of the female patients who perceived one or more transgressions as abusive or wrongful remained silent about at least one of them (70.3%). In 60% of all cases, patients remained silent about abusive or wrongful events. In study III it was examined whether patients remaining silent could be associated with any patient characteristics. Remaining silent was only found to be associated with younger age and a lower self-rated knowledge of patient rights. In study IV, female patients' stories of what contributed to their experiences of AHC were analyzed. This was best characterized as a process where the patient loses power struggles. According to these patients, not only their vulnerability, but also their level of competence contributed to staff's unintended use of domination techniques by which they felt abused.

**Conclusions.** As AHC is defined from patients' subjective experiences it is necessary for the prevention of AHC to listen to patients' stories and complaints. The prevalence of female patients' silence after abusive events could be worrying, as it constitutes a loss of essential feedback for the health care system. Patients do not bear responsibility for the quality of health care processes, but their knowledge may be very valuable for structural improvement of these processes and could be valued as such. Clinical interventions that stimulate these patients to speak up, accompanied by health care staff's reflections on how to respond to patients speaking up, must therefore be explored.

# SWEDISH ABSTRACT / SVENSK SAMMANFATTNING

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**Bakgrund.** Tidigare studier i de nordiska länderna där patienter har tillfrågats, har påvisat en hög prevalens av kränkningar i vården (KV). I kvantitativa studier (n=9600) uppgav var femte svensk kvinna och var tionde svensk man att de upplevt KV någon gång i livet, och många rapporterade lidande än idag av sina upplevelser. I kvalitativa studier har framkommit att kvinnliga patienter upplever KV som *att bli tillintetgjorda*, och manliga patienter upplever det som *att bli mentalt vingklippta*. Det finns bristfällig kunskap om vad som bidrar till förekomsten av KV och hur företeelsen kan fortsätta att uppkomma i ett sjukvårdssystem som är till för att lindra lidande.

**Syfte.** Det övergripande syftet i denna avhandling var att förstå vad KV är, och vad som bidrar till att situationer av KV förekommer, sett ur kvinnliga patienters perspektiv.

**Metod.** Studie I utformades som en begreppsanalys, baserad på hur *abuse in health care*, den engelska motsvarigheten till KV, har använts i vetenskaplig litteratur och i fallstudier. För att analysera skillnader och likheter med relaterade begrepp, jämfördes *abuse in health care* med begrepp såsom patient(o)-tillfredsställelse, medicinska misstag och personliga identitetshot. För studierna II och III utformades ett frågeformulär med syfte att undersöka i vilken utsträckning patienter förblir tysta gentemot vården, efter att ha upplevt kränkande eller felaktiga etiska överträdelser inom svensk sjukvård. Hypotesen var att patienter i hög utsträckning förblir tysta gentemot vården efter den här typen av händelser, vilket i sin tur kan bidra till att hämma strukturell förbättring genom att återkoppling därmed uteblir. Frågeformuläret besvarades av kvinnliga patienter som rekryterades på en kvinneklinik i södra Sverige (n=530). Studie IV byggde på en konstruktivistisk grundad teoriansats där informanter som hade rapporterat KV i frågeformuläret i studierna II och III, intervjuades (n=12). Intervjuarna fokuserade på informanternas berättelser om vad som bidrog till att de upplevde KV.

**Resultat.** Som ett resultat av begreppsanalysen beskrevs *abuse in health care* som patienternas subjektiva upplevelser av möten i sjukvården som brister i omsorgen, där de kände att de hade förlorat sitt människovärde och upplevde lidande. Studie II visade att majoriteten (70.3%) av de kvinnliga patienter som hade upplevt etiska överträdelser som kränkande eller felaktiga, förblev tysta gentemot sjukvården, åtminstone vid ett tillfälle. Den totala tystnaden gentemot sjukvården efter kränkande eller felaktiga händelser var 60%. I studie III analyserades samband mellan att förbli tyst gentemot vården och olika patientegenskaper. Att förbli tyst visade enbart samband med yngre ålder och lägre självskattad kunskap om sina rättigheter som patient. I studie IV studerades kvinnliga patienters berättelser om vad som bidrog till deras upplevelser av KV. Detta karakteriserades som en process där patienter förlorar maktkamper. Enligt dessa patienter kunde inte endast deras sårbarhet, utan även deras kompetens, bidra till att personalen oavsiktligt använde sig av härskartekniker, som fick patienterna att känna sig kränkta.

**Slutsatser.** KV är definierat utifrån patienters subjektiva upplevelser. För att kunna förebygga KV är det därför av vikt att lyssna på patienters egna berättelser och erfarenheter rörande dessa upplevelser. Dock är det höga antalet patienter som förblir tysta efter kränkande upplevelser oroväckande, då det innebär en stor förlust av viktig återkoppling för sjukvården. Patienters kunskap kan vara mycket värdefull i samband med strukturellt förbättringsarbete av vårdprocesser. Deras kunskap bör erkännas och tillmätas värde, även om patienter inte bör sättas i en position där de bär ansvar för kvalitén av dessa processer. Kliniska interventioner med fokus på att stimulera patienter att agera eller säga ifrån, utan att de upplever att de förlorar maktkamper, bör därför utforskas vidare.

## LIST OF ORIGINAL PAPERS

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This thesis is based on the following four original papers, which are referred to in the text with Roman numerals (I-IV)

- I. **Brüggemann AJ**, Wijma B, Swahnberg K. Abuse in health care: a concept analysis. *Scandinavian Journal of Caring Sciences*, 2012; 26:123-32.
- II. **Brüggemann AJ**, Wijma B, Swahnberg K. Patients' silence following healthcare staff's ethical transgressions. *Nursing Ethics*, 2012; Published online 30 April 2012, doi 10.1177/0969733011423294.
- III. **Brüggemann AJ**, Swahnberg K. Patients' Silence towards the Health Care System after Ethical Transgressions by Staff: Associations with Patient Characteristics in a Cross-Sectional Study among Swedish Female Patients. *Submitted*, 2012.
- IV. **Brüggemann AJ**, Swahnberg K. What Contributes to Abuse in Health Care? A Constructive Grounded Theory Study of Swedish Female Patients' Stories. *Submitted*, 2012.



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## **PREFACE**

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During the fall of 2006, being a master's student at the time, I attended a seminar about bridging the gap between quantitative and qualitative methods. One of the presentations was given by Barbro Wijma and Katarina Swahnberg. Their stories about abuse in health care and how patients respond to these events caught my attention and I became curious. That same evening I read one of their articles and wrote a two-paged comment containing questions and thoughts that I had. What exactly is abuse in health care? Why does it happen? Do patients accept these events? Barbro Wijma and Katarina Swahnberg invited me to a meeting to discuss these questions as well as the possibility for me to work with them. In the spring of 2008 I officially started my work as a PhD student, concentrating on my initial questions of which this thesis is the result.

## ACRONYMS

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AHC	Abuse in Health Care
NorAQ	The NorVold Abuse Questionnaire
TEP	The Transgressions of Ethical Principles in Health Care Questionnaire
ViolEP	The Violations of Ethical Principles Questionnaire

# INTRODUCTION

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The title of this thesis contains three concepts that must be explored before introducing the research field: *abuse*, *health care*, and *a patient perspective*.

## Abuse

The English word ‘abuse’ comes from the Latin word *abuti*, which literally means misuse, or use in a wrong way. According to contemporary dictionary definitions abuse can both refer to the misuse of something or of someone (1). The former can refer to substance or alcohol abuse, or really any kind of maltreated physical or abstract thing. The misuse of someone, which is of interest in the current thesis, is widely studied and many different concepts have evolved out of it, based on: the type of abuse (e.g., psychological abuse or sexual abuse, which can be either verbal or non-verbal), the means of abuse (e.g., telephone abuse or internet abuse), the victim (e.g., child abuse or abuse of the elderly), the perpetrator (e.g., intimate partner abuse or parental abuse), or the location where the abuse took place (e.g., work-related abuse, domestic abuse, or abuse in health care). There is no consensus on the definition of abuse (2) and different perspectives exist on what a clear definition should look like (3). A positivistic perspective would seek for an objective definition including specific acts that might count as abusive which are distinct from non-abusive, harmful acts. A humanistic perspective takes a broader stance and includes any harmful act that can interfere with people’s ability to achieve their developmental potential (3), or sees abuse as “avoidable insults to basic human needs” (4, p. 292). As this thesis will show, abuse in health care here is understood from a humanistic perspective rather than from a positivistic one.

## Health care and regulations in Sweden

Health care systems concentrate on the provision of medical services. Swedish health care is mostly tax-funded and primarily organized at the national and regional level (5). At the national level, the government and the *Riksdag* (the Swedish parliament) have a legislative function, and government agencies such as the National Board of Social Health and Welfare (*Socialstyrelsen*) have the responsibility to implement governmental decisions in policies and regulations. The bulk of executive responsibility concerning health care lies in the hands of the 21 county councils (*landsting*). Care for the elderly and people with a physical

or severe intellectual disability is the responsibility of municipalities (*kommuner*; 5).

The law formulating the aims and ground rules for the Swedish health care system can be found in the Health and Medical Services Act from 1982. This act includes the aim to achieve good health and care on equal conditions for the whole population, which should be given with respect and dignity (6). Patients' main rights are formulated in this act and include the right to autonomy and integrity, safe and continuous care, as well as the right to receive individual information about one's health and care. The Health and Medical Services Act also gives patients the right to be offered information about different treatments, but patients cannot choose a specific medical treatment if not deemed medically necessary. One of the latest additions to the assembly of patient rights was established in the Act on System of Choice in the Public Sector (7), which gives individual patients the right to choose between public and private medical service providers. This act aims to increase patients' freedom of choice and to invite private service providers to compete with each other as well as with public providers.

According to the new Patient Safety Act from 2011, the National Board of Health and Welfare is the main responsible agency for the evaluation of the quality of care (8). This responsibility includes the evaluation of (potential) medical errors, which health care providers are obliged to file (this part of the act is also known as *Lex Maria*), and the evaluation of patient complaints. If patients' complaints do not imply an immediate risk for patient safety, the Board may decide to refer patients to a local Patients' Advisory Committee (*patientnämnd*). Such complaints may concern a breach in the encounter between patient and health care provider that is not considered to hazard patient safety. There is a possibility for patients to receive economic compensation for injuries caused directly by the health care system, according to the Patient Injury Act (9). The experience of abusive treatment cannot be compensated for according to this act, as abuse (*kränkning*) is not included in the definition of a personal injury, which is the only injury compensated for (10). If, however, the abusive treatment was a criminal act, it could be dealt with as such under the Swedish penal code instead of within the patient rights system.

## The patient's perspective

Stemming from the Latin verb *pati*, to suffer, according to a dictionary definition, a patient is "a person who is receiving medical care, esp. in a hospital, or who is cared for by a particular doctor or dentist when necessary" (11). A similar

definition seems to be valid in Swedish regulations, even though it is only mentioned in a law proposition preceding the Patient Injury Act, where a patient is defined as anyone who has established contacts with the health care system considering their own health (12). Some have argued that the role of the patient changed over the past decades; patients went from being passive receivers of care to being active consumers of care (13). Others found that patients may pursue either role depending on context (14) or the severity and rarity of disease (15). Contemporary changes toward “consumerism”, assuming rational patients who aim toward self-improvement, may have contributed to such changes in patienthood (13).

Foucault contrasted the patient’s view to his concept of the *clinical gaze* (16). He uses this concept to illustrate how medical science broke down humans into body parts and diseases, separating them from the persons they were (17). Social history of medicine, as a discipline, was also mainly preoccupied with a caregiver perspective. However, since the second half of the 20<sup>th</sup> century, there has been a growing interest in historical investigations into experiences by the other part of the medical encounter, i.e., the patient (16, 18). Before this time, patients’ medical histories were mainly studied through clinical notes, which are indirect accounts of patients’ experiences through a medical gaze (16). Predominantly after World War II (19) patients were starting to be seen as active participants within medical encounters, and this increased attention to patients’ perspectives on their care. Initially, this increased attention was aimed at improving medical outcomes such as compliance (20); later, patient evaluation outcomes such as patient satisfaction became seen as valuable in and of itself (19, 20).

The growing interest in the patient’s perspective also appeared in the social sciences. Within the sociology of health and illness, a change occurred in the starting point of analysis, from a biomedical definition to the patient’s narrative (21). Even though these narratives are direct accounts of experiences of illness, patients not only build their narratives on lay knowledge but also on medically-based ideas (22). The patient’s perspective may therefore not be seen as totally disconnected from the medical discourse. Neither should this perspective be seen as something constant; something that patients always carry with them. Rather, the patient’s perspective is constructed in a context of interaction between the patient and, in most cases, staff (23).

## Abuse in health care

In line with legal changes, an increase in patients' rights, and the changing status of the patient's perspective, there has also been growing attention to patients' untoward experiences in health care (24). In the late 1990s, the research network NorVold initiated research into patients' experiences of abuse in the health care system.

Initially, within NorVold, the phenomenon of interest was labeled *övergrepp i vården* in Swedish, which was translated as *abuse in health care* in English. At the request of the ethical review board the Swedish label was changed into *kränkningar i vården* before the first studies were conducted, while the English equivalent remained unaltered. In practice, however, the concept of *övergrepp i vården* and *kränkningar i vården* were used synonymously in the first years of study, although the phenomenon that the research group explored remained one and the same. In more recent years, as well as in this thesis, solely *kränkningar i vården* was used. It can be argued that *kränkning* is closer to other English concepts, such as *offense*, than to *abuse*, and this will be part of the discussion later on in this thesis.

Abuse in health care was first operationalized in the NorVold Abuse Questionnaire (NorAQ) by means of three questions, which aimed at capturing different levels of severity (Table 1; 25). In studies using NorAQ it is assumed that patients have experienced abuse in health care if they answer "yes" to any of these three questions. Abuse in health care was later preliminarily described as "any act perceived as abusive by the child or adult patient in any health care setting" (26, p. 4).

**Table 1. Questions operationalizing abuse in health care in the NorVold Abuse Questionnaire**

Mild abuse	Have you ever felt offended or grossly degraded while visiting health care services, felt that someone exercised blackmail against you or did not show respect for your opinion – in such a way that you were later disturbed by or suffered from the experience?
Moderate abuse	Have you ever experienced that a “normal” event, while visiting health care services suddenly became a really terrible and insulting experience, without you fully knowing how this could happen?
Severe abuse	Have you ever experienced anybody in health service purposely – as you understood – hurting you physically or mentally, grossly violating you or using your body and your subordinated position to your disadvantage for his/her own purpose?
	<b>Answer alternatives (the same for all questions):</b> 1 = No, 2 = Yes, as a child (<18 years), 3 = Yes, as an adult (≥ 18 years), 4 = Yes, as a child and as an adult

The questions about abuse in health care according to NorAQ were validated in a female general population sample using in-depth interviews as a gold standard (n=64; 25). The questions showed good sensitivity (86%), which means that relatively many women who told about abuse in health care in the interviews also reported this in NorAQ. The questions showed even better specificity (98%), meaning that almost all of the women who had no experiences of abuse in health care according the interviews also answered “no” to all of the questions in NorAQ. Reliability was estimated by means of test-retest measures, testing the consistency of answering patterns between two occasions. The reliability was judged to be good for mild and moderate abuse in health care (kappa mild 0.69, kappa moderate 0.54), but poor for severe abuse in health care (kappa 0.31), probably due to the low prevalence of the severe forms. The male version of NorAQ (m-NorAQ) also showed good sensitivity (93.1%) and good specificity (89.5%; 27). Test-retest reliability was judged to be good (kappa mild 0.65, kappa moderate 0.63) although the kappa value for severe abuse in health care was low here as well (0.18), again probably due to very low prevalence (28).

Studies based on these NorAQ questions have shown varying lifetime prevalence of abuse in health care in female patients in five Nordic countries (n=3641): Denmark 23.8%, Finland 25.2%, Iceland 28.1%, Norway 13.2%, and Sweden 19.7% (29). A slight difference in prevalence was found between the Swedish patient sample (19.7%) and a randomized female population sample (15.5%; 30) Corresponding prevalence in male patients (n=1667) has only been studied in Sweden and was 8.1% (27). More than half of the Swedish women and men

reporting abuse in health care were currently suffering from the event that had taken place (27, 30).

Several factors were shown to be associated with experiences of abuse in health care in studies using NorAQ. Exposure to childhood abuse (emotional, physical, or sexual) was found to lead to an increased risk for adult experiences of abuse in health care in a case-control study in female gynecology patients (31). The risk for such *re-victimization* increased when they were exposed to several types of abuse during childhood. Those who had reported adult abuse in health care were also found to be younger and had higher educational levels (29, 31). For a sample of female patients who had a background of emotional, physical and/or sexual abuse in childhood, adulthood abuse in health care was associated to poor self-rated health, but not to educational level (29). In a Swedish male patient sample, associations were found between experiences of abuse in health care and having been born in a foreign country (27).

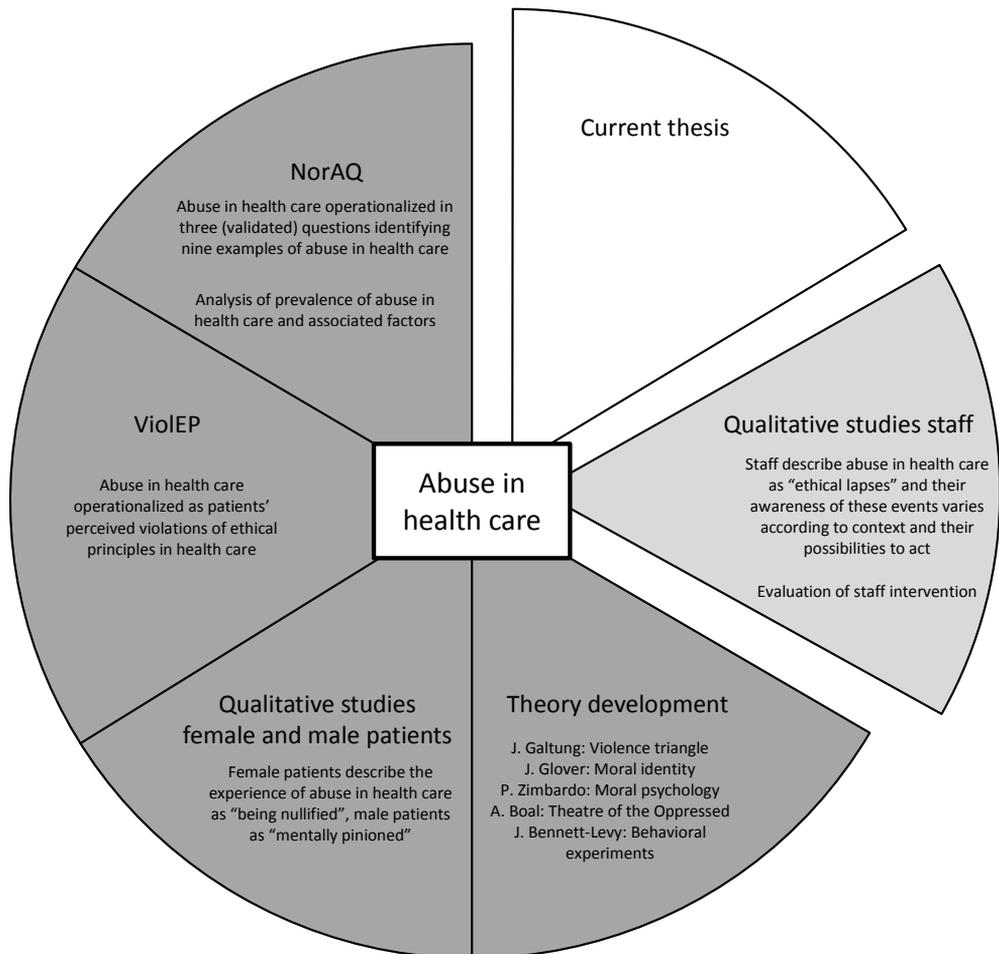
Abuse in health care has also been operationalized as patients' perceptions of violations of ethical principles in health care. In the Violations of Ethical Principles Questionnaire (ViolEP), 30 concrete examples are given in which the ethical principles of autonomy, justice, physical nonmaleficence, sexual nonmaleficence, and integrity were violated (32). In a female patient sample (n=420), a majority reported experiences of such violations (73%), and 68% of those exposed perceived the event as abusive. ViolEP showed a high sensitivity (88%) but low specificity (62%) in capturing abuse in health care using the NorAQ questions as a gold standard. This can be explained by (i) the construction of the questionnaires, as ViolEP contained 30 examples, while NorAQ contained three questions describing nine examples, (ii) ViolEP covers a wider range of acts, and (iii) many of the acts described in ViolEP may be considered less severe than the acts described in NorAQ (32).

Parallel to quantitative studies, patients' stories about their experiences of abuse in health care were analyzed in qualitative interview studies with a grounded theory design. Female patients (n=10) described their experiences as experiences of *being nullified*, entailing feelings of powerlessness, ignorance, and a lack of care and empathy (33). To some level, male patients (n=13) shared the women's experiences of feeling ignored, but the men also felt frustrated and experienced a crisis of confidence. Their experiences were best described as experiences of *being mentally pinioned*, implying a loss of ability to act in accordance with their own convictions and a loss of their value as human beings (34).

Apart from elaborating on patients' experiences, the occurrence of abuse in health care was attempted to be understood from a theoretical perspective,

building on theories of violence and moral psychology. Theory development also included pedagogical theories and theories about behavioral experiments so as to make a start at developing staff interventions against abuse in health care.

**Figure 1. Abuse in health care was described, measured, and analyzed in different ways when the current project started. Parallel to the current project, staff's perspectives were further examined.**



At that moment in time, 2008, the current project was started. Up to that point, abuse in health care had been described, measured, and analyzed in different ways (Figure 1), while a clear conceptual definition was lacking. Hence this thesis begins with a concept analysis, converging the different uses of the concept

(study I). Although there was a growing understanding of the prevalence of abuse in health care and what experiences of abuse in health care meant to patients, no empirical studies about what contributes to the occurrence of abuse in health care had been conducted. This thesis had a starting point in the research presented above, as well as in some of the theories on violence and moral psychology (which will be presented below), and initially assumed the above-cited description of abuse in health care as *any act perceived as abusive by the child or adult patient in any health care setting* (from here on called AHC).

Parallel to the current thesis, two other lines of research were conducted by other members in the research group. First, AHC was studied in a male population sample (n=2924) using NorAQ and prevalence was found to be 7.3% (compared to 8.1% in a patient sample; 35). Factors associated with AHC in this sample were *being born outside the Nordic countries, being on sick leave or being retired, and having a lower income*. Second, staff's descriptions of what AHC means according to them were analyzed (n=21). Although staff defined AHC as ethical failures toward patients, they at the same time avoided responsibility for these events. This dualism was described in the core category *ethical lapses* (36). Staff's awareness of AHC was found to vary according to context and possibilities to act, more so than being a personal characteristic (37). In a first effort to intervene against AHC, a staff intervention based on a drama pedagogy developed by Augusto Boal (38) was developed and tested. In a series of workshops, staff roleplayed short scenes depicting problematic situations of AHC; they interacted by replacing the protagonist in the scenes and tested alternative paths of behavior with a different outcome. Initial results of the intervention based on this method indicated that staff experienced an increased capacity to act against abuse in health care after the intervention (39). Also, staff showed increased awareness of AHC, and their descriptions of AHC resembled patients' stories (40, 41).

# THEORETICAL FRAMEWORK

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In this framework, the main theoretical assumptions and considerations underlying the current thesis are described. After epistemological and methodological considerations, several theories are presented that may help in understanding AHC. Finally, these theories are connected to each other and applied to AHC and the current thesis.

## Epistemological assumptions

Epistemology is the study of knowledge and helps to answer questions such as: What is knowledge? What can we know? What are sources of knowledge? (42) Further relevant questions are: how can we acquire knowledge by means of scientific methods? And what is the status of such knowledge?

In the realm of the social sciences, a major shift of thinking occurred early in the 19<sup>th</sup> century when Comte introduced the concept of *positivism*. Comte's scientific system introduced assumptions from the natural sciences into the field of sociology, leading to a view that earlier, pre-positivistic social science studies were merely pseudo-scientific (43). Positivism builds on the assumption that the scientist is (and should be) a value-neutral observer who is completely separated from what is being observed (44). Because of this claimed objectivity, positivism ranks scientific knowledge above common sense. During the second half of the 20<sup>th</sup> century, growing critique against positivism arose and other epistemological assumptions were juxtaposed against positivism.

In the current thesis, the main positivistic assumptions were rejected. It is assumed that the scientist cannot (and should not) be value-neutral and isolated from what is studied, nor is scientific knowledge truer than other types of knowledge *per se*. In this thesis knowledge is seen as value-laden and as the result of social interaction with phenomena in specific contexts. More specific, in this thesis the feminist epistemology *agential realism* as developed by Barad (45, 46) is assumed. Building on the quantum-physician Nils Bohr's philosophy of science, Barad tries to converge *social constructivism* (assuming that things, including scientific facts, in general are the result of social processes; 47) with *realism* (the assumption that there is some kind of reality independent of observations). *Agential realism* presumes that an observation can never be separated from an observer and, hence, that reality does not exist outside nor beyond these observations (48). That what is observed are phenomena, not

observer-independent entities, and these phenomena should be the referents of science (49). Therefore observation apparatuses, or research instruments, not only influence what is observed; they are an integral part of the studied phenomena (49).

Agential realism does not build on, but can be expanded by the concept of *situated knowledge*, another element of feminist epistemology as developed by Harding (50) and Haraway (51). The fact that knowledge is situated means that it is interpreted and constructed in a specific local and cultural setting. Situated knowledge also emphasizes the importance of seeing that which is being observed as an agent, not as some kind of passive entity to be observed out there (51). If it is assumed that knowledge is situated, objectivity gets stronger the more this situatedness is scrutinized in the scientific process (50). Science becomes less objective if cultural values underlying research processes remain hidden in the striving for value neutrality. Also, our understanding of phenomena can become richer if multiple standpoints are included in the research process.<sup>1</sup>

## Qualitative and quantitative methods

The contrast between positivism and more constructivist epistemologies is reflected in the use of different methodologies. Researchers assuming positivistic epistemology tend to use quantitative methods, while constructivists mainly prefer qualitative methods (44, 52). In general, quantitative studies are used to quantify relationships, while qualitative research usually aims to study the underlying meaning of phenomena (53). As quantitative and qualitative methods are based on different paradigms, it has been argued that they are incompatible (52, 54). However, even quantitative methods can be used within constructivist or agential realist research, if it is also accepted that quantitative research is as much affected by the researcher's subjectivity (or situatedness) as qualitative research is (55). Some questions considering, e.g., the prevalence of problems can be studied more appropriately using quantitative methods, while qualitative methods are needed to understand human experiences (55).

There may be different reasons to use both quantitative and qualitative approaches within a single research project (56). *Triangulation* is used to converge results from different methods. *Complementarity* is used to illustrate or

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<sup>1</sup> This thesis is mostly written in the passive voice, which contradicts these epistemological assumptions. However, as research within the medical field is usually published in this voice, it was chosen to conform to this norm in the current thesis.

elaborate results from one method with results from another method. *Development* is used when results from one method inform another method in order to increase its validity. Through *initiation*, researchers seek to contradict results from different methods or question results from one method by using another method. *Expansion* is aimed at extending the breadth and range of studies by using different methods for different research components (56, p. 259). In the current thesis, *expansion* was the rationale for using both methodologies, as the research questions asked for different methods.

## A theoretical understanding of abuse in health care

In this section, several branches of theories are introduced and consecutively applied to AHC.

### **Structure – agency**

After leaving behind the dichotomies realism versus constructivism and quantitative versus qualitative method, it becomes necessary to resolve another dichotomy in order to understand the view of AHC in the current thesis.

One of the main debates within the field of social sciences is whether structures or agents guide human conduct. Functionalists and structuralists claim that social reality mainly consists of structures and larger systems (57). In contrast, symbolic interactionism assumes that the basic unit of social reality is action conducted by people (58). Both paradigms have been criticized; structuralism had underestimated the power of individual behavior, while interactionism was criticized for not taking the power of structures into account. In the second half of the 20<sup>th</sup> century, alternative views on social reality were developed to reconcile these two paradigms, amongst others by Giddens.

Giddens proposes a view where social practice is the central unit of social reality (59). In practices, defined as routinized behavior, agency is enabled and constrained by structures, which in their turn are reproduced by agency. This dualism is the foundation of Giddens's *theory of structuration* and important for the understanding of AHC in the current thesis, recognizing the influence of both agency and structure. Giddens defines structures as the rules and resources for action, which function in a constraining and enabling way. Giddens rejects that structures are entities externalized from actors engaging in them, but does state that structures can be tied to a physical space. His term *locale* emphasizes the setting in which an interaction takes place, and in which social relations are

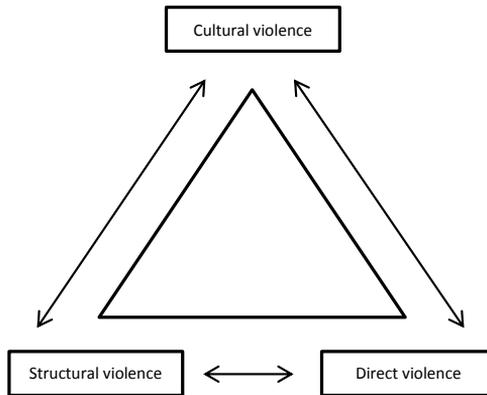
concentrated (60). Agents are defined as actors who can choose between different paths of action, i.e., who have at least one other alternative to act. No structures exist without agents reproducing them, but neither can agents act without reproducing structures. This reproduction is usually an unforeseen consequence of intentional behavior by agents, as, most of the time, we are unaware of these consequences. Many routines are part of our daily life and guide our behavior without us noticing that we reproduce them each time we act by them. Structure and agency are hence viewed in a dualistic relationship rather than in a traditional dichotomist way.

### **The violence triangle**

Johan Galtung broadly defines violence as the avoidable impairment of human needs, or any avoidable harm that increases the gap between the *actual* and the *potential* for human beings (4, 61). Starting from this definition, Galtung distinguishes three forms of violence (4). First, direct violence, which involves face-to-face incidents in which person A is harmed by person B. This need not always be an intentional act, but the consequences must reasonably be interpretable as avoidable. Second, structural violence, which is more invisible than direct violence, involves processes that structurally bring avoidable harm to people. Different from direct violence, structural violence is not committed by a single perpetrator but is indirect and is the result of societal systems leading to social injustices. An example of this in the Swedish health care system is the structural difference in health care access and quality of care between women and men, in most respects to the disadvantage of women (62). Third, cultural violence, which is the most invariant and invisible of the three, is rooted in the strong cultural and historical beliefs that humans have learned since childhood. This type of violence refers to cultural expressions that contribute to social injustices and avoidable harm. Considering structural inequalities in access to care, this can, for instance, be legitimized by cultural notions about a *national gender order* or by patriarchal norms in general. Such notions can make structural or direct gender violence “feel right”.

Critical to Galtung’s theory is the interrelationship between the three types of violence, which he pictures as a triangle (Figure 2). The most important message from this model for the understanding of AHC is that the invisible structural and cultural violence feed events of direct violence, and can even legitimize it (4).

**Figure 2. Galtung's violence triangle**



## **Moral behavior**

A general distinction can be made between morality and ethics. Morality is commonly described as what people see as right and wrong, and ethics is a theoretical reflection upon this morality. AHC contains many moral aspects, as it centers on patients' harmful experiences in a setting that is aimed to ensure the wellbeing of persons (63).

James Rest's model of moral behavior theorizes the process that individuals go through in order to perform a moral action (64-66). First, a person must become aware that a situation contains moral elements, through a capacity also labeled *moral sensitivity*. Second, the person now comes to a *moral judgment* by weighing the different moral components against each other. Third, this judgment is balanced against other non-moral values (such as self-actualization) and leads to a *moral motivation* to act according to the initial moral judgment. Fourth, if the person is morally motivated to act, she still needs *moral character* including moral identity, virtues, and practical skills to perform the action. All these components are necessary for a person to come to moral action. Of special interest in the current thesis is moral character, or moral identity, which Jonathan Glover has studied.

In the book *Humanity*, Glover investigates the moral history of the twentieth century and tries to understand how it is possible that ordinary people can perform inhumane acts (67). Studying large atrocities such as World War II, the killings under the Mao and Stalin regime, and the Hiroshima bombings, Glover concludes that the neutralization of people's moral identity is central. Moral

identity is part of human character, a sense of who we are, and what kind of person we want to be (67, p. 402). A strong sense of moral identity may be a protective factor against immoral behavior. However, certain mechanisms can neutralize parts of this identity, for instance: (i) institutional momentum and moral inertia, (ii) fragmentation of responsibility, and (iii) moral slide. First, institutionalized rules can justify certain policies and create moral inertia, which in turn can justify immoral behavior. Second, a shared responsibility can lead to the feeling that no one is responsible and moral identity is neutralized. Third, if a moral slide from one precedent to another occurs, behavior can gradually become more immoral (67, p. 114-115). Although these mechanisms describe the neutralization of identity in situations of war, Glover argues that they can also be active in everyday life. Recently, a medical student used theories and data about the holocaust to understand more about the medical profession. In this essay, she reflected upon the risk for *moral erosion* in becoming a physician and how to stay *morally intact* (68). By investigating how physicians could end up participating in the holocaust, she exposed vulnerabilities for moral erosion inherent in the medical profession and contemporary medical culture.

## **Gender**

The term gender was developed during second-wave feminism and defined as social roles based on biological sex (69, 70). By gendered, then, it is meant how societal aspects are organized and divided between the categories of men and women (71). Most feminists agree that these aspects, and hence gender, are social constructions. Some see this construction in addition to a biologically-determined sex, while others claim that the concept of sex and the division between female and male are social constructions as well (69, 72). Viewing sex and gender, or at least gender, as socially constructed instead of biologically determined puts societal differences between men and women in another perspective. This view enables feminists to critique the norms on which these differences are built, implying that a change of norms could lead to societal changes and changed gender patterns. One example of such a norm is to use the male body or men's behavior as a general model for women as well (73). Other norms concern specific aspects of what is masculine and what is feminine. Not only are such norms of descriptive character, they can also have (negative) social consequences for those deviating from the norm.

Feminist social scientists have problematized the position of female patients in health care. In many ways, it is argued, women are subject to patriarchal structures that dominate health care. This leads to women experiencing a loss of control over their bodies and their lives to a male dominated health care system

(74). For example, Miles claims that many aspects of women's bodily functions and social problems, more so than men's, are unnecessarily medicalized, i.e., diagnosed and treated as a medical problem (75). Examples include the medicalization of menopause, pregnancy, and appearance (76).

The interaction between health care staff and patients can also be affected by feminine and masculine norms. Patients and staff enter the health care encounter with gendered images and expectations, which have consequences for the encounter, diagnoses, as well as treatments. Patients may traditionally view male doctors as competent-looking and authoritarian, while female doctors can be seen as nurturing and understanding. Staff, in turn, may stereotype female patients as being more vulnerable and weaker than male patients (75).

### **Joining theories and applying these to abuse in health care**

Giddens's definition of structures as rules and resources for behavior is used in this thesis. Using this definition, Giddens would probably not make a distinction between structure and culture as Galtung does, as cultural norms and ideals are just as much part of these rules and resources. Most likely, Giddens would accept that cultural systems of knowledge and practice are social structures that are rarely transformed and stable over time (77, 78). As these types of norms and practices are so deeply rooted in larger social systems such as gender patterns, they are mostly reproduced instead of transformed. The moral inertia of which Glover speaks can also be seen as an example of such a stable pattern of thought.

Applying these theoretical insights to AHC means that these events, which normally take place when at least two people interact, should not be seen as isolated from structures, including cultural norms. Examples of such structures may be the clinical gaze as presented earlier, health care hierarchies, or the inappropriate use of specialized Latin medical language (79). These structures in health care are probably gendered, i.e., they may have a different effect on men and women, as patients and staff enter health care encounters with expectations based on gender norms. Institutional momentum and moral inertia may contribute to why such structures are still in place and why it is hard for staff and patients to recognize and counter them.

Considering a neutralization of moral identity, this may affect staff as well as patients. First, staff may act according to institutionalized policies that unintentionally could lead to AHC, although they feel legitimized by these very policies and other structures. Second, the same may count for patients who feel

forced to remain silent or choose not to speak up during or after AHC because of strong institutionalized structures, despite being morally motivated to do so.

Further applying Giddens's structuration theory to Galtung's violence triangle sheds light on the importance of reproducing and transforming structures through direct events of violence committed by individual agents. Instead of merely looking at structure and culture to explain the occurrence of direct violence, structuration theory adds the importance of direct events for the reproduction of structures (and therefore culture). AHC cannot be understood without studying health care structures, but these structures cannot be understood and changed without studying the direct events of AHC in which they are reproduced by patients and staff. Each time AHC takes place in an interaction, the structures that enabled it from the beginning are repeated or slightly transformed.<sup>2</sup>

Staff and patients enter health care encounters with a shared set of social rules.<sup>3</sup> On a level of what Giddens calls *practical consciousness* (59), patients and staff know how to interact and apply these social rules without thinking about how to behave. During such routine behavior, most social rules are reproduced while some are slightly changed, without actively being reflected upon. However, in some cases routine behavior does not work and individuals are forced to actively think about their behavior on a level of *discursive consciousness* (59). On this level, habits can be broken and discursively reflected upon to better handle the social situation.

It can be assumed that most of the time, AHC is an unforeseen consequence of staff's behavior, conducted on a level of practical consciousness, implicitly molded into daily routines. If patients experience AHC but cannot give signals to staff, or do not dare to speak up, it is hard for staff to become aware of these unforeseen consequences, and consequently they see no reasons for actively adjusting their routines. If patients are enabled to speak up and to give signals when they experience AHC (or when they feel AHC is at risk) there is an opportunity for change, as staff can reflect upon their behavior and routines. This occurs at a level of discursive consciousness and it can mobilize staff to bring about a change

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<sup>2</sup> The feminist concept of *doing gender* seems to fit very well in the theory of structuration. Doing gender builds on the idea that norms have no ontological status until they are acted upon. Gender, then, is seen as both an outcome and rationale for social arrangements (80). As long as gender norms are acted upon, they are reproduced and continue to exist.

<sup>3</sup> Examples of shared rules include how to greet, where to sit, the order of asking questions and answering, what is feminine and what is masculine, but also what staff and patients ought not to do during an encounter.

to the social practice in which they act. These feedback mechanisms are central to social change in the theory of structuration (59).

Situations of AHC that Galtung would label structural or cultural violence are more indirect than direct violence and may not even involve a perpetrator or an agent. Glover's illustration of the fragmentation of responsibility may be an example of how a sequence of individual acts can contribute to a patient's experience of AHC, even though no single member of staff is solely responsible. Somehow, however, individuals or a collective of individuals must have engaged in behavior that made a patient feel abused. Feinberg's definition of offense, for instance, not only contains an element of a *disliked* mental state; this state is also caused by the wrongful conduct of another (81). Considering the latter, people cannot be offended by objects unless they are created by someone else at some point in time.<sup>4</sup> A patient form containing discriminating questions, which is a form of cultural violence, can therefore be offensive, as it was created at an earlier point by a group of health care staff or a social institution. Galtung, Glover, and Giddens would agree that the codification of a rule can legitimize action upon this rule, make it feel normal, and make it part of routines, despite some of its untoward consequences.

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<sup>4</sup> Weckert gives as an example that a rock formation that resembles a part of the human anatomy is not offensive, while a similar shaped sculpture may be (82).

## AIMS OF THE THESIS

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The overall aim of the thesis was to understand what AHC is and to start exploring what contributes to its occurrence, focusing on a female patient perspective.

### Study aims

- Study I To analyze the concept of AHC and how AHC is different from the related concepts of medical error, patient dissatisfaction and personal identity threat.
- Study II To examine to what extent female patients remained silent toward the health care system after they had experienced abusive or wrongful transgressions of ethical principles. Also, to estimate the validity of a new questionnaire.
- Study III To identify what female patient characteristics are associated with remaining silent toward the health care system after having experienced abusive or wrongful transgressions of ethical principles.
- Study IV To understand what factors contributed to female patients' experiences of AHC by analyzing patients' narratives.

### Hypotheses

The following hypotheses were tested in study III.

It was hypothesized that patients' silence was related to older age, lower social status, and to not being born in Sweden, as these variables were found to be associated with lower levels of assertiveness in medical settings or of informal complaining (83-86). Patients with a background of other kinds of abuse (outside health care) remained silent to a higher degree, as a consequence of a fear of blame by others (79). Moreover, poor health and little knowledge of patient rights were also believed to be associated with patients remaining silent to a higher degree.

# MATERIALS AND METHODS

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## Design

The thesis started off with a qualitative concept analysis of AHC. Thereafter, different quantitative and qualitative methods were used (Table 2).

**Table 2. Overview of the materials and methods of the studies included in the thesis**

Study	Design	Material/participants	Data collection (year)	Method
Study I	Concept analysis	Scientific articles (n=22), book section (n=1), and report (n=1) about AHC and related concepts	2009	Method of concept analysis developed by Walker and Avant (87)
Study II	Cross sectional quantitative, descriptive	Consecutive female patients visiting a women's clinic (n=530)	2009-2010	Self-administered postal questionnaire
Study III	Cross sectional quantitative, analytical	Subsample of study II (n=293)	2009-2010	Self-administered postal questionnaire
Study IV	Qualitative	Purposeful and theoretical sample, subsample of study II (n=12)	2010-2011	Constructivist Grounded Theory (88)

## Study I: concept analysis

Concept analysis is one way to enhance clarity of concepts and has been defined as “the formulation and clarification of a mental construct, systematizing relevant information in ways that enable its appraisal and enhancement as an element that serves to both advance theory and guide practice” (89, p. 180-181). Relevant information can exist of scientific literature and cases, and data about how the concept is used in practice. The result of such an analysis can be synthesized into a theoretical definition, which is “precise, understandable to others, and appropriate for the context in which the term will be used” (90, p. 242). One way to choose a method of analysis is to depart from the maturity of the concept. Considering immature concepts, which AHC is according to criteria set up by Morse et al. (91), it is suggested to use a method derived from the work by Wilson (92). One such Wilsonian method has been developed by Walker and Avant and is widely used (87), especially within the caring sciences.

## **Studies II and III: questionnaire**

Quantitative methods emphasize the measurement of variables, mostly in numeric forms to be analyzed with statistical methods (93). There are two main designs within quantitative research: experimental and non-experimental. Experimental research usually aims to manipulate certain variables in order to test causal relationships in a controlled setting (53). In non-experimental studies researchers are often observers, and either interested in describing phenomena or in studying relationships between variables relevant to the phenomenon that is studied (53). Studies II and III in the current thesis were based on a quantitative non-experimental *retrospective* design using self-administered postal questionnaires. Considering study aims II and III, focusing on prevalence and underlying relationships of the phenomenon of interest, a quantitative approach seemed appropriate.

## **Study IV: qualitative research method**

Contrary to quantitative research, researchers using qualitative methods aim to “study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (93, p. 2). As the study aim was to understand patients’ descriptions of what contributed to their experiences of AHC, a qualitative design was chosen. Grounded theory is a qualitative research method that concentrates on social processes (53, 94), which was the main reason for using this method, as AHC is often the result of complex social interactions. Grounded theory, as developed by Glaser and Strauss (94), aims to discover the core variable that underlies complex interactions by inducing this theoretical variable from data. Seen from the epistemological framework in this thesis, this original variant of grounded theory is problematic in several ways. First, it assumes an external objective reality to be discovered by the researcher. Second, the researcher is assumed to be completely neutral in the research process. Third, one of the aims is to achieve context-free generalizations (95). This *objectivist grounded theory*, as Charmaz calls it, can be contrasted to *constructivist grounded theory* (88, 95). The latter better fits the epistemological framework in this thesis as it emphasizes a relativist epistemology with multiple realities and standpoints of both researcher and participants, considers knowledge to be constructed, and sees generalizations as conditional and situated (95). Within a constructivist grounded theory design qualitative interviews were used, as these gave a direct account of people’s experiences and an opportunity for in-depth exploration of the topic (88).

## Material and participants

### Study I

The material used for the concept analysis included nine published scientific articles, one report, and one book section on the concept of AHC. Thirteen scientific articles were included to analyze the related concepts: four on medical error, six on patient satisfaction and dissatisfaction, and three on personal identity threat. On top of this literature we also had access to data from ViolEP (32) and transcriptions of an interview study with staff at a women's clinic (36).

### Studies II and III

Between September 2009 and May 2010, consecutive female patients at a women's clinic in the south of Sweden were asked to participate in a questionnaire study. Patients included came for an outpatient appointment, were at least 18 years old and able to speak and understand the Swedish language, and had a known address. It is unknown how many patients were eligible during the data collection. The questionnaire was sent to 891 patients of whom 534 (60%) answered. Four questionnaires were judged invalid and were not included in the dataset, resulting in a sample of n=530 for study II. For study III, only participants who reported experiences of any abusive or wrongful transgressions were included (n=293; Table 3).

**Table 3. Overview of the participants' background characteristics in studies II and III**

	Sample study II (n=530)*		Sample study III (n=293)**	
	N	%	N	%
Age (yrs)				
≤ 34	153	29.1	97	33.1
35-49	182	34.7	110	37.8
≥ 50	190	36.2	84	28.9
Education (yrs)				
< 10	92	17.5	37	12.7
10-12	218	41.5	121	41.6
>12	215	41.0	133	45.7
Country of birth				
<b>Sweden</b>	466	89.6	258	89.6
<b>Other Nordic country</b>	8	1.5	5	1.7
<b>Other European country</b>	20	3.8	10	3.5
<b>Outside Europe</b>	26	5.0	15	5.2
Household income (SEK/month)				
< 7000	17	3.3	8	2.8
7-14900	61	11.8	30	10.4
15-24900	92	17.8	45	15.6
25-34900	87	16.8	58	20.1
35-44900	98	18.9	54	18.8
45-54900	86	16.6	49	17.0
55-65000	48	9.3	29	10.1
>65000	29	5.6	15	5.2
Any lifetime emotional abuse***				
<b>Yes</b>	135	25.9	104	35.9
Any lifetime physical abuse***				
<b>Yes</b>	104	19.8	79	27.1
Any lifetime sexual abuse***				
<b>Yes</b>	94	17.8	70	24.1
Any lifetime AHC***				
<b>Yes</b>	130	24.9	122	42.2
Self-rated health				
<b>7 (very good)</b>	58	11.1	21	7.2
<b>6</b>	132	25.3	59	20.3
<b>5</b>	119	22.8	67	23.0
<b>4</b>	100	19.2	59	20.3
<b>3</b>	73	14.0	56	19.2
<b>2</b>	31	5.9	24	8.2
<b>1 (very bad)</b>	9	1.7	5	1.7

\* deviations in percentages exist due to item non-response

\*\* subsample of the larger sample from study II

\*\*\* according to questions from the Norvold Abuse Questionnaire (25). A question aiming to cover mild physical abuse was excluded due to low concurrent validity.

## Study IV

Patients were eligible for study IV if they reported experiences of AHC according to the NorAQ questions included in the questionnaire from studies II and III. The informants were selected by means of purposeful and theoretical sampling, which are important research strategies within (constructivist) grounded theory (88, 94, 96). Theoretical sampling is a form of purposeful sampling, which enables the

researcher to refine categories and capture variations in how different people experience the process or phenomenon of interest (88). Earlier studies on how people experienced AHC were used as a starting point, as these could shed light on which variables might affect experiences of situations of AHC (Table 4). Twelve women declined participation for various reasons, e.g., illness or unwillingness to talk about the events. In total, twelve women agreed to participate and they were interviewed between November 2010 and June 2011 (Figure 3). The women had different backgrounds considering age (ranging from 30 to 78), educational level, social status, severity of AHC, experiences of other types of abuse, and self-rated health (Table 4). Three women were born outside of Sweden. The total sample size of twelve was the result of using theoretical saturation as a tool to decide when to stop gathering data. The categories can be judged saturated if new data does not give new theoretical insights, i.e., it does not change the properties of the theoretical categories (88). Saturation was reached after ten interviews, and two more interviews were conducted to stabilize the categories.

**Table 4. Overview of the informants' background characteristics in study IV and criteria to select informants**

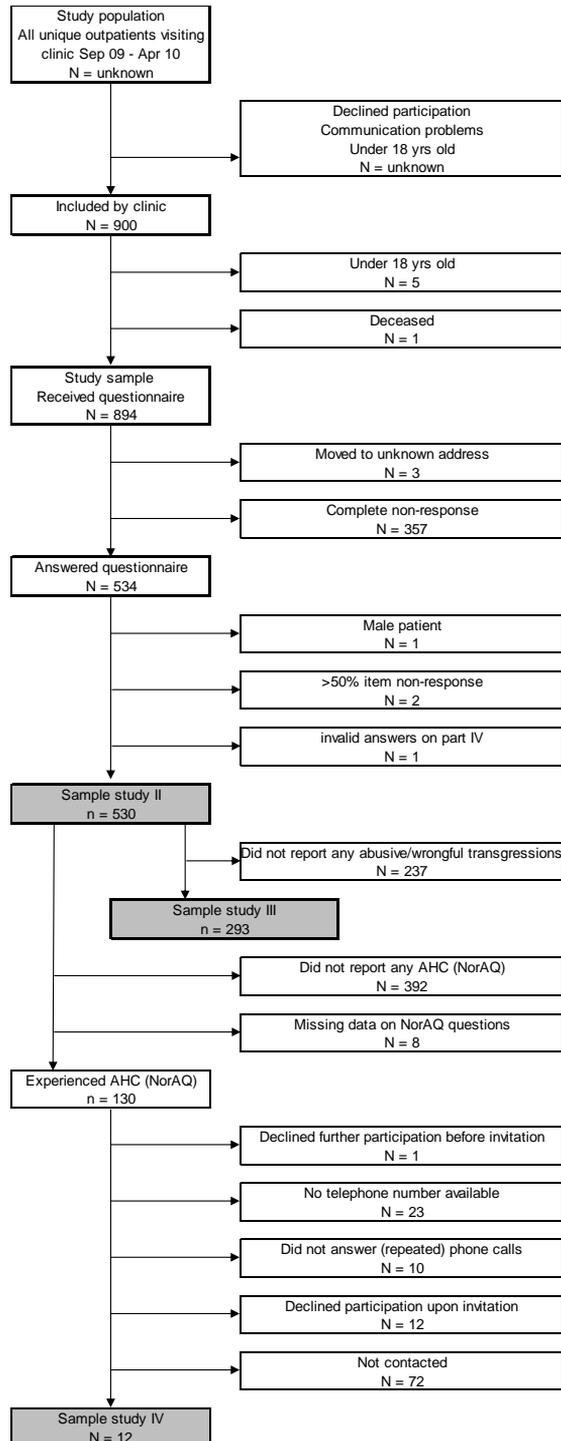
Informant	Year of birth	Educational level (years)	Subjective social status*	Abuse in health care (severity)	Other types of abuse**	Self-rated health***
1	1944	< 10	6	mild/moderate	-	5
2	1974	10-12	6	mild/moderate	EA <18; PA <18; SA <18	6
3	1932	< 10	1	mild/mod/severe	-	6
4	1962	> 12	4	mild/mod/severe	EA ≥18; PA ≥18	4
5	1971	> 12	6	mild/moderate	-	4
6	1970	> 12	8	mild	EA </≥18; PA </≥18; SA </≥18	5
7	1970	10-12	3	mild/moderate	-	4
8	1981	> 12	7	mild/moderate	-	6
9	1968	10-12	7	mild/moderate	PA ≥18	3
10	1951	> 12	6	mild/moderate	EA ≥18	3
11	1950	> 12	8	mild/moderate	-	6
12	1958	> 12	6	mild/moderate	EA <18; SA <18	4

\* self-rated social status (0-10, 10 being the highest), MacArthur scale (97, 98)

\*\* EA = emotional abuse, PA = physical abuse, SA = sexual abuse, lifetime experiences </≥ 18 years of age

\*\*\* measured on a 7-point scale (1=very bad; 7= very good)

**Figure 3. Flow chart of the participants in study II – IV**



## Data collection

### Study I

This concept analysis was based on a design as developed by Walker and Avant, mainly using scientific literature as data (87).

#### *Procedure*

The data searches were performed using CINAHL (Cumulative Index to Nursing and Allied Health Literature), PubMed, and Google Scholar. Search terms for AHC were 'abuse(d) in health care' and 'abuse(d) in the health care system'. Only studies on patients' abuse in the health care system were included. We also searched for *kränkningar i vården*, the Swedish equivalent of the concept. The following search terms were used for the related concepts: medical error ('medical error', 'medical mistake', 'health care errors', 'hospital adverse event', 'patient safety'), patient satisfaction ('patient satisfaction', 'consumer satisfaction in health care', 'patient dissatisfaction') and personal identity threat ('personal identity threat'). These search terms were combined with the terms 'concept analysis', 'concept', 'defining', 'definition', or 'what is', to narrow the search results. At first the article titles were scanned for relevance, and thereafter abstracts were read, followed by the whole text. Data was included according to how the search results appeared in the databases or search engine; relevance (Google Scholar, CINAHL) or date (PubMed). When we noticed saturation, i.e., when data was repeated, we stopped including articles. For AHC, all relevant texts were included.

### Studies II and III

Studies II and III were based on a cross-sectional design using postal questionnaires.

#### *Procedure*

Patients coming for an outpatient appointment entered the clinic at the reception, where they received a first information letter and the possibility to decline participation. The secretaries made a note in their administrative system when the patient had received information about the study. This way, patients who made multiple visits during the period of data collection would not receive the information more than once. Patients who did not decline participation received a second letter and a questionnaire by post at their home address. Two reminders with two-week intervals were sent out.

### Questionnaire

The questionnaire on which studies II and III were based was developed by the research group and was called the Transgressions of Ethical Principles in Health Care Questionnaire (TEP). TEP was constructed to capture patients' experiences of transgressions of ethical principles, based on events operationalized in ViolEP (32). In ViolEP 30 events were presented in which the ethical principles in health care were transgressed.<sup>5</sup> These events were constructed based on clinical experience, ethical theory, and policy documents. Respondents answered whether they experienced any such event and if they felt violated by it. TEP included 23 out of the 30 events from ViolEP, distributed across the ethical principles as follows: autonomy [5]; justice [2]; physical nonmaleficence [4]; integrity [4]; and sexual nonmaleficence [8]. Central to TEP is patients' silence toward the health care system after they experienced abusive or wrongful transgressions of ethical principles by health care staff. Seen from the theoretical framework in this thesis, not remaining silent can be a feedback mechanism that is essential for the process of structural change.

The silence operationalization used in TEP had a starting point in Rest's earlier described four component model of moral behavior, which sees moral action as a process (65, 66). In TEP remaining silent is operationalized as the experience of a transgression that the patient judged wrongful or experienced as abusive, without having spoken up or complained to health care staff or the health care system (Table 5). It should be noted that patients may still have spoken about this to their next of kin or to a therapist, but in TEP, silence toward the health care system is the central issue.

**Table 5: Transgression and silence questions in the Transgressions of Ethical Principles in Health Care Questionnaire**

Have you ever experienced in Swedish health care that...	<b>A</b> Did you perceive what happened as abusive?	<b>B</b> Did you judge what happened as wrongful?	<b>C</b> Have you talked about what happened with the health care staff, complained, or made clear in any other way that you experienced what happened in this way?
<i>Example cases of transgression</i>	Yes / No	Yes / No	Yes / No

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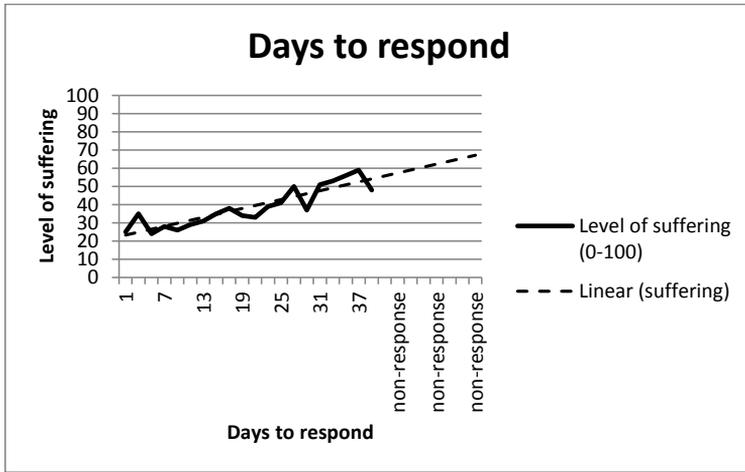
<sup>5</sup> In this thesis and in TEP, the word 'transgression' is preferred over 'violation' or 'disobedience', which were used in ViolEP. 'Disobedience' and 'violation' more strongly imply that an event was a wrongful act *per se*, contrary to 'transgression'.

Remaining silent can have its roots in moral motivation or moral character, two components that were not included in TEP. Examples of such silence might be that a patient judges an event as wrongful but does not prioritize acting upon this judgment. Hence, moral motivation could be lacking if other non-moral aspects, such as illness-recovery, are more important and outweigh this judgment. But even if moral motivation is present, the patient could lack practical skills on how to file a complaint or experience fear to speak up, which Rest both classifies as moral character. Moral judgment in TEP was split into the perception of an event as abusive and the judgment of that event as wrongful. Situations that patients judged as wrongful are potentially situations of AHC and patients' feedback upon such events may be helpful for staff as well. From a risk analysis standpoint: events that are 'merely' wrongful are what Cooke and Rohleder call 'the incidents', and full-blown abusive situations are 'the accidents' that must be prevented (99).

TEP also included questions about patients' backgrounds. Sociodemographic questions included age, education, country of birth, occupation, household income, and Subjective Social Status. The latter is an item on which the respondent rates her own social status in comparison to the rest of society concerning the topics of money, work, and education (97, 98). Questions about health included their number of health care visits, whether they visited a psychiatrist or psychologist, and general self-rated health. Besides AHC, three other types of abuse were measured: emotional, physical and sexual. These questions were taken from NorAQ and have been validated in an earlier Swedish female population sample using interviews as a gold standard (25). The questionnaire concludes with questions about knowledge of patient rights.

A measure that was added afterwards was how many days it took for the respondents to respond. Such a measure has been used to test for a response bias in a sample where the characteristics of non-respondents are not known. By assuming that non-response is an extrapolation of time to respond, associations between a variable and *days to respond* could point at a response bias for that variable (100, 101). The basic idea is that non-response is a linear extension of late response (Figure 4).

**Figure 4. Example illustration of a hypothetical situation in which it is expected that respondents may suffer less than non-respondents**



For study III, remaining silent toward the health care system was used as a dependent variable. The variable was calculated as the number of times that the respondent had acted or spoke up relative to the number of opportunities the patients could have remained silent or spoken up (0-100%, where 100% indicated ‘remained silent after all events’ and 0% meant ‘spoken up after all events’). This variable was transformed into an ordinal scale (1=0%, 2=1-99%, 3=100%) because the continuous variable showed a U distribution that was hard to model. This variable was preferred over a dichotomous variable, as it was deemed important to not lose information from between the two extremes. Independent variables included the abovementioned patient characteristics.

### Study IV

A qualitative design was chosen for study IV, building on constructivist grounded theory approach.

#### *Procedure*

Following the principles of purposeful and theoretical sampling, potential informants were selected from a larger sample of study II. The women were approached by telephone and invited to participate in the interview study. It was explained to them why they were selected and what the aims of the study were. If the women agreed to participate, an interview was scheduled and they were

asked to think about their experiences of AHC up front. An interview was analyzed before each next informant was invited, and the interview guide was evaluated in between. The interviews were held in a conference room at the same hospital where the women were originally recruited for studies II and III. For logistical reasons, one interview was conducted by telephone while the informant was at home. Before the start of the interview, the informants received additional information about the study and they were asked to sign an informed consent form. After they had given their consent, the audio-recorded interview commenced. Interviews lasted an average of 44 minutes, ranging from 18 to 68 minutes. When the interview was finished, the interviewer and the informant reflected upon the interview as a sort of closure. Each interview was transcribed verbatim and memos were written during the entire process and after each interview to develop theoretical ideas. A logbook was kept to reflect on the data collection process and to adjust questions or procedures where necessary. This logbook was one tool to enhance reflexivity, which is important in a constructivist grounded theory study (102).

#### *Semi-structured interviews*

The interviews were semi-structured using a thematic interview guide (Table 6).

**Table 6. Interview guide study IV**

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#### **Main questions**

- Can you think of a situation where you experienced abuse in health care?
- Can you tell me what the situation looked like? Why, when, and where did you seek care?
- What contributed to this situation occurring? What happened between you and staff?
- What did staff do during the incident? What did you do yourself?
- Was there any feedback from staff to you, or from you to staff?
- What were the consequences of the incident for you, also on the long term?
- Can you think of another situation where you experienced abuse in health care? (to top)

#### **Follow-up questions**

- What do you mean by that? Can you tell me more about that aspect? How did this make you feel?
-

## Data analysis

### Study I

The method of concept analysis developed by Walker and Avant consists of eight steps (87). Even though the model is presented as a linear process, the actual analysis is iterative and circular.

1. Select a concept
2. Determine the aims of analysis
3. Identify all uses of the concept
4. Determine the defining attributes
5. Identify a model case
6. Identify borderline, related, contrary, invented, and illegitimate cases
7. Identify antecedents and consequences
8. Define empirical referents

Because of criticism of the method, a few steps were slightly altered. These changes also made the method more suitable with reference to the research aim, as well as more in line with the epistemological assumptions in this thesis. First, step five was adjusted to include multiple model cases. With model case, Walker and Avant mean an example of the concept that includes all defining attributes. However, from a feminist perspective it is problematic to present one model case as being universally valid (103). Chinn and Kramer (104) suggested that the inclusion of multiple cases in different contexts could expand meaning. We therefore studied multiple model cases, of which two are presented in paper I. Second, only borderline, related, and contrary cases were included in the analysis. It has been argued that invented cases reduce the validity of the analysis (105) and illegitimate cases are not necessary if the concept is not commonplace (87), which is why both were excluded. Third, in step seven during the analysis it was unclear how to treat antecedents that could *potentially* contribute to the occurrence of AHC. Walker and Avant state that antecedents are those events or incidents that *must* be present before the concept occurs. But it was found problematic that factors that increase the risk for AHC, and hence *may* contribute to the occurrence of AHC, did not have a place in the analysis. Therefore, identifying potential antecedents was included in the analysis, supported by communication with Dr. Walker, who also saw a need to identify this type of antecedent for further research on the concept (personal communication, November 9, 2009). Potential antecedents may also be of clinical relevance in the prevention of AHC.

## **Study II**

Descriptive statistics were used to estimate prevalence. To test whether “days to respond” related to reported transgressions, ANOVA tests were performed, including Tukey’s post-hoc test. How well TEP captured abusive events was tested by measuring how well these events converged with events of AHC according to the NorAQ questions (25). Both variables were dichotomized into yes/no, creating a 2x2 table. TEP was expected to capture a wider range of events than NorAQ. As it was important to capture abusive situations well, the convergent validity was judged ‘good’ if high sensitivity was found, i.e., if a high number of reports of AHC according to NorAQ were also reported in TEP (106).

## **Study III**

Univariate tests were performed to identify associations between patient characteristics and patients’ silence toward the health care system. Cramer’s V and Kruskal’s Gamma were used for nominal and categorical/interval predictors, respectively. The variables that showed significant associations with remaining silent were then included in an ordinal logistic regression, through a Generalized Linear Model. All these variables were included to test for their main effects.

## **Study IV**

Within the constructivist grounded theory methodology, the principle of analysis by constant comparison was applied (88). This means that all data was constantly compared to other, new data. First, statements and codes were compared within an interview, and later with statements and codes in other interviews. The data was analyzed line-by-line, using in vivo codes, i.e., codes using the informants’ own wording, to capture relevant content. Next, these in vivo codes were grouped using focused coding, still using in vivo codes. Thereafter, these codes were analyzed on a next abstraction level, synthesizing them into theoretical categories. Finally, a core category was constructed, capturing the intricate relationships between the categories and answering the research question.

## Ethics

Studies II, III and IV were approved by the regional ethical review board in Linköping, Sweden (reg. no. M116-09). Informed consent was given by all patients who participated.

AHC is a sensitive topic to think and talk about, as a researcher, as staff, and especially as a patient. Recalling abusive events may have been discomfoting to patients when they answered TEP for studies II and III. To legitimize these feelings, the questionnaire contained a final question asking whether the questions raised feelings of discomfort. The patients were also offered the opportunity to contact the project coordinator, but no one used this opportunity for this particular aim. There also was a crisis team including a psychotherapist and a hospital pastor who were stand-by in case informants needed immediate help to cope with their experiences of AHC. Returning the questionnaire was equaled to giving informed consent.

In study IV, the patients were asked to sign an informed consent form before the start of the interview. Patients were told that they could withdraw from the study at any time and that the interview material was treated confidentially within the research group. A few patients experienced visible discomfort during the interview, expressed through words or tears, but all twelve patients chose to finish the interviews. It was assumed, however, that most patients experienced the interviews in a positive way, as an opportunity to tell and confirm their stories. Venting emotions related to these events might lower patients' stress levels (107) and lessen the feelings of shame for the AHC they experienced (79). Some patients were explicitly grateful to receive an opportunity to talk to someone who would listen to their stories.

All in all, it was judged that initial feelings of discomfort were outweighed by the positive effects of the informants being able to tell their stories, as well as by the possible positive effects of the research project on the health care system.

## RESULTS

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### The concept of abuse in health care

Four main attributes of AHC were identified in the concept analysis. Critical attributes are characteristics of the phenomenon that must be present before it can be labeled AHC. The first critical attribute is that patients feel they lose their value as a human being. Second, patients suffer. Third, the event is most often unintentional. Fourth, the events are characterized as encounters devoid of care.

Although the third attribute, the unintentional character of the events, need not always be present, it was found that this characteristic distinguished AHC from dictionary definitions of abuse. For that reason, as well as when considering clinical implications, it was deemed important to emphasize this as an attribute. The following case was used as a model case to illustrate these attributes, although the doctor's intentions can be questioned.

“The most terrible thing I ever experienced in health care was a doctor who threw a stethoscope on the ground and yelled at me to pick it up. While picking it up he yelled at me ‘you do not have back pains’ and started to dictate journal notes in his tape recorder, stating that ‘the patient is simulating pain’. I had much, much pain in my back and felt terrible by the abuse of being mistrusted and that the doctor did not talk to me but to his tape recorder instead. I have avoided doctors ever since. Horrible.” (*From the Violations of Ethical Principles Questionnaire*)

It was concluded that little is known about the antecedents of AHC, i.e., elements that must be present in order for the phenomenon to occur. Logically, there must some kind of encounter between the patient and the health care system, and the patient must have the capacity to suffer. On top of these antecedents, *potential antecedents* were formulated that were found to be associated to AHC. These included patient characteristics such as experiences of childhood abuse, young age, high educational level, poor self-rated health (as found in studies with a Swedish female patient sample; 29, 31) and birth in a foreign country (as found in studies with a Swedish male patient sample; 27). Here, staff hierarchies, power asymmetries and taboos were included as well, although these are insufficiently studied. Consequences of AHC for patients could be post-traumatic

stress symptoms, avoidance of health care services, and long-term suffering (29, 33, 34, 79). For staff, AHC may lead to feelings of shame and guilt (108). The health care system as a whole may lose public confidence and patients may choose not to file complaints (34).

Demarcating AHC against related concepts both clarified AHC and showed how it differs from these concepts. AHC is different from medical error, as AHC is defined from the patient's perspective. Medical errors are defined from a health care perspective and they can possibly lead to AHC, but this need not necessarily be the case. Patient satisfaction, on the contrary, does take a patient perspective, but leaves little room for dissatisfying events. Personal identity threat is a concept very similar to AHC, but it seems to focus little on the structural and cultural context in which the phenomenon occurs.

The results of this analysis were captured in the following theoretical definition of AHC:

Abuse in health care is defined from patients' subjective experiences of encounters with the health care system, characterized by events that lack care, where patients suffer and feel they lose their value as human beings. The events are most often unintentional and nurtured and legitimized by the structural and cultural contexts in which the encounter takes place. The outcomes of abuse in health care are negative for patients and presumably for staff and the health care system as well.

## Patients' silence

The concept analysis showed that little was known about what contributes to the occurrence of AHC. When potential explanations were examined, one hypothesis about a possible mechanism was that patients might remain silent toward the health care system after experiencing AHC, which might in turn hamper structural change toward better encounters. This hypothesis was further examined in studies II and III. High prevalence of female patients' experiences of staff's transgressions of ethical principles was found: 64% of all patients (n=530) had experienced such transgressions at some point during their life. The majority of experiences concerned transgressions of the principle of autonomy. Transgressions of the principles of physical and sexual nonmaleficence were perceived as abusive to the highest degree, and patients remained silent about

these events most often. Patients remained least silent about transgressions of the principle of justice, e.g., that another patient was allowed to pass in the queue without having a reason (Figure 5). A majority of patients who had perceived a transgression as abusive or wrongful had remained silent about at least one event (70%), and half of the patients had remained silent in all cases. In 60% of all cases, patients remained silent about abusive or wrongful events.

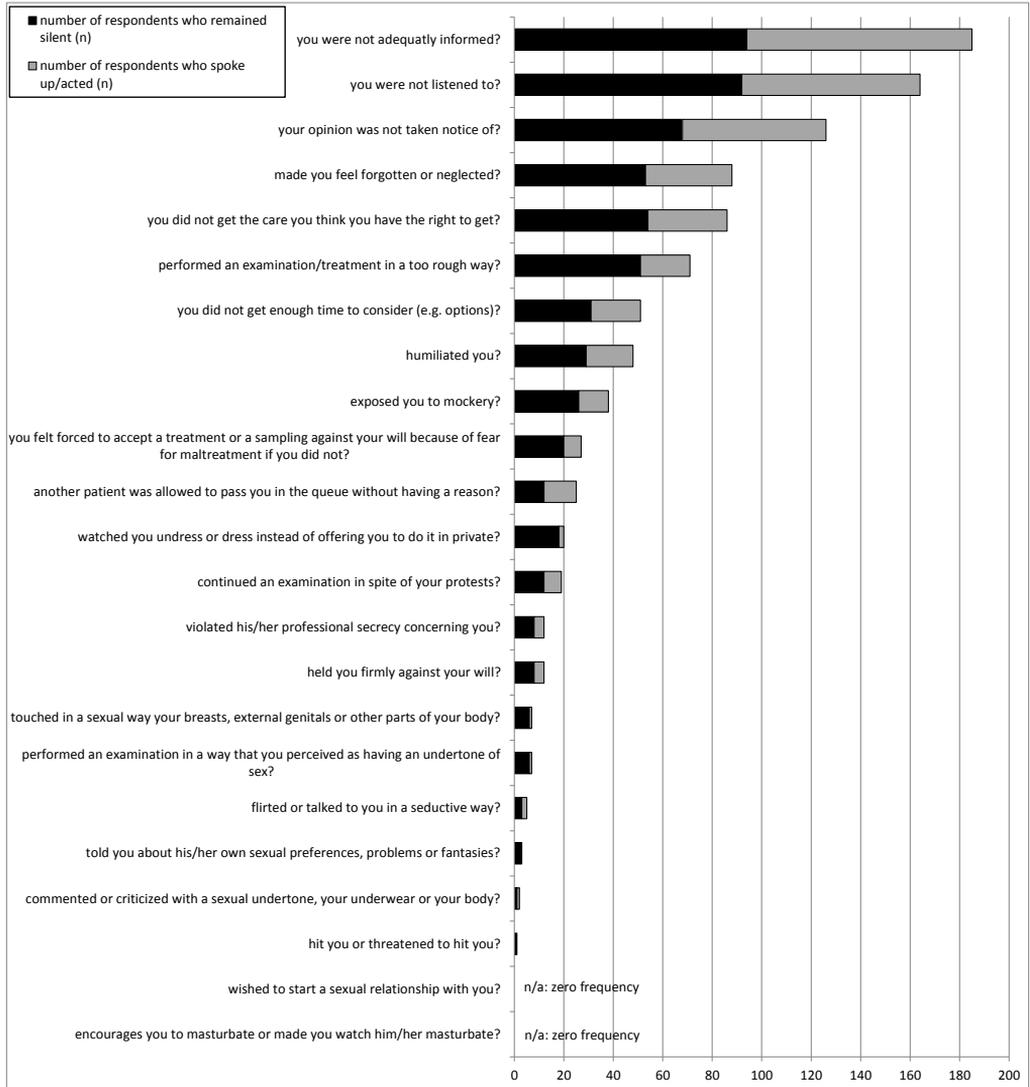
A majority of the patients reported no feelings of discomfort answering TEP (76%), but a minority reported mild or severe feelings of discomfort (23% and 2%, respectively).

The amount of days it took for respondents to answer did neither associate with the amount of reported transgressions, nor with their reported level of remaining silent.

## Validity of TEP

TEP captured AHC according to NorAQ very well, as sensitivity was estimated to be 82%, and specificity was 80%. TEP captured more abusive events than NorAQ, resulting in a positive predictive value of 58%.

**Figure 5. Patients' silence after abusive or wrongful transgressions. Have you ever experienced in Swedish health care that (staff)...**



It was found that remaining silent was associated to younger age and a lower self-rated knowledge of patient rights (study III). The association between age and remaining silent showed a rather abrupt change at 30 years. In a multivariate analysis, both variables had an independent effect on remaining silent, even though the knowledge of patient rights could explain more variation. More knowledge of patient rights was not associated with experiencing more events or perceiving more events as abusive.

## Losing power struggles

Other explanations for the occurrence of AHC were explored in a qualitative study. Female patients' narratives about what contributed to their experiences of AHC were best captured by the core category *the patient loses power struggles*, which stands for the clash between the categories: *the patient's vulnerability*, *the patient's competence*, *staff's domination techniques*, and *structural limitations*. The theory presents factors that contributed to the informants' experiences of AHC, as seen from their perspective. The informants entered health care being in a vulnerable position, they were exposed to domination techniques that staff may have unconsciously used, and subsequently the informants lost a power struggle. The informants could react to these techniques by soliciting their expert knowledge as patients, catalyzing the use of domination techniques by staff and thereby risking experiencing AHC. Structural limitations, such as budget cuts, could directly lead to the informants experiencing AHC without any direct interaction with staff, but they could also indirectly influence staff's use of domination techniques. The core category could also indicate why patients remain silent toward health care professionals afterwards, if they feel defeated as the result of lost power struggles.

## DISCUSSION

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In this chapter, results from the studies and questions that arose during the project will be discussed, as well as the theoretical framework and methodological challenges encountered. Detailed discussions of the results and methods of the individual studies are presented in the four papers.

### Conceptual issues of abuse in health care

#### **The problem of a uniform definition**

In this thesis, AHC was initially described as *any act perceived as abusive by the child or adult patient in any health care setting*. Before the start of this thesis, the phenomenon of interest had been measured and studied in many different ways, all capturing parts of AHC, as shown in Figure 1. In study I, one of the aims was to analyze these different measurements and results in order to converge them into one comprehensible definition, which could function as a basis for future research and theory construction. Stating that the concept analysis resulted in a theoretical definition, however, is questionable. First, it has been argued that highly abstract concepts may overlap with other concepts to a large extent, which makes it difficult to identify the uniqueness of such concepts (109). This was also shown in study I, where AHC was found to overlap with *personal identity threat*, but also with *patient dissatisfaction*. There may also be overlap with a range of related concepts not analyzed in study I, such as offense or violation, which will be discussed in the next section. Second, trying to obtain uniformity dismisses any kind of contradiction or exception, which may actually hamper theoretical development within the field. Even though Walker and Avant (87) discuss the tentativeness of the results of a concept analysis, they do not address the question of whether defining highly abstract concepts can and should be done at all. To counter these two problems of definition, one could choose to, instead of defining AHC, which is an *exclusive* process, rather describe it, which is an *inclusive* process (109). This does not in itself change the results of the concept analysis, but it does change the status of the critical attributes and the definition, or rather the description. The boundaries presented here between AHC and related concepts may not be as sharp as those presented in study I, but instead of viewing exceptions as phenomena outside of the scope of AHC, they should rather be included as additional interpretations to enrich understanding of the research field (109).

To expand upon this discussion, the problem of overlap and translation will be discussed, as well as the question of what an objective definition of AHC could look like.

### **The problem of translation**

While working on the thesis, there was a continuous awareness of a potential gap between the Swedish concept *kränkningar i vården* and the English concept *abuse in health care*. The issue of translating concepts has been recognized in cross-cultural research and the *conceptual* or *functional equivalence* of concepts in different languages has been discussed. Two constructs are equivalent when they can be discussed meaningfully in different cultures, and when they show the same antecedent-consequent relations in those cultures (110). It can be discussed whether *kränkning* and *abuse* are conceptually equivalent, which is important for the interpretation of the current results.

As the concept analysis showed, AHC differs from dictionary definitions of abuse in that it need not imply intentional harm. This gap can be explained by a breach in conceptual equivalence; a *kränkning* need not be intentional, while *abuse* seems to entail an intention, or perceived intention to harm another person (2). Other English translations could have avoided this specific breach. Offense, for example, can be taken without the presence of any (perceived) intention to harm (or even to offend; 81). However, other breaches exist between *kränkning* and *offense*, and the same counts for other related concepts such as affront or insult; these concepts exclude severe harm, especially as a result of sexual or physical misconduct. As AHC consists of a complex set of antecedents, attributes, and consequences, there is probably no single English construct that covers each single aspect. Conceptual equivalence between *kränkning (i vården)* and any English construct might therefore never be completely achieved. Part of this problem lies in the great variety of phenomena covered by the concepts, but also in the fact that equivalence is not only a linguistic matter, as concepts are embedded in situations and cultures (111).

Based on the above reasoning, it was judged that *abuse in health care* was an adequate translation of *kränkningar i vården* and in our research they were used interchangeably. The concept analysis presented in this thesis contributes to the clarity of the concept of AHC, and states that there need not be an intention to harm. The present discussion emphasizes the importance of concept analyses.

## Exploring an objective approach

It has been questioned whether AHC should be described from the patients' perspective only. It can be argued that researchers should determine what is abusive and what is not by creating an objective definition. An argument in favor of this position is that an objective definition would benefit clinical reflections on which behavior should be allowed and which should not. It could also help to protect patients, as an objective notion can legitimize their experiences of abuse.<sup>6</sup> In the current thesis, patients' abusive experiences were the phenomenon of interest and subjectivity was inherent to this phenomenon, and hence not problematic. However, it can be interesting to discuss and explore the possibilities of an objective definition, in addition to a subjective one, as this is also important to consider in the design of interventions or policies. Combining subjective and objective concepts is not unusual in clinical practice. For example, considering the estimation of quality of life, both the patients' subjective perception as well as an objective part can be included in treatment decisions. The subjective part represents the impact on the patient's life, while the objective part can be used to discern the treatment effect from other effects, and it can be used to evaluate the impact of different treatments (112). In a similar vein, it could be beneficial to dismantle patients' experiences of AHC according to an objective approach, in order to examine where to intervene and how to prevent similar instances in the future.

This section aims to start exploring an objective approach to AHC. By an objective approach is meant an approach that does not only build on the patient's experience, but also one that could function as a complement to a subjective approach, for example for aims of policymaking. Feinberg, in his work on the concept *offense*, acknowledges the concept's subjectivity, but argues that there is a need to identify objectively what offensive behavior comprises of and which behavior should be criminalized (81). Feinberg's analysis can be a good starting point for exploring an objective approach to AHC, although the aim here is to see what an objective notion of AHC may look like and which behavior should be avoided, rather than to decide which behavior should be criminalized.

Assuming that AHC is a subjective experience, this gives rise to the following questions: Can anything be abusive? If so, how should health care staff behave if

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<sup>6</sup> It can even be argued that an objective definition of AHC may protect staff's and patients' moral identity in case both staff and patients normalize certain situations and no longer subjectively judge them as abusive. It should also be added that a subjective definition of AHC might legitimize patients' feelings about AHC as it could show that many others report similar experiences.

any act can be perceived as abusive by patient? Is all AHC necessarily wrong? These questions call for a normative criterion that determines which actions are to be avoided and which can be permitted.

Feinberg accepts that virtually anything can be taken as offensive, but sets four standards to determine the *seriousness* of the offense (81, p. 35):

1. The magnitude of the offense: intensity, duration, and extent.
2. The standard of reasonable avoidability: the more difficult it is to avoid the offense (for the offended person), the more serious the offense is.
3. The Volenti maxim: voluntarily induced states of offense (by the offended person) are not to be seen as offenses.
4. The discounting of abnormal susceptibilities: if the offense depends on the offended person's abnormal "skittishness" it is not deemed offensive.

Weckert claims that the vulnerability of the offended also affects the seriousness of the offense (82), so a fifth standard can be added.

5. The vulnerability standard: if the offended already feels vulnerable, the offense is more serious.

An effort to objectively define the seriousness of an abuse may be helpful for staff or a clinic in reflecting upon their behavior, if relying on the patients' subjective account is somehow deemed problematic, e.g., if staff has difficulties accepting or understanding the patients' view. Applying these five standards to AHC needs discussion. The first and third standard can probably be applied as they are. Regarding the second standard, it can be questioned whether any patient can reasonably avoid AHC, if the only way to do so is not to encounter health care staff and not seek care.<sup>7</sup> On top of that, it could be argued that it is not the patient's responsibility to avoid potentially abusive situations. Hence, for all patients may count that they most likely cannot reasonably avoid situations of AHC. Standard four is more complex to analyze and apply, as it is not completely clear what Feinberg means with abnormal. He seems to assume the standpoint that normal susceptibility should be related to a normal person in a community (81, p. 33). In my opinion, susceptibility should be viewed as context-related. Since patients are dependent on the care provided by health care staff, since they can suffer from severe illness, and since they can feel powerless (33, 34), even "normal" persons can be highly susceptible in such circumstances. It may be hard

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<sup>7</sup> In several studies it has been found that some patients indeed apply this strategy after severe AHC in order not to expose themselves to possible AHC situations (33, 113).

to judge “normal” susceptibility in specific health care situations. A more reasonable interpretation of susceptibility would be that everyone is susceptible to different degrees in different situations, instead of talking about “skittish people” in general. Feinberg states that if certain types of acts can easily be done in a way that does not offend the skittish, then this high susceptibility is no reason to discount the offense (81, p. 65). Feinberg adds that the seriousness of the offense is not dependent on whether the taking of offense was reasonable or not. His main argument for this is that in a democracy we should not judge whether someone’s emotional responses are reasonable or not (81, p. 35). Considering the fifth standard, it was shown in study IV that informants’ vulnerability was a contributive factor to their experiences of AHC. Although not all patients are equally vulnerable, it is very likely that to some degree there will always be a power imbalance between patients and staff. Analysis of standards two, four, and five shows that offenses in health care settings are by definition more serious and morally problematic than similar offenses outside health care settings. This could explain why “minor offenses” can be experienced as AHC and cause deep suffering in patients.

According to Feinberg, for a normative criterion of offense, the seriousness of the offense should be balanced against the reasonableness of the offender’s conduct. This reasonableness depends, for instance, on the personal or social value of the conduct, and the motive of the offender.

Consider the following example. *A gynecologist performed a Pap smear test on a patient and cell changes were found. The gynecologist informed the patient about this in a letter, in which she also explained that the patient has to undergo surgery. The patient also received information that the gynecologist had put her on a waiting list for this surgery, to save valuable time. The patient felt deeply abused by this and explained to the gynecologist that she felt it should have been up to her to choose whether to operate or not and decide about her own body.* Many members of staff and even patients would probably find the gynecologist’s behavior reasonable, and perhaps even praiseworthy for trying to save time for the patient.

The above-discussed normative criterion, following Feinberg’s model, would probably not classify this as a wrongful action that must be avoided; the “offender’s” conduct seems very reasonable and may thereby outweigh the seriousness of the offense. In any way, it is important to correctly deal with the patient’s feelings, as health care staff is still responsible for the patient, who is deeply hurt, and it should be noted that situations in which staff’s behavior is praiseworthy while at the same time patients feel abused are probably very uncommon.

This initial exploration may offer a first tool for building an objective approach to AHC. Applying Feinberg's theory on offense to AHC may increase the understanding of situations of AHC through an analysis of the seriousness of the abuse and the reasonableness of staff's behavior.

## Complaining, speaking up, and the role of staff

In study II it was found that in many cases patients remained silent toward the health care system when they had experienced abusive or wrongful ethical transgressions by staff. Following the theory of structuration (59), this means a lack of feedback and thereby opportunities for staff to change their routines. If these events go by unnoticed and are interpreted as unproblematic encounters by staff, the social rules are likely to be reproduced and can enable similar situations to take place in future encounters.

Stating that a decrease in silence can lead to structural change calls for the discussion of two underlying assumptions: (i) patients can be stimulated or motivated to speak up, and (ii) staff can accept patients' feedback and use it to change their practice.

A discussion of the first assumption involves examining the reasons why patients remain silent. According to Rest's four component model on which the structure of TEP is based, patients' silence stems from a lack of moral motivation or moral character. Rest's assumption, however, can be questioned. Is it really a lack of moral character if patients feel *nullified* (33) or *mentally pinioned* (34) after AHC, and therefore cannot speak up? Is it not more likely that moral character is context-dependent and varies from time to time, depending on a person's emotional status or engagement in certain moral questions, rather than being a constant?

Not much is known about patients' willingness to speak up specifically about abusive situations, but a study on South African maternal care identified patients' fear of victimization as one source of silence (114). More research on patients' speaking up against staff was done within the field of patient safety. Even though in this field it may be much clearer to both patient and staff that staff did not comply with the rules, it may tell something about patients speaking up in general.

Concerning complaining, there may be organizational barriers that make it hard for patients to follow complaining procedures (115). Such procedures may also be more time-consuming than direct feedback to staff. With regard to directly speaking up to staff, in one study researchers asked patients what types of things they would be willing to ask or say to staff (116), related to patient safety. The main findings were that encouragement by staff increased patients' willingness to speak, and that patients were less likely to ask challenging questions than factual questions. An example of a challenging question was to ask a nurse or physician whether they had washed their hands. Several studies have examined patients' willingness to ask staff about hand hygiene. In a survey study, many patients reported they would not feel comfortable asking a nurse or physician to perform hand hygiene (117). However, studies using an experimental design found that soap/sanitizer usage increased during and after an intervention period in which patients asked staff whether they had sanitized their hands (118). In both studies, patients felt less comfortable asking physicians than nurses. This finding was confirmed in a review about patients' willingness to engage in error reduction (119). The main result in this review was that patients' perceived subordination and their illnesses were the main reason for not getting involved in error reduction. A fear of being "a difficult patient" made patients assume a passive role in protecting their safety (119).

In this respect, the results from study IV are of interest, as it was found that informants who solicited their own competence could experience AHC as they were overruled by staff's domination techniques. Besides factors that involve the patient-staff relationship, there may be cognitive factors that affect patients' willingness to speak (119). In study III it was found that, besides younger ages, higher self-reported knowledge of patient rights was associated to a relative increase in speaking up. Patients' stronger belief that they know their rights may increase their motivation to speak up, also because their actions are legitimized by formal regulations.<sup>8</sup> It was theorized that this self-reported knowledge is related to patients' feelings of self-efficacy, i.e., the belief in one's own capabilities (120).

Self-efficacy and believing that one's own participation can contribute to higher patient safety has been found to affect patients' willingness to act against clinical errors (119). Feeling powerless to contribute to change was also found as a factor that inhibited patients from expressing their dissatisfaction, as well as fear of retribution (115). In short, patients' silence toward the health care system is a

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<sup>8</sup> As discussed in study III, it is of lesser importance in the current thesis whether the patient has "correct" knowledge of these rights.

complex phenomenon embedded in their self-efficacy and probably also in the present patient-staff relationship. For patients to be able and willing to speak up it is paramount that staff encourages patients to do so (116, 119). This may be of particular importance for highly vulnerable patients, for example for those who have a history of abuse, where staff often unwittingly plays a key role in the patients' concealment process (79, 108).

Encouraging patients to ask questions and speak up is related to the second assumption, namely that staff can accept feedback and change their practice. If staff is not able or willing to accept the patient's story or perceives few alternative behavioral paths, then it is improbable that patients' feedback will lead to change. Moreover, the results from study IV are also relevant. Here was found that many informants who chose to speak up for their rights perceived themselves as overruled by staff and experienced AHC as a consequence. An intervention that stimulates patients to speak up must then be accompanied by an intervention through which staff can train how to receive and use patients' feedback. However, no general methods for these interventions exist and earlier research has shown that it can be difficult for staff to transform patients' feedback into change. Research about the improvement of quality in care in general has shown that general practitioners are interested in receiving patients' feedback by means of satisfaction surveys, and willing to learn from it, but they have difficulties putting this into practice (121).

In this respect, there are general problems with patient surveys, especially those measuring patient satisfaction, making it hard to achieve practical changes. First, and this is especially relevant for AHC, the use of global scores tends to disguise dissatisfying events while resulting in high scores, thereby making it "unnecessary" for health care providers to carry out changes (20, 115, 122). Second, patient satisfaction studies can identify areas for improvement but they cannot identify which improvements in particular increase satisfaction. A related problem is that, in practice, members of staff may get survey results with details on the areas that should be improved, without any resources to do so (123). Third, such surveys are essentialist in their nature, as all individuals are assumed to have identical experiences. "This may obscure the uniqueness of individual experiences, thus preventing deeper understanding of issues related to providing care that is acceptable for people in need of that care" (123, p. 296). A general problem with the measuring of patient satisfaction and expressing dissatisfaction is "the gratitude factor"; patients tend to be thankful for the received care and thus unwilling to criticize possible shortcomings (24).

Besides the use of written patient surveys, patients can also give feedback by means of complaining (124). Gal and Doron (86) have questioned whether

informal complaining (speaking up to staff) could be a well-functioning feedback mechanism, for the reason that some dysfunctional aspects of care may remain invisible to policymakers. They therefore discourage informal complaining and emphasize the importance of formal complaining instead. However, formal complaints, i.e., any registered grievances to official institutions, have two disadvantages that informal complaints do not have that problematize the abovementioned second assumption. A focus on the importance of formal complaining leaves little room for discussion between patient and staff, and staff receives no direct opportunity to show their regret for patients' suffering. Also, and more importantly, a direct confrontation between patient and staff may offer more opportunities for behavioral change, as both parties can respond to each other's claims in the situation itself. Patients' informal complaints may also be more acceptable to staff than formal complaints (125).

Besides the importance of staff encouraging patients to speak up, from this discussion follows that the method of feedback and its uptake by staff could also be considered. For any such method to be effective it is important that staff has the competence and skills to implement feedback and use it to change their practice (124).

One comment must be made before moving on to discussing domination techniques. Besides the importance of structural change, patients speaking up can also be of major importance to the patients themselves. Not only may speaking up lead to better treatment (107), the expression of negative feelings, or "venting", may be beneficial as it increases patients' satisfaction, and possibly lowers their stress levels (107), and might lessen potential feelings of shame and guilt as a result of fear for negative reactions by others to the AHC they experienced (79).

## Abuse in health care and domination techniques

The main result in study IV was that female patients who experienced AHC described these events as a consequence of a lost power struggle, a crystallization of an unjust power-over relationship (126). Most of these struggles were lost because patients perceived that staff utilized domination techniques. In a South African context, the use of domination techniques was also recognized and described as "uniform and insignia (epaulettes), verbal assertions of distance, [and] displays of lack of compassion" (114, p. 1793).

Domination techniques need not be of intentional or manipulative character. Rather, with reference to structuration theory, these techniques are most often an unintended consequence of learned behavior, embedded and reproduced in routine behaviors. The Foucauldian notion *techniques of domination* may be helpful in the understanding of these domination techniques. Foucault views these techniques as modes of power through which people can transform or be transformed, either in relationships to others, or to the self. Techniques of domination are those “which determine the conduct of individuals and submit them to certain ends or dominations, an objectivizing of the subject” (127, p. 18). But according to Foucault these techniques, and power at large, should not be analyzed from within, seeking for an explanatory reference, but rather in its external visage by studying its effects (128). It is hence not of interest for a Foucauldian analysis of power to consider an individual’s intentions or beliefs, rather, “[l]et us ask, instead, how things work at the level of on-going subjugation, at the level of those continuous and uninterrupted processes which subject our bodies, govern our gestures, dictate our behaviours etc.” (128, p. 97). Domination techniques are interpreted in the Foucauldian way in this thesis.

As an illustration, in her feminist critique of the masculine hegemony, Norwegian social-psychologist Berit Ås applied the concept of domination techniques (*hersketeknikker*) to understand how men subordinate women in society (129). Ås described five such domination techniques: making invisible, ridiculing, withholding of information, double punishment, and heaping blame and putting to shame (129). Three similar techniques were found in study IV. First, making invisible is seen in the codes not listening to the patient and not seeing the patient. Second, ridiculing is similar to what was labeled contemptuous behavior toward patients. Third, double punishment, “damned you if you do and damned you if you don’t”, is not found as a single code but can be seen in situations where patients solicited their competence. Patients who used their competence could be “punished” by experiencing AHC through staff’s domination techniques, while patients who did not do this may not have received the care they thought they deserved.

How can these domination techniques be understood within the theoretical framework used in this thesis? As domination techniques are explicated in the behavior between two individuals, Galtung would see these techniques as behavior leading to events of direct violence (4, 61). According to the violence triangle, these techniques would not exist in isolation from structures and culture. The reproduction of these techniques in practice can make them part of the structural context in health care, i.e., they become part of the social rules, thereby legitimizing future use of such techniques, which goes hand-in-hand with what Glover calls the neutralization of moral identity. The domination

techniques probably also legitimize each other. If a patient is made to feel invisible in a health care encounter, or is even “objectified”, this may legitimize the use of other domination techniques such as ridiculing. Seeing domination techniques as part of the social rules, i.e., structures, they only unfold in encounters with patients. Without patients’ subordination to staff, no power relations exist, nor can domination techniques be reproduced and persist over time. This is not a normative statement or a question of responsibility; it rather illustrates Foucault’s view that power is not possessed by individuals but instead exists in relationships. However, being subordinated does not mean that there are no possibilities for resistance against domination techniques. According to Giddens, “all forms of dependence offer some resources whereby those who are subordinate can influence the activities of their superiors” (59, p. 16). This theoretical assumption was confirmed in a study on abuse in a South African maternity ward, where relatively powerless female patients found ways to gain agency amidst social constraints, albeit limited (130). This can be compared to the informants’ use of their competence in study IV, which may indicate that in many instances they tried to gain an active role in the encounter. If such efforts instead lead to experiences of AHC, then this may be one explanation for the high levels of silence found in study II. The apparent paradox between the patients’ active role found in study IV and silence found in study II is discussed below.

Staff’s use of domination techniques and patients’ reactions to them can also be seen within a larger medical discourse. Traditionally, patients are expected to be passive and compliant, which may still be a rule by which both staff and patients abide, creating the feeling that there are no alternatives to act (131). In the worst case this may lead to a type of cultural violence where this discourse legitimizes AHC through *manufactured consent* on the side of patients, who accept that there is no alternative to subordination to domination techniques (132). However, by analyzing hidden mechanisms behind AHC and domination techniques, staff and patients receive opportunities to reflect on their behavior on a level of discursive consciousness and to reflect upon alternative behavioral paths. Such paths have been sketched both for those who are at risk of using domination techniques as well as those who are at risk of becoming victim to these techniques, and offer *counter strategies* and *validation techniques* respectively (133).

## The paradox of struggle and silence

There is an apparent paradox between the results from study II and study IV. In study II, there was a high prevalence of silence, while in study IV it was

emphasized that the informants solicited their competence in the encounters. Part of this paradox can be explained by the fact that, on average, the twelve informants from study IV reported lower levels of silence in TEP (39%, range 0-100%) than the total sample in study II (60%, range 0-100%). However, even the four informants who reported  $\geq 60\%$  relative silence in TEP were represented in the category of *the patient's competence*, indicating that they were active in their encounters with staff. Another more likely explanation is that the paradox mirrors the different study aims of study II and study IV. The latter focuses on the informants' stories about what happened *before* and possibly *during* the event, while study II focuses on the patients' reactions *after* the event. The results may, hence, represent different processes that show that even active patients who solicit their competence may remain silent after experiencing AHC.

## Limitations

### **Retrospective studies**

In all retrospective studies there is a risk for recall bias in people's reports. Different from a memory failure, this bias is not randomly distributed throughout a population and can therefore affect the study results (134). It is difficult, however, to estimate the range and impact of this bias. In studies II and III the abovementioned gratitude-factor may have blurred the memory of some patients' experiences of AHC and their response to these events. As these experiences are blurred, they may not be reported as abusive transgressions in TEP, thereby underestimating the prevalence of such events.

It is likely that experiences of severe AHC are remembered in more detail than events of less severe AHC, as they might be more significant emotionally. This might have resulted in a bias in study IV toward more severe events. Whether this affected the results is not known, but it could be that there are different factors that contribute to severe or less severe events of AHC. On the other hand, the informants' rich memories of these severe events may have increased the trustworthiness of their stories.

As study III was based on a retrospective cross-sectional study, it was impossible draw conclusions about causality. It is not known, for example, how high patients rated their knowledge of patient rights at the moment of the transgression, or if patients who spoke up looked into their rights after the transgression.

## **Attrition**

An analysis of complete non-response may give insights into which patients were included in the studies and which ones chose to decline participation. However, it is not known how many patients declined participation and who they are, and neither is it known if patients who did receive the questionnaire but chose not to answer it are different from the patients who responded. When nothing is known about these non-respondents, analysis of “days-to-respond” is one of the few methods available to test for complete non-response bias. None of the dependent variables in study II or III showed any associations with days to respond, and it was hence presumed that, considering these variables, respondents did not differ significantly from non-respondents. This potentially increased the validity of the prevalence numbers in study II, and of the associations found in study III.

## **Patients from a women’s clinic**

Analyzing differences between respondents and non-respondents says nothing about how the study population differs from other populations. Do patients who visit women’s clinics differ from other patients or the general population? Compared to numbers from a general female population in the same region in 2009 (using data from Statistics Sweden), the patients included in the main sample (from study II) were younger, higher educated, and fewer were born outside of Europe. As young age and high education levels are known to be associated with experiences of AHC, this difference could explain, to some extent, why the prevalence of AHC in the study sample according to the NorAQ questions (24.1%) was so much higher than the general population (15.5%; 30) and than an earlier sample of gynecology patients from the same region (14,0; 30).

Patients visiting a women’s clinic may be healthier than other patient groups, as many patients who come for screening procedures may be relatively healthy. Compared to the general population, however, this patient group is still sick-listed to a higher degree (30). Being in good health may affect patients’ ability and willingness to speak up, as was hypothesized in study III. Even though no such association was found, probably due to difficulties in measuring health at the time of the event, the relatively good health of the sample may have contributed to lower levels of silence than what could have been expected in less healthy patient groups.

## Swedish setting

An important limitation to the results from all four studies is the specific cultural setting in which the studies were conducted. The concept analysis was built on results from studies conducted in the Nordic countries, and TEP and the interviews were conducted among a sample of patients from a Swedish women's clinic. Even though all studies included data from patients with different ethnic backgrounds, they all spoke and understood Swedish, and the phenomena of interest occurred within the Swedish health care system. The results of all four studies are situated in this specific setting and could have looked differently if the studies were conducted in other countries.

First, regarding the results from the concept analysis, antecedents and consequences of AHC may be different outside of the Swedish context. In a South African setting, for example, the nurses' struggle for a middle class identity was seen as contributing to the endeavor to create distance to patients, ultimately ending up in abuse (114). Additionally, discourses surrounding gender, class, and in particular race probably impact staff-patient interactions differently in South Africa than in Sweden, considering a context of post-apartheid (130). This may be reinforced by the fact that high-income earners in South Africa can buy themselves top quality private care, while all patients in Sweden have the same rights to a great extent. Furthermore, in South Africa there may be different hospital hierarchies and working conditions that relate to "aggressive behaviours of nurses" (130, p. 98). There might also exist a general difference in what is considered abusive and what is not, partly as a consequence of culture-specific taboos and processes of normalization. Things that may be abusive in Sweden may be acceptable to both patients and staff in South Africa. Differences can also exist relating to the consequences of AHC, but no such studies from other countries have taken place as of yet. Fewer differences exist within the attributes of AHC. In the two South African studies, patients' descriptions of the abuse very much resemble the attributes found in the concept analysis, as it was found that the abuse compromised patients' humanity, and that the encounters were devoid of care (114, 130).

Second, the prevalence of patients' silence toward the health care system may vary greatly from one culture to another. The general tendency to express oneself critically about others may differ between countries. Studies in, for example, Iran and Indonesia have shown high scores in measuring patient satisfaction, probably due to a deeply rooted tendency to withhold criticism (135, 136). These tendencies are probably less serious in a Swedish context. In cultural settings with a high threshold for expressing criticism it is not sure that more knowledge of patient rights can contribute an increase in such expressions.

Third, experiences of staff utilizing domination techniques may also be culturally specific. Rather similar to study IV, in one of the South African studies, patients' experiences of abuse arose from their sense of being made to feel invisible, being withheld of the ground rules of what to expect and what can be expected from them, and being ridiculed (114). However, the South African study also identified many instances of physical domination over patients, in particular the slapping of patients. No such instances were found in study IV and only two patients reported they were hit or threatened to be hit by staff in TEP (paper II, p. 8). Even though physical abuse may occur in Swedish health care, it seems much more widespread and accepted by staff in South Africa.

### **Female patients**

The results of studies II-IV only apply to a specific female patient sample, which presumably affected the results of these studies.<sup>9</sup> Patients' silence and patients' stories about what contributes to AHC are likely to be gendered, not in the least because male and female patients describe their experiences of AHC in different ways (33, 34). Men and women may also use different strategies for coping with dissatisfying health care encounters, as women tend to apply more indirect approaches instead of directly confronting a physician (137). These strategies can relate to how patients are gendered in the health care system, and especially to what status men and women have in society at large. In one study it was found that female patients who are active in their care and treatment were seen as "difficult" patients, while this was not the case for men (138). Such gendered patterns could partly explain the high prevalence of silence that was found in study II. Future research in the area should also include male patients.

Another gender aspect that could be related to experiences of AHC and domination techniques is the threshold for perceiving something as abusive or not. In one experimental study it was shown that, given a set of scenarios, women rated more scenarios as offensive than men (139). Nonetheless, another study showed that, in an experimental setting, differences in taking offense were better explained by personality differences than gender differences (140). However, a comment to the latter study is that personality traits in themselves are highly gendered, especially in European cultures (141), but no analyses were conducted to account for this finding in this study.

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<sup>9</sup> Study I, the concept analysis, included studies with male and female samples.

## **Patients who reported abuse in health care**

A general limitation to most research about patients' stories of AHC, including to study IV, is that only patients who are able and willing to put their experiences of AHC into words are being studied. In this thesis this can be defended as being part of a strategy of 'purposeful sampling', but it could be argued that patients who feel no need to share their stories may have dealt with their experiences of AHC in a different way. These stories, however, never reach the ears of researchers.

## **Young patients**

Even though the samples from studies II and IV included patients from a wide range of ages, few patients over the age of 65 years were included. In study III, this may have been one of the reasons why no association was found between remaining silent and higher age.

## **The researcher's role**

"Finally, I get to say something." So far in this thesis I have been invisible as a researcher by writing in a passive voice, presenting the research process as if it happened spontaneously, without a researcher behind it. Feminist critics have called this *the god-trick*, presenting scientific "facts" as if they appear from nowhere (51). This contrasts with the epistemological framework in this thesis, in which I as a researcher have become part of the phenomena of interest by studying it, along with the instruments I used. In this discussion I would like to reflect upon two examples of how I as a researcher co-constructed the results that were presented in the current thesis.

First, the construction of a questionnaire (TEP in my case) seems to be an obvious part in the construction of the consequential results, but it is seldom discussed as such. In designing TEP I imposed part of my reality upon the respondent, who may struggle to fit her own reality within mine (142). If the respondent chooses to answer the questionnaire, these answers are hence the result of her interaction with me and TEP (143). Many of these answers may have been triggered by me sending out the questionnaire, rather than that they already existed out there. Some answers may not only have been triggered, but may even be the result of the filling out of the questionnaire (143). An example of this is that asking respondents whether a health care encounter was abusive or

not may have respondents reconstruct what they thought were “merely” wrongful events into abusive ones, in order to emphasize the seriousness of the transgression. Another example of my constructive role in the quantitative studies is not only *how* I tried to measure certain phenomena, which is related to validity, but *what* I measured, which is a choice.

Second, in conducting the qualitative study it was very obvious to me that I affected and co-constructed the data collection as well as the results. How a researcher should deal with her or his preconceived ideas of the studied phenomenon is one issue on which traditional or *objectivist* grounded theory and *constructivist* grounded theory differ (95). According to the former approach, the researcher is supposed to be unbiased and should ideally know very little of the field so as not to “disturb” the analysis by these ideas (94). But according to the latter approach, the researcher is a “situated knowledge producer” (95, p. 139) who not only acknowledges preconceived ideas but uses them in order to better understand the phenomenon of interest. By using abductive methods, the researcher goes back and forth between these preconceived ideas and the data, scrutinizing both (95). When I started study IV I had already done study I and had collected data for studies II and III. Most importantly, I had already used the different theories presented in this thesis to understand AHC and why it occurs. This knowledge helped me greatly to understand the position that patients are in, their dependency, and the suffering AHC can have as a consequence. But it was also important that I could question my own ideas by listening to patients and looking at the data. It came as a total surprise to me that patients’ knowledge about their body and the health care system was working against them. Looking back in my logbook, after a few interviews I wrote, “Could it be that the more you know about the health care system, the more you can feel abused?” What at first seemed to be a paradox only started to make sense once I understood that the process I was studying was experienced as a power struggle by patients, something I had not thought of before.

Compared to preconceived ideas about the phenomenon of study, the role of the researcher’s emotions has received little attention, although it may be assumed that these emotions are part of the entire process of a grounded theory study (144). I felt great empathy for all the women I talked to, which enabled me to somewhat imagine what they felt. During several interviews, the women intensively re-experienced the situations they described and they became very emotional, which in turn triggered strong emotions within me. Above all, this motivated me to show my respect and gratitude to the women, but it also motivated me to understand these painful experiences that I am studying even better. Where it concerns sensitive issues such as AHC, I believe that the researcher’s emotional engagement is necessary in order to understand what is

happening. Or, as Stern put it, “if you really want to know what’s going on, you have to feel it; you have to be affected by it; you have to let it move you” (145, p.57). According to positivists, such emotional engagement biases research and threatens objectivity, and should be avoided as much as possible (144). Jagger called this *the myth of dispassionate investigation* (146). After having conducted study IV, I no longer only question this kind of reasoning from a theoretical perspective, but also from a researcher’s perspective. Being emotionally disconnected from the stories the women told me would not have been more scientific; it would have been inhumane, disrespectful, and it would have yielded useless, empty data.

I have been an active part in producing the results of my studies, by making choices, by having feelings, and by showing respect.

## Safeguarding validity and trustworthiness

Issues that concern the validity and limitations of the results in the current thesis have appeared throughout the discussion so far. In this section it will be described which strategies were applied in order to safeguard the validity and trustworthiness of the studies.

A general comment that counts for all four studies is that accepting agential realism and allowing researchers to be emotionally engaged in their studies does not mean that their results are unscientific or invalid. On the contrary, according to feminist epistemology, such an approach can increase objectivity, as the researcher’s own preconceptions and context are scrutinized in the scientific process.

The results of the concept analysis are tentative and will change over time as the concept of AHC develops further. Transparency of methodological concerns and openness of interpretations enlarge the reliability of the study through its repeatability, even though no other researcher will find identical results if they would repeat the study (87). By using patients’ and staff’s stories about AHC, instead of constructed cases, the analysis was closest to a firsthand perspective, which increased the validity of the results. Walker and Avant’s method has been criticized for being positivistic, reductionist, and rigid (89, 147). Walker and Avant counter this critique by emphasizing that a concept analysis never ends in a final product. Also, the apparent rigid step-wise model is a simplified way of presenting how the concept analysis is really done, and may give a positivistic

impression. In fact, the analysis is done in a circular, abductive way, working back and forth between the different steps, rather than in a linear fashion (87).

Considering studies II and III, TEP captured most events of AHC as captured by the NorAQ questions. TEP also captured more events than the NorAQ questions, which can be explained by the same reasons why ViOLEP captured more than NorAQ, namely (i) the construction of the questionnaires; TEP covers many more examples than NorAQ, (ii) TEP covers a wider range of acts, and (iii) events in NorAQ can be considered more severe than most events in TEP. But these reasons make it harder to understand why TEP misses about 28% of events that the women reported as AHC according to NorAQ. Or in other words, what kind of events was TEP insensitive to? Two explanations are possible. First, it could be that TEP did not list some important events, thus patients could not report these experiences of AHC. This could either be a consequence of limits to the operationalization of ethical principles, or of limitations in the principles themselves. Second, the follow-up question “Did you perceive what happened as abusive?” in TEP may in some cases not capture the experiences described in the NorAQ questions. This seems improbable because the NorAQ questions use similar wording as the TEP follow-up question, either using *kränkt* and/or Swedish equivalents (such as *förnedrad*, *skändat*). However, there is a linguistic difference that was not thought of during the translation of TEP. The TEP question uses *kränkning* as a substantive, while all the NorAQ questions use verbs (*kränkt*, *skändat*) or an adjective (*kränkande*). Whether this matters is a question beyond the scope of this thesis, but one that would be interesting to pursue within the aims of concept development and validity improvement of future measurements.

The validity of the silence operationalization was judged at face value by an expert on questionnaire design and by colleagues. Also, the wording in the question was compared to actions that patients had taken after having experienced dissatisfying health care encounters (115). It was concluded that TEP covered most of these events, and that the events that were not captured were not of major importance for structural change. For example, patients could switch health care provider, which was deemed not to be included in the TEP operationalization (if not accompanied by other forms of feedback). However, these switches are expected to contribute little to structural change because there is an excess of demand for care and leaving a provider often does not give that provider any clues about how to improve practice (148, 149). For that reason, such actions were not included and hence do not limit the validity of the silence operationalization in TEP. Patients’ actions within their *informal networks* were also excluded, such as talking to acquaintances, as it was expected that this would have no direct effect on health care structures. However, such actions

could eventually contribute to breaking the taboo of talking about AHC, and consequently change patients' and staff's behavior in the long run.

Instead of talking about the validity of study IV, qualitative studies are often judged by their trustworthiness (93), which consists of four elements: credibility (comparable to internal validity), transferability (comparable external validity), dependability (comparable to reliability), and confirmability (comparable to objectivity; 150). Credibility and dependability were safeguarded parallel to each other by emphasizing the transparency of method and investigator triangulation. By having described the limitations of the setting and the sample, others can estimate the transferability of the results to their setting. An important note here is that the aim of qualitative studies is not to generalize, but to include an adequate sample of informants who have knowledge of the topic, and the time and will to participate and reflect upon it (151). In addition to that, in study IV theoretical sampling was applied to increase the spectrum of patients' descriptions and thereby the transferability of the results. The setting and sample were limited in many ways. Besides the earlier mentioned limitations, the sample was also limited to adult patients with no severe mental disabilities. Considering confirmability, reflexivity throughout the entire study was underlined, and methodological and theoretical reflections were recorded in a logbook. Memo-writing was used as an intermediate step between data analysis and manuscript writing (88). Writing notes about theoretical ideas helped to increase the abstraction level of categories and provided an overview of the analytical progress (88). The use of examples and direct citations in paper IV offers the reader an opportunity to judge how codes and categories are supported by data. The confirmability of the results was also increased by comparing the results to an earlier study by other members of the research group, which was on female patients' experiences of AHC and what these meant to them. The core category *being nullified* implied, among other aspects, a feeling of *powerlessness*. This core category seems consistent with the findings from study IV, where a process that contributes to AHC was described as losing power struggles.

## CONCLUSION

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This thesis started with an analysis of the concept of AHC. It was concluded that this rather immature concept stands for patients' subjective experiences of encounters in health care characterized by a lack of care, where they felt they lost their human value and experienced suffering. But what contributes to the fact that AHC occurs and can continue to prevail? One hypothesis was that patients might remain silent toward the health care system after experiencing AHC, which is a loss of essential feedback for the health care system. A quantitative study showed that high numbers of female patients experienced abusive ethical transgressions in health care and many of them reported that they remained silent toward the health care system. This silence was found to be associated with younger age and less knowledge of patient rights. Other factors that could contribute to experiences of AHC were explored in a qualitative study. The informants' stories about what contributed to their experiences of AHC were best recapitulated as *the patient loses power struggles*.

As AHC is defined by patients' subjective experiences it is necessary for the prevention of AHC to listen to patients' stories and complaints. However, the prevalence of female patients' silence after abusive events is worrying, as it constitutes a loss of essential feedback for the health care system. Clinical interventions that stimulate these patients to speak up, accompanied by health care staff's reflections on how to respond to patients speaking up, must therefore be explored.

## CLINICAL IMPLICATIONS

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This thesis provided some insights in the complexity of AHC, as a theoretical concept, but also as an ethically problematic phenomenon within health care settings. Clarity of the concept may help other researchers as well as clinicians to recognize when AHC is about to take place, when it is ongoing, or when it has already occurred by describing its antecedents, attributes, and consequences.

The fact that AHC is often paired with a tendency toward silence on the side of the patient leads to a loss of feedback to staff that may be essential for structural changes that aim to better health care encounters. Health care staff may run the risk of interpreting silence as a false form of patient satisfaction with the encounter in question. Stimulating patients to speak up may be a key to valuable knowledge about how to improve clinical practice.

However, female patients who had experienced AHC felt that a struggle for power and taking an active role might catalyze staff's use of domination techniques, which could contribute to experiences of AHC, even though staff was most likely unaware of this consequence. Motivating patients to speak up must therefore be accompanied by health care staff's reflections on how to respond to patients speaking up. Becoming aware of the risk of using domination techniques can be an important step in that direction.

Patients do not bear responsibility for health care processes, but their knowledge could be very valuable for structural improvement of these processes and ought to be valued as such.

## **FUTURE RESEARCH**

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Based on the results of the four studies in this thesis and on the theoretical discussion of these results, the following research questions could be of interest in future research.

- What is the prevalence of remaining silent toward the health care system about abusive experiences in a male patient sample, and what male patient characteristics are associated with this silence?
- How can patients' awareness of alternatives to silence be increased?
- How can patients' self-efficacy in situations of AHC be increased?
- How can staff encourage patients to speak up?
- How does staff react to patients who speak up or complain?
- How can staff be supported in their use of patients' feedback?

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