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_Elder abuse explored through a prism of perceptions:
Perspectives of potential witnesses_

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A deed knocks first at thought
And then it knocks at will.
That is the manufacturing spot,
And will at home and well.

It then goes out an act,
Or is entombed so still
That only to the ear of God
Its doom is audible.

Emily Dickinson

To my brother Jeff
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ABSTRACT

The overall aim of this thesis was to deepen understanding of elder abuse (EA) by exploring and comparing perceptions held by experts, older persons, representatives of potential support organizations, and family members. Experts’ perspectives (I) were examined through risk indicators and screening questions (a) located in EA literature and (b) selected by an international Delphi panel. Risk indicators most commonly found in the literature or selected by the panel were compiled into consensus lists. There were differences between risk indicators and questions in the two lists. In papers II and III participants were interviewed in focus groups about their perceptions of EA. Older persons (II) considered EA to be due to changing society and family systems where children are not brought up to respect older persons. EA was mainly conceptualized as ageism, criminal actions, mistreatment in residential care, and societal abuse. The abuser was perceived as a stranger or a healthcare worker. Fear was discussed as a major consequence of EA; especially fear among women. Abused persons were described as carrying the responsibility to seek help. Witnesses were described as hesitant to get involved. Improvements in society such as educating children and healthcare workers were considered ways to cope with EA. Besides family and friends there were few spontaneous suggestions for where to seek help and support in society. These suggestions included healthcare, police, church, and volunteer organizations. Representatives of these suggested organizations were interviewed in focus groups about their perceptions of EA (III). Perceptions of both causes and conceptions of EA were very similar to perceptions of older persons (II). Four themes emerged in the data; good intentions in abusive situations, older generation’s responsibility for EA, failing to report abuse, and prevention of abuse. Participants (III) also expressed ageist attitudes themselves and findings included victim blaming and tolerance for EA. Participants perceived that anyone could be provoked to abuse, and that abusers can be considered victims in abusive situations. Confidentiality was discussed as a barrier to reporting and the need for educating children to show respect for older persons was identified. Interviews with an adult family member (IV) explored her experiences of witnessing abuse situations between her uncle and his wife. In her desire to protect and remain loyal to her family she felt powerless and tolerated abuse. She longed for support she could trust but was locked into passivity by her feelings of shame. Synthesis of findings (I – IV) revealed issues of isolation, autonomy, vulnerability, victim blaming, perceiving the abuser as a victim of circumstances, ageism, tolerating EA, shame, and power as essential elements in EA. Based on the findings, alternative descriptions of EA are offered as a challenge to existing EA definitions. Findings suggest that a key to unlocking EA is compassion, understood as the ability to see a situation as if we were in it ourselves, experiencing the potential for disrespect, shame and unworthiness inherent in abusive acts.

Keywords: elder abuse, Delphi technique, focus groups, narrative analysis, risk indicators, ageism, victim blaming, shame, power, compassion
This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


When first approached to participate in an elder abuse research project my initial reaction was, “Elder abuse, what is that?” The idea that someone could actually hit an old woman seemed grotesque and absurd. My first assumptions were that elder abuse is due to caregiver burnout and that dementia behavior and substance abuse were at the root of the problem. But after reflecting on my own experiences as a municipal eldercare nurse I soon associated to several other situations that I had witnessed and incidents I had participated in that could be considered abusive. Today I would name them situations of elder abuse. Yet at the time I do not recall any surprised responses or even that anyone questioned the incidents. I do remember feeling at a loss, alone, and without support or encouragement in situations that left me with the definite feeling that something was “wrong”.

My initiation to the field of elder abuse was as research assistant in the project Global Response to Elder Abuse. This project was a cooperative effort between the International Network for the Prevention of Elder Abuse (INPEA), the World Health Organization (WHO), HelpAge International and academic partner institutions around the world. The first two studies in this thesis are an outcome of involvement in that project. The Global Response project had the ultimate aim of developing a global strategy for the prevention of abuse of older people (World Health Organization 2002a).

During participation in this project I became convinced I should continue with elder abuse research inter alia because the field seemed vastly under-researched. While there was a general lack of elder abuse research there was a particular absence of studies investigating perceptions of elder abuse and the meaning elder abuse situations have for stakeholders such as experts, support persons, and the involved persons themselves. The predominance of studies seemed to have quantitatively investigated types and prevalence of elder abuse. This focus would not have been problematic for me if elder abuse could be exclusively calculated and addressed objectively with quantitative methods. But complex situations such as elder abuse reflect a world of parallel and multiple truths were no one opinion or perception has the preferential right of interpretation. Elder abuse involves persons and violent experiences, a combination that seems related to deep feelings and moral dilemmas; a combination best addressed subjectively e.g. using qualitative methodology. A third and most critical methodological knot in elder abuse research concerned how elder abuse was being defined. It appeared at times to be arbitrary or even a matter of taste which definition was used in a project or policy. There also was an absence of studies where views and perspectives of involved persons -whose experiences logically should lie at the core of any elder abuse definition-, were sought and incorporated into the definitional process. I experienced this as an abuse itself. The problems of limited research, lack of qualitative perceptions studies, and problematic definitions lie at the heart of this thesis.
BACKGROUND

Highlighting elder abuse for the first time as a specific phenomenon has often been attributed to British authors Baker (1975) and Burston (1975) in their descriptions of “granny battering”. Terminology for the dyad directly involved in the “battering” varies in the literature between victim/perpetrator and abused/abuser. In this thesis the terms abused and abuser will be used to designate those directly involved. “Elder abuse” has been referred to in the literature by a variety of terms including elder mistreatment, elder maltreatment, inadequate care, abuse of the elderly/older persons, resident abuse, domestic violence in old age, neglect, and self-neglect. With the exception of self-neglect all of these designations are included in this thesis as descriptions of elder abuse.

Reports from the UK, Canada, and the USA indicate that the prevalence of elder abuse in the elderly population is approximately four to six percent (Ogg and Bennett 1992; Pillemer and Finkelhor 1988; Podnieks 1992). Actual numbers though are difficult to ascertain and it is suspected that most elder abuse is unreported (Glendenning 1997; National Research Council 2003). In Sweden, a survey directed to older persons (65 – 80 years old) about their personal experiences of elder abuse found that 16% of participating women (n = 592) and 13% of men (n = 499) reported having experienced some form of abuse since turning 65 years old (Eriksson 2001). These results give reason for concern when considering Sweden is experiencing the same demographic revolution of a rapidly aging population evident worldwide. The adult population in Sweden 65 years and older is estimated to increase by 24% during the next decade (2007-2017) (Statistics Sweden 2007). Even if the percentage of elder abuse does not increase; the incidence of elder abuse can be expected to increase proportionately with a growing older population (Glendenning 1997). Elder abuse is a reality for a growing number of older persons. It is questionable whether the healthcare system or other potential support providers are prepared for this reality or have the needed knowledge.

Elder abuse is included in the panorama of family violence including for example domestic violence and child abuse (American Psychological Association 1996; Quinn and Tomita 1997). In general and in comparison to the other areas of family violence, there is relatively limited research conducted on elder abuse. However, elder abuse has been increasingly recognized as a serious social issue during the last thirty years (Glendenning 1997; World Health Organization 2002a; World Health Organization 2002b) and a research area of highest priority (United Nations Office on Ageing and International Association of Gerontology 2002). A recent systematic review revealed a dearth of elder abuse research. A total search of database citations located in CINAHL, PsycInfo, and PubMed using the search term “elder abuse” resulted in a total of 3,059 citations. Only 2,418 of these were unique entries and of these only one sixth (432 references) could be categorized as research. In comparison a similar database search within the field of family violence using the term “child
Elder abuse research is limited in more ways than just restricted quantities. Articles have originated in relatively few countries and cultures. For example only 24 countries were represented in the database citation search results and nine of these countries have emerged on the elder abuse scene within the last five years. Research articles and dissertations from the USA represent $\approx 61\%$ of the registered research with $\approx 86\%$ of elder abuse research originating in English speaking countries. Perspectives from for example developing countries are a noticeable gap in the literature. Other conspicuous gaps in elder abuse research include the slow increase and relatively small number of qualitative research articles (approximately 15% of total research) as well as relatively infrequent involvement of older persons and family members as research participants (Erlingsson in press). These gaps reveal that very little is known about the phenomenology, etiology, magnitude, and consequences of elder abuse (National Research Council 2003) and that elder abuse research, despite a span of thirty years, is still in initial stages (McDonald and Collins 2000). As a “new” field of research distinguishing characteristics and the meaning of concepts need to be clarified in order to document etiology, incidence, or prevalence, and to achieve an understanding allowing for definition (Hudson and Carlson 1994).

**Defining elder abuse**

*Theoretical frameworks connected to elder abuse*

The lack of consensus on a definition, together with the resulting lack of comparable research results, data sets, and testing has complicated the process of theory formulation (Ansello 1996). Nevertheless a variety of explanations and theories have been proposed accounting for elder abuse. Three theories that have been perhaps most visible in elder abuse research are the theory of symbolic interaction, the social exchange theory, and situational theory (Glendenning 1997). Especially situational theory has garnered much attention in connection to caregiver stress and burden. Today many consider that although stress and burden are contributing factors they do not completely explain elder abuse (Wolf 2000). More recent discussions have linked elder abuse to broader societal issues and include ecological frameworks as appropriate theories explaining elder abuse (Nahmiash 2002; National Research Council 2003; Schiamberg and Gans 1999). This horse and cart problem of proposing theories explaining abuse, while lacking a consensus on a definition, is characteristic of the definitional challenges in the field of elder abuse. Quandaries include for example, that development of overreaching definitions or frameworks has been based on reported cases of elder abuse. Yet these reported cases were, in turn, originally identified using a variety of definitions.
(Not) defining elder abuse

One issue agreed upon in elder abuse literature is that there is no agreement on one, comprehensive, uniform definition of the term “elder abuse” (Anetzberger 2005; Manthorpe et al. 2004; National Research Council 2003). Definitions seem to vary according to the purpose for which they are needed (Glendenning 1997). This situation has been described as “definitional disparity” (Barnett et al. 1997, p. 256) and “definitional disarray” (Pillemer and Finkelhor 1988, p 52). Despite the absence of consensus on any one definition and the frequently described difficulties to define elder abuse (Bennett 1990), there remains a plethora of definitions. This lack of agreement has been considered a problem as evaluating or building knowledge in the field is impossible in the absence of a common definitional framework (Hudson 1991; Johnson 1986; Johnson 1991; National Research Council 2003). These description difficulties are indicative of a definitional dichotomy among authors where some seem to consider “elder abuse” as a definable concept while others instead seem to be describing “abuse of older people.”

The power of the paradigm is that it shapes, in neatly unconscious and thus unquestioned ways, perceptions and practices within disciplines. It shapes what we look at, how we look at things, what we label as problems, what problems we consider worth investigating and solving, and what methods are preferred for investigations and action. Likewise, a paradigm influences what we choose not to attend to; what we do not see.

Patricia Maguire
Doing Participatory Research (p. 11)

Elder abuse paradigm

What constitutes elder abuse is debated perhaps more than in other areas of family violence. There is, for example, the aspect of needing to specify age parameters of what constitutes “elderly” (Barnett et al. 1997) as well as expanding the general family violence description to include a greater variety of acts against the victim e.g. financial abuse (Sengstock and Barrett 1993). The traditional description of elder abuse typically found in previous literature has been summarized as, “Elderly people become frail, difficult to care for, and sometimes demanding. These characteristics cause stress for their caregivers; as a result of this stress, the caregivers become abusive or neglectful toward the elder” (National Research Council 2003, p. 98).

As the above description reveals, elder abuse has been characterized along the lines of child abuse and protection, and conceptualized within a healthcare paradigm where the older adult is seen as dependent and vulnerable. There is an underlying assumption that elder abuse victims are unable to speak for themselves. In addition, elder abuse has almost exclusively been discussed from a caregiving/receiving perspective. Parallel with this focus are discussions that have suggested that elder abuse be considered from a domestic violence angle applying a feminist perspective of power and coercion in a relationship (Penhale 2003; Straka and Montminy 2006).

In all attempts to conceptualize and define elder abuse it is considered vital to include the perspectives of older persons and family members (McDonald and Collins 2000;
National Research Council 2003). Yet in contrast to definitions of domestic violence which have grassroots origins, older persons have not been involved in the definitional process for elder abuse (Penhale 2003; Straka and Montminy 2006). A challenge for elder abuse research is to link these top down (elder abuse paradigm) and grassroots (domestic violence paradigm) approaches in a model that best explains and describes abuse of older persons and includes perspectives of all involved parties, both the directly involved dyad as well as potential witnesses.

Types of definitions

It has been proposed that the essential elements in an elder abuse definition include the intentionality of the action, documentable harm, assignable responsibility/laying blame, and vulnerability of the abused (Hudson 1996; Phillips 1996). Other authors argue that such an approach is too simplistic and assert the need for a thorough description of each case that takes context and morality into consideration (Hardwig 1996; Murray 1996). Elder abuse definitions generally entail typologies and taxonomies reflecting the heterogeneity of elder abuse. In the absence of research studies exploring that heterogeneity, elder abuse definitions are considered to be influenced by legal distinctions, less informed by scientific classification and rather on the level of common sense classes (National Research Council 2003). Typologies typically include a wide variety of categories that lack conformity and easily become too inclusive (McDonald and Collins 2000). Most commonly these categories are physical abuse, psychological abuse, financial abuse, and sexual abuse (Glendenning 1997; Lachs and Pillemer 2004; National Research Council 2003). Three basic approaches to defining elder abuse have been located in the literature; connotative, structural, and denotative approaches. It is the consequences of abuse that are focused in connotative definitions. Structural criteria look to the actions and behaviors in order to define abusive actions. Denotative definitions include descriptive lists (Stones 1995) of the principle factors that have been associated with elder abuse.

Risk indicators

Principal factors associated to elder abuse are referred to in elder abuse literature both as risk factors and risk indicators and involve personal characteristics and aspects of environment or lifestyle that increase the chances of elder abuse occurring. Risk factors are primarily those factors with a causal relationship to elder abuse. Risk indicators are most often markers or red flags that, although not directly causal, do point to an increased risk that an abusive situation exists (Saveman in press). Risk factors and indicators are key ingredients in elder abuse detection that can be predictive of the presence of an abusive situation (Hwalek and Sengstock 1986) and are also used as constituent elements of definitions (National Research Council 2003). It is considered crucial for healthcare and other practitioners to have an awareness of risk indicators in order to make connections to signs, symptoms, and behaviors of abuse (Nagpaul 2001). Yet the terms risk factor and risk indicator are utilized inconsistently, and at times interchangeably. The term risk indicator with its
broader application has been considered a better term (Saveman in press). For these reasons the terms risk factor and risk indicator will both be referred to in this thesis with the more inclusive term risk indicator.

**Definitional review**

One way to shed some light on the current state in the field of elder abuse is to track definitions over time. Seven definitions have been commonly referred to in elder abuse literature (see Appendix A). These definitions originate in the USA (n = 4), Norway (n = 1), and the UK (n = 2). The two most recent definitions provide clear examples of the bifurcation in defining abuse situations as elder abuse (National Research Council 2003) or as abuse of the older person (Department of Health 2000). Fulmer and O’Malley’s (1987) definition stands out in comparison with other elder abuse definitions. In this definition elder abuse is described as inadequate care where the actions of a caretaker create unmet needs for the elderly person (Fulmer and O’Malley 1987). The concept of needs is echoed in later definitions, but as “basic needs” and not “needs for care” (Hudson 1991; National Research Council 2003). Johnson’s (1986) definition also stands out by defining abuse as the “suffering unnecessary to the maintenance of the quality of life of the older person” (p.180). Johnson’s definition is the only one of the reviewed definitions that defines abuse as the consequence of an action instead of as the act or action itself. Other key concepts found in several definitions are “a relationship connoting trust”, “violation”, “resulting in harmful effects”, “vulnerable elder”, and “intentional” (see Appendix A). This last term “intentional” is noteworthy for two reasons. First, arguments that identifying intentionality is only appropriate to intervention and treatment and does not belong in the identification mode of a definition (Johnson 1986). Secondly, tempering the abusive action with the adjective “intentional” makes it possible for some actions which cause harm for the elder not to be classified as abuse. The abuser, safe in his or her innocence of not intending harm, will not be considered an abuser and the older person will not be considered abused or as having the need for/or right to receive assistance.

The relationship between the abuser and the abused is described both in general or more specific terms in these definitions; (a) self- or other- inflicted abuse of the older person by someone who is overwhelmed, (b) two actors in a social act, (c) any relationship involving an older person or a vulnerable person, (d) responsible party(-ies) and the older adult, (e) caretaker of an elderly person, or (f) caregiver or other person and a vulnerable elder. In the National Research Council report (2003) it was proposed that the relationship between the abused elder and the abuser is at the heart of a common understanding of elder abuse. Yet in these reviewed definitions it can be seen that there is anything but a common understanding of the relationship. In the area of elder abuse it seems to instead be an act or actions and not the relationship that is at the core of existing definitions.

Only one of the reviewed definitions addresses the etiology of elder abuse by including the adjective “overwhelmed”. An objection could be raised here that “need
of care” and “needs”, as well as the adjective “vulnerable” could also be considered etiologically. Since there are numerous studies (Lachs et al. 1997; Phillips et al. 2000; Pillemer and Finkelhor 1989; Reis and Nahmiash 1998) that question a causal connection between burden of care, the older person’s disability, and the occurrence of elder abuse, it could instead be considered that “needs” and “vulnerability” in these definitions are prerequisite factors and not causes of elder abuse.

These definitions raise many questions concerning the abuser (as caretaker or someone overwhelmed, or just anyone), the abused (an actor in a social act or someone vulnerable and/or overwhelmed), and does abuse only happen in relationships where there is an expectation of trust? Must elder abuse be an intentional action, or is elder abuse suffering unnecessary to the maintenance of the quality of life of the older person? If it is the second option one wonders who judges whether the elder is suffering unnecessarily. This subjective element has been discussed as part of the intrinsic definition of elder abuse (Johnson 1986). Values and beliefs figure strongly in elder abuse identification, especially values associated with healthcare such as beneficence, autonomy, and costs and benefits (Phillips 1996). The National Research Council report (2003) has recognized the presence of value judgments in situations of elder abuse and therefore makes a strong recommendation for further basic research on experiences of elder abuse and the meanings for the persons involved (National Research Council 2003). The persons who subjectively judge elder abuse situations, especially witnesses, have important roles to play in how/if the abuse is reported and what interventions are considered. However, there is relatively little research on how potential witnesses of elder abuse perceive elder abuse or how these witnesses perceive their possibilities to provide support or intervention.

Definitions and witnesses’ perspectives of elder abuse

One example of the importance of witnesses’ perspectives is that it is likely to be a witness who identifies and reports an abusive situation. It is estimated that 70% or more of case identification comes from witnesses such as healthcare professionals. Self-reporting of elder abuse by the abuser or the abused elder is not common (Fulmer et al. 2004). Cognitive impairment in the abused elder is a serious hindrance (Kosberg and Nahmiash 1996; Quinn and Tomita 1997) making self-report impossible. Elder abuse literature also frequently names shame, self-blame, and fear of reprisals as major barriers for abused older persons in revealing elder abuse. A common opinion found in elder abuse literature is that elder abuse is a hidden phenomenon and that reported cases are only the tip of the iceberg (National Research Council 2003; Tatara and Kuzmeskus 1996). If true one wonders who is hiding the abuse: is it only the abused and the abuser? Or are “hidden” cases of elder abuse simply not seen or judged as situations of abuse and perhaps ignored and tolerated by witnesses? Garcia (2003) suggests that elder abuse is not really hidden but represents what society does not want to see so is tolerated by society. If this idea is accurate then no legal, social, or medical intervention plan will ever be effective in providing support and safety for abused older persons since implementing intervention would seem to depend on the perceptions and moral judgments of those
members of society witnessing elder abuse. Many researchers believe we need to incorporate perceptions of elder abuse among both experts, the general public (Hudson and Carlson 1994), professionals and practitioners (Weeks et al. 2004), and older persons themselves (Moon and Williams 1993) in order to achieve an understanding that will allow development of an elder abuse definition. One perspective currently lacking in this list of potential witnesses to elder abuse are the perceptions of family member witnesses.

**Systematic literature review of witnesses’ perspectives**

In order to review previous research concerning witnesses’ perspectives on elder abuse searches were conducted in databases PubMed, Sociological Abstracts, CINAHL, and PsycINFO (May 5, 2007) and through manual searches of reference lists and library holdings at the University of Kalmar for articles with general content on perceptions of elder abuse published within the last 15 years. Seventy-seven articles were located. Non-pertinent articles were excluded using the following criteria:

- Focus on perceptions of the abused or abusers
- Focus on family violence where elder abuse findings were too limited or too confounded with data on other family violence areas
- Evaluation of training programs
- Narrow aims concerning very specific types of abuse (e.g. side rail use or restriction), types of perceptions (e.g. awareness of/criminalization of elder abuse), or types of variables (e.g. parental attachment styles)
- Articles written by the same author(s), published in different journals using identical methodology and reporting very similar results from the same study
- Articles published in non-peer review publications

Nineteen articles were selected for review that: (a) had a primary focus on potential witnesses’ perceptions of elder abuse and (b) were pertinent as a point of reference or point of departure for this thesis. In five articles there were mixed participant groups; family caregivers and significant others were included in two studies, the general public in three studies, older persons in six studies, and professionals in twelve studies. Professionals as participants in these perceptions studies were most often nurses (seven articles), social workers (four articles), and physicians (four articles). Participants from other professions such as clergy were represented in only two studies (see Appendix B). These nineteen articles reflect the patterns of participant involvement seen in elder abuse research in general (Erlingsson in press).

Descriptions of elder abuse etiology were scarce but included uncooperative elders (Moon and Williams 1993), older people not keeping up with changes in society (Brownell et al. 2003), the presence of overwhelming demands, or demands on unwilling/unable elders (Saveman et al. 1993). In the majority of the reviewed articles categories of abuse were predetermined by fixed survey questions or by vignettes, statements, or scenarios. The abuse categories most frequently included in these studies were physical abuse, psychological/emotional/verbal abuse, financial abuse,
and neglect. Other categories such as sexual abuse, abuse of medications, and societal abuse were infrequently used.

Seven articles had more open research designs such as ethnography (Hirst 2000), focus groups (Anetzberger et al. 1996; Brownell et al. 2003; Wilson 2002), or in-depth interviews (Saveman et al. 1993; Saveman et al. 1996; Saveman et al. 1992). The categories of physical abuse, psychological/emotional/verbal abuse, and financial abuse emerged in all seven of these articles as well. Social worker participants in Wilson’s study (2002) included sexual abuse as a category of abuse. Neglect was named as a type of elder abuse in five of the articles (Anetzberger et al. 1996; Hirst 2000; Saveman et al. 1993; Saveman et al. 1996; Saveman et al. 1992). Grandparents interviewed by Brownell and co-workers (2003) added disrespect to their list of abuse types. Disrespect was an issue echoed in other perception articles even though not explicitly named as a type of abuse (Hudson 1994; Saveman et al. 1993).

**Risk indicators and perception of risk**

In the USA the National Research Council (2003) published a comprehensive report on conceptual, logistical, and methodological issues of elder abuse. In this report several of the most commonly named risk indicators are discussed either as (a) indicators validated by research, (b) possible/plausible indicators of abuse, or as (c) contested indicators of elder abuse. Risk indicators considered to be validated by scientific study were:

- Shared living arrangements
- Social isolation
- Dementia disease in the abused person
- Intra-individual characteristics of abusers (mental illness, hostility, alcohol abuse)
- Abuser dependency (dependent on victim for housing and financial assistance)

(National Research Council 2003)

Despite the fact these risk indicators were considered validated they were mentioned infrequently in the reviewed perception articles (each risk indicator named in ≤ 3 articles).

The risk indicators considered as possible/plausible indicators of elder abuse were:

- Race
- Relationship between the abused and the abuser
- Victim’s personality characteristics, e.g. aggression or passive ways of coping
- Gender (women as victims)(National Research Council 2003)

Five of the reviewed perception studies support evidence that race/ethnic group/cultural background are important indicators of increased risk in situations of elder abuse and that such indicators should be an area of focus in future research (Anetzberger et al. 1996; Hudson 1994; Moon et al. 2001; Moon and Williams 1993; Pablo and Braun 1997). Relationships between abuser/abused were described as personal relationships between individuals and were made up of a variety of groupings including professional/older resident, grandchild/grandparent, husband/
wife, spouse/spouse, adult child/parent (cf. Brownell et al. 2003; Hirst 2000; Podnieks and Wilson 2003; Saveman et al. 1996; Wilson 2002). Relationships between an authority or agency and older persons were not discussed despite that societal abuse was named a category of abuse in three articles (Hudson 1991; Hudson 1994; Saveman et al. 1993). Personality characteristics in the abused, such as aggression (Hirst 2000; Saveman et al. 1996) and passive coping strategies (Brownell et al. 2003; Podnieks and Wilson 2003; Saveman et al. 1996; Wilson 2002) were also discussed as indicators of an abusive situation.

In the reviewed articles perceptions varied concerning the role of gender in abusive situations. In one study district nurses discussed both men and women as abusers as well as those abused (Saveman et al. 1996). Weeks and co-workers (2004) conducted a gendered analysis in their multi-disciplinary study. All professional groups, including both men and women responded that it is women who are most often abused and that abusers are most often males. In Wilson’s (2002) study social workers discussed older persons as non-gendered individuals who were instead referred to with gender-free terms such as service users, victims, carers, abusers or perpetrators.

An additional gender issue apparent in the reviewed articles was the role of participants’ gender. Many of these studies included exclusively or predominantly female participants (cf. Brownell et al. 2003; Hirst 2000; Limandri and Tilden 1996; Moon and Williams 1993; Pablo and Braun 1997; Saveman et al. 1993; Saveman et al. 1996; Saveman et al. 1992). A few articles did not specify gender of the participants but did specify professions such as social work and nursing. Since women predominate in the fields of social work and nursing it might be assumed that such articles also mirror women’s perceptions (cf. Hudson 1991; Wilson 2002). Weeks and co-workers found that more females than male professionals detected relatively higher level of abuse (Weeks et al. 2004). Child and co-workers (2000) reported differences not only in how elder abuse was perceived depending upon the participant’s gender but also depending on the woman or man’s age. An example of this is that middle-aged women were less willing to report elderly abusers than middle-aged abusers (Childs et al. 2000).

Several commonly cited risk indicators have been contested as having relevance for elder abuse. These include:

- Intergenerational transmission of violence
- Physical vulnerability or frailty of the abused
- Abused elder’s dependency on abuser and need for assistance/caregiver stress

(International Research Council 2003)

Intergenerational transmission of violence was not a major finding in any of the reviewed perceptions articles. Issues of vulnerability, frailty, dependency, and caregiver burden were often included as major findings or topics of discussion (Gebotys et al. 1992; Harrell et al. 2002; Hirst 2000; Moon and Williams 1993; Pablo and Braun 1997; Saveman et al. 1993; Saveman et al. 1996; Weeks et al. 2004; Wilson 2002). A general pattern seen in the findings of the reviewed perception
articles was that possible/plausible and contested indicators were included as much or more than indicators considered validated in the National Research Council (2003) report.

**Reporting abuse and providing support**

Reporting abuse and providing support were also major discussion topics in the reviewed perception articles. This focus is not surprising since the majority of reviewed articles included these areas in the purpose statement or as part of a survey. To report or not to report abuse was discussed as a moral dilemma (Harrell et al. 2002; Podnieks and Wilson 2003; Saveman et al. 1992; Wilson 2002). Several articles concluded that in an abuse situation one had to take the whole context into consideration (Anetzberger et al. 1996; Brownell et al. 2003; Hirst 2000; Hudson 1994; Limandri and Tilden 1996; Saveman et al. 1992). Contextual elements included considering potential for harm (Gebotys et al. 1992), intention of the abuser (Hirst 2000; Hudson 1991; Hudson 1994; Moon and Williams 1993; Saveman et al. 1993), not seeing the abuser as malevolent (Brownell et al. 2003; Saveman et al. 1993; Saveman et al. 1996), and the responsibility of the abused person for the abuse (Brownell et al. 2003; Moon et al. 2001; Saveman et al. 1996) i.e., victim blaming.

Moral dilemmas regarding likelihood to report, take action or provide assistance were described in the actions/inactions of different professional groups. Wilson (2002) in her study among social workers found avoidance to be an important professional strategy. Elder abuse was considered too complex and time consuming when the case loads were already excessive. These social workers described being able to choose whether to ignore suspicions of elder abuse as long as abuse had not already been officially identified. Physicians in contrast responded that they were likely to take action and make referrals to service agencies (Harrell et al. 2002; Krueger and Patterson 1997). It is interesting to note that when compared to physicians with actual experience of elder abuse cases, physicians who had never seen a suspected case of elder abuse were much more confident in their ability to identify elder abuse (Krueger and Patterson 1997).

Faith leaders surveyed by Podnieks and Wilson (2003) responded that they would take action if they suspected abuse. Worthy of note in faith leaders’ responses was that they were more inclined to actively react if they suspected abuse themselves. Abuse disclosed by others was feared to sometimes be untrue and resulted in faith leaders less often using active intervention strategies (Podnieks and Wilson 2003). Some nurse respondents also expressed wanting to know “for sure”. Nurses described fear of being wrong and that taking action could result in increased harm. This concern led to nurses taking a “wait and see” attitude (Limandri and Tilden 1996; Saveman et al. 1992). Perceptions expressed by the representatives of the general public were that help should be offered at first suspicion of abuse (Hudson 1994). This variety of best strategies for providing help, i.e., ignoring the situation, “wait and see”, or reacting immediately at first suspicion, gives clues to the diversity of perceptions of elder abuse among potential witnesses with a stakeholder role.
Most of the reviewed articles discussed resources for providing help, support, and/or intervention in elder abuse cases, and reporting to social services was often named (Brownell et al. 2003; Kreuger and Patterson 1997; Moon and Williams 1993; Wilson 2002). A variety of sources for support were described such as respite care, geriatric assessment, institutional care, and social services. Social workers (Brownell et al. 2003; Wilson 2002) described themselves as support providers. Physicians (Krueger and Patterson 1997) and faith leaders (Podnieks and Wilson 2003) implied in their responses that they also considered themselves as support providers. However, Saveman and co-workers (1992) found that nurses did not trust their ability to provide support. Several sources of help were mentioned only by older person participants for example, banks, telephone companies (Moon and Williams 1993), schools, support groups, elected officials (Brownell et al. 2003), and family (Brownell et al. 2003; Moon and Williams 1993).

That family was listed as a source of support is paradoxical considering that “family” was specified in many of the reviewed article’s background, purpose statement, and/or method sections as the abusive dyad itself, i.e., older persons/care receivers and their care givers (cf. Anetzberger et al. 1996; Gebotys et al. 1992; Harrell et al. 2002; Weeks et al. 2004). Participants’ perceptions of “family” diverged from this description and included both the abusive dyad and a family system of potential support. Considering such perceptions it seems crucial to include not only the abused elder and the abuser in elder abuse research, but other family members as well. Through research with families, one can gain understanding of individual family members (e.g. in the role of witnessing abuse) (cf. Ericksen and Henderson 1992), and increase understanding of elder abuse in the family unit as well (Emery and Lauman-Billings 1998; Murray 1996). More explication on family relationships and elder abuse is required (Roberto et al. 2006). Yet the role of family is another area in elder abuse literature that needs further study. Database searches (PubMed, Sociological Abstracts, Cinahl, & PsycINFO search date: May 5, 2007) revealed only three studies examining elder abuse from a family perspective, (Drayton-Hargrove 2000; Greene and Soniat 1991; Hamilton 1989). Anetzberger and co-workers (1996) indicate that the focus of elder abuse research cannot remain centered on individual and intrapsychic considerations but must start to include cultural and family contexts.
Rationale for the thesis

Elder abuse is a complex problem (Anetzberger 2001; Anetzberger 2005), a problem that currently seems to defy definition. Definitional disparity is a hallmark of the field of elder abuse and is evident in the variety of existing elder abuse definitions. Differing definitions reveal many of the debated issues of abuse, for example which indicators entail increased risk for abuse. Risk indicators are constitutive elements that have guided development of elder abuse definitions and have been evaluated in expert literature to be validated, possible/plausible, or contested. This categorization of risk indicators does not match with those indicators perceived as significant by participants in previous research on potential witnesses’ perceptions of elder abuse. This raises the question of whether elder abuse should basically be considered a contested concept, i.e., a concept that is complex, evaluative, and sufficiently open-textured to sustain multiple, reasonable interpretations of what the concept values (Gallie 1956). While the search continues for an uncontested definition, perhaps the best method for understanding the term elder abuse is to follow Wittgenstein’s (1953) advice and learn from how it is used in the discourse of those who employ it. One way to find answers is to explore the perspectives and perceptions of experts, the general public, and involved persons. These perspectives and perceptions should be the foundation of any viable definition. Yet currently there doesn’t seem to be any definitions that have included perceptions of the people involved in elder abuse situations; a fact that casts suspicion on existing definitions.

How do experts’, the general public’s, and involved persons’ descriptions match or differ from descriptions of elder abuse as seen in existing definitions? Increasing knowledge of elder abuse perceptions through further research is crucial, especially in countries such as Sweden where elder abuse perceptions have barely begun to be explored. By examining perceptions and exploring what meaning situations of abuse hold for stakeholders, a more complete description can emerge and increase depth and nuance in the knowledge of elder abuse available today. It seems appropriate to investigate commonalities and differences in elder abuse perceptions and explore the interface of these perceptions and existing elder abuse definitions.
AIMS

The overall purpose of this thesis was to deepen understanding of elder abuse by exploring and comparing perceptions held by experts, older persons, representatives of potential support organizations, and family members.

The specific aims

• To examine and compare expert opinions from elder abuse literature on risk indicators and screening questions to perspectives of international elder abuse experts (I).

• To explore perceptions of elder abuse among older persons in Sweden (II).

• To explore perceptions of elder abuse among representatives of organizations considered as potential sources of help and support in Sweden in cases of elder abuse (III).

• To explore the experiences of witnessing situations of elder abuse within the family from the perspective of an adult family member (IV).

• To explore commonalities and differences in elder abuse perceptions in the findings of papers I - IV and elucidate elements essential to perceiving situations as elder abuse.
MATERIALS AND METHODS

Papers I and II were conducted within the framework of a larger project to develop a global strategy for the prevention of elder abuse (WHO 2002a). Papers II and III are twin studies in that they have the same basic aim and use the same sampling, data collection, and analysis methodology. The findings from paper II guided the choice of organizations represented by participants in paper III. Purposeful, convenient sampling procedures (Polit and Beck 2004) were used in all four papers (I – IV).

Table 1. Overview of papers I - IV

<table>
<thead>
<tr>
<th></th>
<th>Focus</th>
<th>Samples</th>
<th>Data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Experts’ perspectives on elder abuse risk indicators and screening questions</td>
<td>a) Elder abuse literature; grey literature &amp; published articles/books</td>
<td>a) Literature review</td>
<td>Manifest content analysis and descriptive statistics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b) 17 member Delphi panel representing 12 countries</td>
<td>b) Modified Delphi technique</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>Perceptions of elder abuse</td>
<td>Community dwelling, older persons (N = 37)</td>
<td>6 focus group interviews (2 groups each with women, men, and women + men)</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>III</td>
<td>Perceptions of elder abuse</td>
<td>Representatives from organizations considered to have potential support functions in elder abuse situations (N = 31)</td>
<td>6 focus group interviews where each group was made up of representatives from the same organization; police, Swedish Lutheran church, primary care, municipal eldercare, crime victim support, and a caregiver support organization</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Perceptions of being a witness to elder abuse in the family</td>
<td>Niece witnessing abuse involving her elderly uncle and his wife</td>
<td>Individual interviews</td>
<td>Narrative analysis and poetic re-transcription</td>
</tr>
</tbody>
</table>
Paper I

In order to locate risk indicators and screening questions searches were made in databases Medline, Cinahl, PsychINFO, ERIC, EBSCO, and Elsevier. Searches were also made utilizing the general internet search engine Google. A networking letter was disseminated to members of the International Network for the Prevention of Elder Abuse (INPEA) and World Health Organization (WHO) personnel in the Aging and Life Course unit. First, risk indicators were located and sorted by manifest content analysis in the identified sources from the literature search. Screening questions were also identified. Risk indicators were included in a questionnaire that was sent to a panel of identified elder abuse experts who had been located through INPEA and WHO. Panelists were asked to rate each item as low, medium, or high risk indicators of elder abuse. Screening questions were included in a second questionnaire.

The panel included 17 elder abuse experts (eleven women and six men) representing countries; Argentina, Austria, Brazil, Canada, Chile, India, Lebanon, Kenya, Mozambique, Sweden, United Kingdom, and the USA. Panel members represented various professional and academic fields including medicine (n = 4), nursing (n = 4), sociology (n = 3), social work (n = 3), psychology (n = 2), and health management (n = 1). Following Delphi methodology (Polit and Beck 2004) each panelist provided an initial response to questionnaires used in Round One. Responses were then analyzed both at the level of the whole panel and the level of the individual participant. In Round Two questionnaires were re-disseminated and an individualized feedback form was included that allowed for review of personal responses in comparison to responses of other panel members. In Round Two each panel member had the opportunity to change their initial responses after review. Those risk indicator items and screening questions rated highest by the entire panel were included in Delphi panel consensus lists. The Delphi process of multiple rounds (cf. Polit and Beck 2004) was modified due to project time constraints and the Delphi questionnaires were sent out for evaluation by panelists in only two rounds.

SPSS 11.0 was used for (a) a cluster analysis to compare responses between panel members in Round One and (b) descriptive statistics of both Round One and Round Two. Additionally, manifest content analysis was utilized in order to locate risk indicators most commonly found in the risk indicator references. An evident cutoff point occurred when a risk indicator was named in five or more references. The same procedure was done with screening questions. An evident cut-off point occurred when questions were named in three or more of references. The resulting lists of most commonly named risk indicators and screening questions were included in a literature review consensus.
Papers II and III

Community-dwelling older persons (63 years and older) were eligible for participation in paper II. Participants were located through telephone or e-mail contact with senior citizen organizations or by third-party contacts. Participants in paper III were recruited based on findings from paper II, i.e., older persons’ perceptions of where or from whom one would seek support in elder abuse situations. Local officials in six organizations were contacted verbally and provided with printed information about the aim of the study. These officials agreed to help arrange focus group interviews and were responsible for contacting and disseminating information on the study to probable participants, who in turn could choose to volunteer for participation. All participants in papers II and III were provided with both printed and verbal information about the project’s aim and method.

Data was collected through focus group interviews (Kitzinger 1995; Kreuger and Casey 2000). A topic guide with sample questions was available during the interview in order for the moderator to identify topics that had not yet been discussed and to direct participant dialogue to explore these topics. The moderator initiated discussion with the question, “What does elder abuse mean to you?” When needed, questions were posed on new topics or in order to encourage participants to further explore the context of elder abuse, types and causes of abuse, prevalence, and intervention. Interviews lasted approximately one hour, were audio-recorded, and transcribed verbatim.

The transcribed interviews were first read and re-read together with listening to the taped recordings in order to get a sense of the whole and distinguish common issues across interviews and specific tendencies within each group. Also noted were participants’ conversational interactions (Kitzinger 1994). Interviews were then analyzed using qualitative content analysis with continuous open coding (Berg 2001) and organization of the codes into categories. The third step involved examining the data for emerging themes, theme being understood as an underlying meaning through categories on an interpretive level (Graneheim and Lundman 2004).

Paper IV

Recruitment of participants for study IV was ongoing during 18 months. Efforts were made to spread information about the study and the possibility to be interviewed through many different channels, including: (a) dissemination of information brochures at conferences concerning family caregivers and dementia disease; (b) personal contact and dissemination of brochures to agencies for crime victim support, Kalmar County Administrative Board, and local acute care; (c) personal contact and dissemination of brochures to women’s shelters, and organizations concerning issues of dementia disease, caregiver support, as well as to senior citizen groups; and (d) personal contacts on a social level. One person, located through the fourth alternative,
was forthcoming and agreed to participate in individual, face to face narrative interviews.

The participant was a nurse educator in mid-life who described her experiences as a niece witnessing abuse situations involving her elderly uncle and aunt. The first interview was one and one half hours long. Sixteen months later a second interview was conducted by phone (approximately 45 minutes). Interviews were audio-recorded and transcribed verbatim. The first interview was initiated by reminding the participant of her earlier mention of elder abuse in her family. Further prompts were unnecessary. The second interview had a more conversational tone with frequent questions posed by the interviewer in order to broaden understandings of the first interview.

The next phase, the thematic structural analysis, proceeded through several steps of re-transcription of the interview as a whole alternating with detailed analysis of the parts using the following process.

1. Focusing on the poetic features of language (cf. Gee 1991) work with the prose transcription began by breaking every sentence into segments which carried with them an evocation to be paid attention to. In this manifestation the text was experienced at once as more open and alive with emotion and meaning.

2. In this open form a thematic analysis was begun by highlighting essential phrases, sentences and passages. Preliminary codes began to emerge.

3. The next step was identifying individual anecdotes in the text. In this study an anecdote is defined as a narrative episode with a point (van Manen 1997), i.e., a section of text with “entrance” and “exit” talk (cf. Poindexter 2002; Riessman 1993) containing a pivotal action or argument.

4. Inspired by the ideas of Labov and Waletzky (1967) each anecdote was chunked into four structural clauses; (a) the Prologue, (b) The Crux, (c) Considerations, and (4) the Epilogue (see Table 2).

5. Anecdotes were then transferred to a four-column table with each clause in a separate column. This structure allowed for both horizontal and vertical analysis of the text. Horizontally the text was analyzed anecdote by anecdote in order to determine the main focus of each particular anecdote and to reconsider and refine the preliminary coding, now bound and grounded in the contextual package of the anecdote. Vertical analysis allowed for comparison of the same type of clause across the entire interview. This proved to be especially fruitful in analysis of Crux and Epilogue clauses.

6. Threads of meaning linking codes led to organizing the codes into themes (cf. Graneheim and Lundman 2004). The structural analysis considered all codes and themes as grounded in single anecdotes, in light of each interview as a whole, and then in the two interviews taken together. This was repeated until agreement was reached between text, codes and themes, and no vital text was left unexplained by the analysis.
### Table 2. Structural clauses of the anecdotes

<table>
<thead>
<tr>
<th>Prologue</th>
<th>The Crux</th>
<th>Considerations</th>
<th>Epilogue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presentation of the problem and orientation.</td>
<td>The plot thickener.</td>
<td>Contemplating the situation/issue.</td>
<td>The results.</td>
</tr>
<tr>
<td></td>
<td>The sticky ingredient.</td>
<td>Reflecting over the action/decision.</td>
<td>The &quot;way it is&quot;.</td>
</tr>
<tr>
<td></td>
<td>The complicating action.</td>
<td>Making sense of the action/decision, possible results and consequences.</td>
<td>The &quot;way it turned out&quot;.</td>
</tr>
</tbody>
</table>

Findings in paper IV are presented both as quotes, codes and themes, and poetic representations. Guidelines used when creating poetic representations were that content, although drawn from anywhere in a single narrative had to reflect the narrative as a whole and be in the narrator’s own words. (cf. Glesne 1997; Poindexter 2002; Richardson 2002).

### Re-analysis of the findings in papers I - IV

The process of re-analysis was based on the findings in papers I - IV and focused on commonalities and differences across all four studies. Re-analysis began with a comparison of risk indicators and was initiated by locating indicators in papers II, III, and IV through a manifest content analysis. To facilitate comparison, risk indicators located in papers II, III, and IV were categorized and sorted into tables originally used in paper I. These were tables for general indicators, and tables for specific indicators for the abused, the abuser, physical abuse, sexual abuse, and financial abuse. This comparison of risk indicators also involved sorting risk indicators as indicators specific for the individual or abusive dyad, as indicators on the level of family, or as indicators on a societal level.

Based on the risk indicators and themes in each paper, the second step in the re-analysis was construction of vignettes that further clarified patterns of perceptions across the five samples; literature search consensus (Ia), Delphi panel consensus (Ib), older persons (II), professionals and volunteers (III), and the family member witness (IV). These patterns included who the abuser/abused were, what the abuser/abused relationship was, and why the abuse happened. This re-analysis process led to a synthesis of identified risk indicators and thematic areas shared by several papers and allowed for elucidation of risk indicators and themes as essential elements in the findings for perceiving situations as elder abuse.
Methodological considerations

Sampling procedures

Locating data and participants through written information proved to be ineffective as a data collection and recruitment strategy. This was most clearly demonstrated in papers I and IV. With the goal of gaining access to people who otherwise would have been difficult to identify (Polit and Beck 2004) a networking letter was disseminated asking recipients in turn to make referrals to other likely suppliers of data, so called “snowball sampling” (Polit and Beck 2004). Despite positive aspects associated with this, there were also potential risks, e.g. that we no longer had control or information on where the letter had been sent, or indeed if it had been forwarded. This concern was also an issue in the information brochure disseminated for study IV.

During participant recruitment for studies II - IV a major concern had been how to make the research as non-threatening as possible for potential participants. Therefore, although face to face recruitment is usually more efficient (cf. Polit and Beck 2004), an impersonal information brochure was used to encourage participants to take part in study IV. However this ethically defensible notion jeopardized many factors important for a successful recruitment. These factors include being persistent, providing incentives, and explaining research benefits to participants (cf. Polit and Beck 2004). Not knowing who finally receives a letter or brochure weakens efforts to re-approach and further encourage potential participants. It is also easier to “plead one’s case” about probable benefits of the research in person or by telephone rather than in a very short text. Explaining research benefits to participants is especially crucial when the only incentive offered for participation is in convincing someone that through their participation they would be contributing to information on which societal improvements could be based. The anonymity involved in a general dissemination of written material to likely participant populations may have played a role in participant recruitment in that anonymous requests might have been more easily dismissed as unnecessary extra work. Endorsement by respected organizations, usually a factor in successful recruitment (Polit and Beck 2004) did not seem to play a role in whether people responded to the networking letter (I) or information brochure (IV).

A limitation of the studies was the restricted sample sizes as seen in the number of participants on the Delphi panel (I), number of focus groups (II & III), and most noticeably in the use of a single case study (IV). This limitation naturally restricts the generalizability of findings. Although the number of persons who volunteered to participate in these studies was relatively small, it was balanced by representation of participants of different age ranges, geographical areas, socio-economic groups, professions, and areas of (past) employment. Considering the exploratory nature of the four studies in addition to a post-factum evaluation of the adequate quality of collected data and interview material, the use of purposive sampling techniques, i.e., seeking participants who would most likely benefit the aims of the study (Polit and Beck 2004), can be considered sufficient sampling procedures in the four studies.
Focus group methodology

The format for data collection in papers II and III was focus group interviews. This data collection method was selected for several reasons: (a) focus group interviews are considered to facilitate discussion of taboo subjects (Kidd and Parshall 2000; Polit and Beck 2004) and elder abuse is considered such a subject (Robinson 1999; Tatara and Kuzmeskus 1996); (b) focus groups provide opportunities to examine each group’s framework for understanding the world (Kreuger and Casey 2000); and (c) the conversational type of communication in focus group interviews helps the researcher tap into people’s knowledge and attitudes that often remain unexplored by more conventional interview methods (Kitzinger, 1995). In other words, focus group interviews can help reveal group meaning, consensus, or dissensus (Kitzinger 1994). Focus group interview technique is also thought to facilitate identification of areas of controversy and agreement, and understanding of how perspectives arise or are modified (Hollander 2004).

Participants within most groups were known to each other previously. This fact could have meant that the participants already had a shared system of values and similar opinions that might have limited the diversity and richness of the discussions. Conversely the fact that most participants within each group were known to each other could also have enhanced a non-threatening discussion atmosphere when faced with a potentially disturbing topic of elder abuse. That certain traditionally taboo areas such as sexual abuse were not discussed raises questions whether focus groups as a forum for discussion of taboo topics are truly successful. Repeated focus group interviews with the same participant groups or individual interviews would perhaps be more suitable interview techniques. One recommendation for further research is to conduct concurrent individual and group interviews.

Content analysis and anecdote analysis

After having utilized content analysis in two studies I was troubled by certain limitations of this method. First, the basic unit for interpretation, the codes, were grouped into categories from throughout the text with no consideration for where material was originally found in the (con)text. Secondly, categories are grouped and abstracted into themes across the whole material of the study, usually across multiple interviews, loosing the context of and in the individual interview. Although this process is a natural step when synthesizing results in a meta-analysis, the quest(ion) of lost context in interview studies such as papers II – IV was a dilemma. In these studies it was crucial to keep in constant and close dialog with material from each interview and as a part of the interview. Inspired by the works of Gee (1991), Labov and Waletzky (1967) and van Manen (1997) I developed an alternative, eclectic analysis method for paper IV. Here codes are bound and grounded in the original anecdote, gaining meaning from the surrounding text. Placing anecdotes and their clauses in a table allowed for both vertical and horizontal analysis and consideration of where codes and themes occurred in the interview. Paper IV was my first attempt at analyzing interviews with this method. I found it opened the text and created
opportunities for a deepened understanding of the narratives. This is a technique that I would like to develop further and that others might embrace in future inquiry.

**Poetic representation**

In paper IV findings were presented as poetic representations, so called data poems. Laurel Richardson (1992) is a pioneer in poetic representation. Rejecting the prose of traditional interview transcriptions, research data is instead transformed into poems. Poetry created from interviews can recreate embodied speech through employing devices such as rhyme, alliteration, line length etc. Poems convey meaning and commend themselves to open, multiple meanings in a way that prose, themes, or facts cannot (Richardson 1992). The resulting poem in its simplicity and power make the account more compelling (Poindexter 2002). This process of poetic re-transcription of interviews likens the process involved in crystallizing a core story from a text. Reading and writing poetry is extremely personal and it is also a personal issue to examine poetry for scientific veracity. In poetic representation the possibility of combining positivistic standards of rigor with qualitative methodology becomes problematic. One must not only trust the researcher but accept the findings into one’s soul. Richardson (1992) calls this an embodied activity. Although the methodology of poetic re-transcription may be forever doomed to dwell in a grey zone of traditional trustworthiness, interviews like the ones in paper IV cry to be expressed through poetry with a veracity felt in the heart.

**Rigor**

Rigor must be recognized while balancing “…between the genius of guessing and the scientific character of validation” (Ricoeur 1976, p. 79). This relationship between guess and validation is threatened by the risk of self-confirmability. It is at this point researchers must use the logic of probability that leads to emphasizing one interpretation before others. However, even if there are many ways of construing a text, not all interpretations are equal (Ricoeur 1976). With this in mind it should then be a prompt to researchers to make their choices explicit by discussing and motivating their chosen interpretations. Such were the aspirations in this thesis.

Accepting findings in qualitative research often requires the research consumer, peer reviewer, or editor to take the leap of faith necessary to accept the multidimensionality and the multiple meanings of words, even rigorous ones, and trust the researcher to be a representative for trustworthiness of their findings. Qualitative findings are often dependent upon the researcher’s intuition, understandings, as well as empathetic interviewing techniques. Morse and co-authors (2002) have instead emphasized the importance of verification strategies, defining verification as, “…the process of checking, confirming, making sure, and being certain [italics added]” (Morse et al. 2002, p. 9). These authors plead repeatedly that verification strategies be used to shape and direct the research development. In addition, prospective qualitative researchers are instructed to think theoretically as a strategy of verification. “Thinking theoretically requires macro-micro perspectives, inching forward without
making cognitive leaps...[italics added]” (Morse et al. 2002, p. 13). A key dilemma in qualitative research is the difficulty in demonstrating rigor by making visible the cognitive steps of interpretation that the researcher creates during the course of an investigation. However we have no full-proof method that proves rigor by following the lively intellect of an individual researcher. Tracking the footprints of cognitive leaps would not in any case reveal what the researcher jumped over or why. Following Ricoeur (1981), rigor and the validity of an interpretation rest on making the best case for one’s conclusions. In making sense out of apparent discordant diversity the construction can take the form of a wager (Ricoeur 1981). It is hard to fuse this notion with Morse et al’s (2002) prohibition on making cognitive leaps and their admonition of “making sure, and being certain”.

Findings in this thesis are not presented as the truth that indisputably withstands tests of time and rigor. Rather, these findings are presented as one way to view the material, one way that will hopefully engage the reader not only in scientific but also in personal reflections, encouraging each reader to dig into their own perceptions, and, hopefully, taking a stand. I would charge that the validity of qualitative research lies in having the power to engage the reader and move the reader to personal reflection. If qualitative research cannot achieve reflection in the reader it is not important the method was followed meticulously, or that one can argue one’s points in contrast to earlier research. Qualitative research needs to move beyond an inexorable rigor to confidence in findings that entreat an exorable reader. Those are the readers I seek to reach with my research.

**Ethical considerations**

The papers are based on voluntary participation by informed persons. Ethical approval of studies II and III were given verbally by the chairman of the Research Ethics Committee at the Medical Faculty, University of Linköping. A written application for study IV was approved by the Regional Ethical Review Board in Linköping (registration number 188/04).

Privacy and security were primary concerns in this research. This was especially important in planning study IV and a safety protocol for that project was developed. Preparations were also made in case an unusual situation arose where a participant required or requested help to deal with his/her emotional response to interview content (II - IV). Planned interventions included receiving support from the research team and if necessary assisting the participant in making contact with the psychologist linked to the project. None of the participants has contacted the research team to seek help or to report any adverse reactions to subject content or investigation style. On the contrary, comments from participants following the interviews have indicated that they felt this research was needed and timely. Despite the risk that interview questions might cause feelings of uneasiness, there was deemed to be a greater potential for beneficence that outweighed the risks by providing participants with the opportunity to tell their stories in an open and encouraging environment. There are many sources that report that the very act of telling one’s story is in itself an emancipating
experience that provides opportunities for healing (cf. Anderson and Hatten 2000; Mishler 1986; Polkinghorne 1986). There is also a potential for beneficence that lies within the expanded knowledge base these studies provide which, in turn, could expedite care of individuals and families living abusive situations.

There are also ethical implications when gathering participants in order to discuss a possibly threatening topic. Precautions to protect participants were taken such as, options for declining participation, being able to leave during the interview, insuring confidentiality, and, as named above, providing access for post-interview support. However, it is impossible to know whether any participants felt that they were pressured into participation. Based on findings in paper IV there is an additional and very important point to consider when planning future elder abuse research interviews, i.e., that participants perhaps suffer from shame and may experience the interview as blaming, thereby increasing shame. This consideration is not to negate the positive aspects of being interviewed that were mentioned above. Research interviews are surely opportunities for participants to find release and insights. Rather, researchers must keep in mind the possibility of shame in elder abuse witnesses, and not lose sight of this potential predicament while interviewing.
FINDINGS

Experts’ perspectives on elder abuse (I)

There were 565 risk indicators located through the literature search. Forty-eight risk indicators were located in five or more sources and were included in the literature review consensus (see Appendix C, Tables C1-C4). Many risk indicators were similar and were combined into one item before inclusion in the Delphi risk indicator questionnaire (263 items). The 42 most popular risk indicators selected by the Delphi panel were included in a consensus list. There were 67 screening questions identified that were included in the Delphi screening question questionnaire. Thirteen out of the 67 screening questions were located in three or more sources and included in a literature search consensus list. The Delphi panel agreed on nine screening questions that were included in a consensus list (I).

The consensus list of risk indicators selected by the experts on the Delphi panel and those most commonly named in expert literature shared 35% content. Consensus lists of screening questions from these two sets of experts were dissimilar. Questions in the literature search consensus were general and indirect with sexual abuse implicit in question phrasing. In contrast the Delphi panel experts selected direct questions and included an explicit question regarding sexual abuse. Within the panel there were differences between the risk indicators and the screening questions selected by panel members who represented developing countries as compared to those members representing developed countries. Cluster analysis of responses from Round One revealed that participants from developing countries answered very similarly to one another. Participants from developed countries responded similarly to each other as well.

Older persons’ perceptions of elder abuse (II)

Elder abuse was considered taboo, unacceptable and an invisible problem by the older persons. Ageism in society was an intrinsic topic in all focus group discussions. Causes of elder abuse included changes in society and family structures, and individual characteristics such as substance abuse in the abuser and the behavior of the abused elder. Conceptions of elder abuse were primarily discussed as either, (a) physical and psychological abuse perpetrated through robbery and crime against elders or as (b) abuse on a societal level with human rights issues as the focus. Participants considered curtailment of the older person’s autonomy as elder abuse, especially lack of autonomy in eldercare. Abuse was also described as “technological abuse” against older persons who can’t keep up with new technology (e.g. internet banking). Neglect, financial abuse, and domestic violence were seldom named and sexual abuse was never discussed despite prompting from the interview moderator. A general lack of respect for older persons was discussed both as a cause and a type of abuse. Abusers were described as strangers, often youths in gangs, or as healthcare personnel.
Consequences of elder abuse were almost exclusively a woman’s discussion topic and mainly involved fear; fear of being attacked or robbed, and fear of reprisals from the abuser if one were to witness against an abuser. Women discussed how this fear resulted in refusing help from strangers and changed patterns of living. Women also expressed beliefs abusers would feel remorse and guilt at their actions. Coping with elder abuse included individual strategies, improvements in society, and victim support. Participants discussed how it was the abused person’s own responsibility to avoid abuse or seek help. Witnesses’ reluctance to get involved was also described. Friends and family were spontaneously discussed as possible resources for support. Other suggestions of where to turn to in society for support were sparse and provided only after interviewer prompting. These support services included police, seniors’ organizations, district nurses, volunteers, and clergy. Education for both healthcare personnel and children was repeatedly discussed, especially as a way to eliminate ageist attitudes at the heart of elder abuse.

Gender differences were evident in discussions and topics. For example men’s discussions were mainly on the level of society’s responsibility for elder abuse while women’s discussions were generally on the levels of the family and individual within a social context. Ageism was implicit in women’s conversations but an explicit subject in the men’s comments.

Professionals’ and volunteers’ perceptions of elder abuse (III)

Although professionals and volunteers discussed elder abuse from the position of their respective organizations, analysis revealed a preponderance of shared perceptions between groups. There was a tendency toward ageism among participants, discussing older persons not as individuals but as a population group with group attributes. No gender differences could be noted between male and female participants in their responses. A descriptive framework of elder abuse was developed which included a limited number of risk indicators (see Appendix C). Context-free abuse and intentional harm, as well as context bound abuse and unintentional harm were described. Elder abuse was described as something “wrong”, “that shouldn’t happen” and as any violation of the older person.

Crime was discussed as physical and psychological abuse, resulting in elders becoming fearful. Physical abuse was also described as perpetrated by eldercare personnel and by spouses, often with the husband as the abuser. Examples of wives abusing their husbands always involved a caregiving context. Sexual abuse was mentioned as men raping their handicapped wives or as healthcare personnel performing services that could be experienced as sexual abuse. Neglect and financial abuse were also discussed. Social service agencies were identified as having a central role in providing support. Most groups considered themselves as potential providers of support although the police described their role as only pertaining to criminal cases of abuse.
Participants described situations that despite good intentions resulted in situations considered abusive. Especially nurse participants described situations of being conflictual. These were situations with pressure from their surroundings to act in one way and their consciences and/or professional ethics telling them to act in a different way. Participants discussed how situations create abusers and anyone can become provoked enough to “cross the line”, expressing the belief that abusers can experience themselves as victims of circumstances in situations that become abusive. Participants discussed abusive actions as acceptable when part of care provided for the good of the older person. Participants described situations where abusive actions were considered necessary in order to set limits for an older person’s “unacceptable” behavior. Participants also described balancing between feeling the need to force help on the older person and letting elders decide for themselves what services they want and can accept.

Participants discussed how older persons themselves carry responsibility for elder abuse situations. They voiced victim-blaming sentiments indicating that abuse could at times be the older persons’ fault, both in individual situations as well as at a societal level. Participants expressed frustration with abused elders’, family members’, and witnesses’ hesitancy to get involved and failing to report elder abuse which was attributed inter alia to experiencing guilt and shame. Participants expressed the belief that family members fail to report abuse in eldercare settings fearing staff reprisals. Ageism and lack of knowledge among healthcare personnel were other contributing factors in failing to report abuse. All groups described frustration with reporting procedures. With the exception of two groups in healthcare, confidentiality was thought to be a major obstacle to reporting and preventing further elder abuse.

A variety of suggestions for preventing elder abuse were described including changing attitudes toward elders, and correcting problems in the healthcare system. The role of education and verbal communication was emphasized. Meetings between generations were proposed as a way to increase understanding across the generation gap. The need to educate children about ethics, morals, and respect for older persons was identified. The need for supporting and educating both personnel and family caregivers was discussed, as well as the unavailability of education and supervision for healthcare personnel.
Family member’s perceptions of elder abuse (IV)

The family member witness, Lisa, was the niece to an 88-year-old man caring full time at home for his wife, six years his senior. His wife suffered from dementia disease but was not formally diagnosed. Although Lisa tells of not seeing, only “suspecting” abuse, her narrative contained several explicit descriptions of abusive behavior. Lisa described her uncle and his wife in conflictual terms, positive as well as negative (for example see Figure 1). Lisa described feeling powerless and immobilized; fearing that any action would be positive for one family member in the abusive dyad but negative for the other. The family member witness felt her personal relationships were hanging in the balance since both options of being passive or taking action led to someone in her family getting hurt. Lisa felt sorry for both her uncle and aunt and considered both as needing support. She expressed repugnance at the thought of intentionally offending anyone and especially tried to avoid offending her uncle, since this would lead to him breaking contact and shutting her out of the couple’s lives. Lisa felt she would be betraying her uncle if he found out that she had sought help and talked about him behind his back. Instead she tried to handle the situation herself by finding legitimate paths of communication with her uncle via giving good advice and counseling. Lisa longed to be offered support she could trust, that would be helpful, and that would allow her to maintain her relationships within the family. She tolerated escalating abuse of her aunt in order to protect her uncle. Lisa also described healthcare personnel as tolerating the situation, seeming either not to see the abuse or to accept it as part of a demanding caregiver situation. Lisa felt that healthcare personnel exploited the principles of patient autonomy and self determination as excuses to avoid having to provide care.

The family member witness Lisa described situations of shame. She related how she often felt marginalized by both health/home care personnel and at times even by her uncle. Her continual offers to her uncle to help were consistently refused. She said it was as if she was “on the outside looking in.” The family member witness described how she would not be able to look herself in the mirror if she intentionally harmed anyone, gave offence, or violated personal rights. She repeatedly described how she knew what she ought to do and how she felt she was not living up to her ethical ideals about how she should act; as a niece, nurse, or human being. She described the reverse however for her uncle whom she considered to be utilizing the caregiving situation in order to finally be appreciated by others and to feel pride in being “good enough.” Only after the abusive situation was resolved and the aunt was placed in residential care where the personnel were described as non-judgmental and understanding did the family member witness gain perspectives on her own previous (in)actions. She had been trapped by her loyalty to family, her desire to protect family, and a deep shame that this was her family.
THE UNCLE

He does an unbelievable job
It’s inhuman that one should do what he does
The kindest uncle that ever was

He has wanted to take care of this
He is 88, six years younger than her
He lives with her 24 hours a day
He never gets out of there
He is so tired
Alone and forlorn
When he gets tired
He doesn’t take care of her
In the way she actually needs
He can be very hard-handed

He does an unbelievable job
It’s inhuman that one should do what he does
The kindest uncle that ever was

But these days he buys a little wine
And then he drinks too much
And goes to sleep
And she lays there
Wet with urine and hungry
And doesn’t get the care she wants
Then she gets worked up
Jumping about and screaming
Kicking, making a scene
He goes crazy then

He does an unbelievable job
It’s inhuman that one should do what he does
The kindest uncle that ever was

After these episodes I think is
When I have seen the bruises
Bruises that were from fingers

(But then it is old skin
She has an easy time bruising)
He has always been patient
Incredibly patient
No one I know would put up with this
For so long
I would never be able to do it

Figure 1. Poetic representation from paper IV.
Synthesized findings from papers I – IV

Risk indicators were a common finding in all four papers (see Appendix C, Tables C1–C4). General indicators were fairly evenly distributed between samples/participant groups. Risk indicators from papers II, III, and IV predominated in the category “indicators specific for the abused”. The reverse was seen in the category “indicators specific for the abuser” where samples from paper I predominated. It was predominantly risk indicators from paper I in the list for indicators of physical abuse and exclusively from paper I in the brief lists of risk indicators for sexual and financial abuse. Risk indicators in papers I - IV were either on the level of the individual/dyad (e.g. “Poor past relationship/poor current relationship”), the level of the family, (e.g. “History of family violence”), or on a societal level (e.g. “Too little time for healthcare personnel to provide care”). Differences could be discerned when comparing general risk indicators between the five samples; literature search consensus (Ia), Delphi panel consensus (Ib), older persons (II), professionals and volunteers (III), and the family member witness (IV). Findings of papers I - IV varied between seeing elder abuse primarily as a human rights issue (II), on the level of larger systems (III), as due to individual characteristics and the dyadic relationship (Ia and IV), or within the family arena (Ib)(see Figure 2).

**Figure 2.** Comparison between samples concerning percentage of general risk indicators of elder abuse on an individual/dyad, family, or societal level named or located in the data.
Four risk indicators were endorsed by all five sample/participant groups. Three were risk indicators specific for the abused, namely confusion (dementia disease), isolation of the elder, and physical impairment of older adult (see Appendix C, Table C2). One general risk indicator was endorsed by all the samples/participant groups; “Poor past relationship/poor current relationship (issues of power, control, coercion, dominance, or manipulation)” (see Appendix C, Table C1). No risk indicators were named in all samples/participant groups that were specific for the abuser or specific types of abuse.

Patterns of perceptions, opinions, and perspectives on elder abuse were noticeable in the four papers. These patterns were exemplified in the vignettes constructed from findings of each paper (see Figure 3). Vignettes revealed several similarities between the five samples/participant groups. These patterns included victim blaming sentiments and opinions that the situation creates the abuser. Both parties in the dyad were considered at fault and both in need of support. Differences between vignettes were whether the abuse was described as due to power imbalances in the dyad (Ia, Ib, and IV) or on a societal level (II and III). Additional thematic areas that were as red threads in the findings included issues of lack of respect of older persons/ageism, tolerance of elder abuse, seeing the abuser as a victim of circumstances, and shame.
Figure 3. Vignettes of elder abuse constructed from the findings in papers I – IV.
DISCUSSION

Discussion of the findings will proceed through four steps. First, findings will be discussed that are specific to one or two of the papers and that are relevant and interesting when viewed in light of other elder abuse research. These findings include gender issues, reporting abuse, and potential support in society. Second, comparisons of risk indicators in all four papers are discussed. Third, essential elements in perceiving situations as elder abuse revealed in the synthesis of the findings are addressed, closing with expanded reflections on elder abuse in connection to shame, power, and compassion. Finally, we return to the subject of defining elder. Based on the findings in each paper, synthesized findings of all four papers and reflections on the findings, several alternative descriptions of elder abuse are presented and an “anti-definition” of elder abuse is proposed as a challenge to current elder abuse definitions.

Discussion of specific findings (I – IV)

Several issues in the findings of papers II and III can be found in other elder abuse perceptions research. Examples include describing elder abuse as “wrong” (cf. Hudson 1994; Saveman et al. 1993; Saveman et al. 1992), involving disrespect of older persons (cf. Brownell et al. 2003; Hudson 1994), and leading to fear, especially fear of reprisals (cf. Krueger and Patterson 1997; Limandri and Tilden 1996). Perceptions often espoused by participants in papers II and III were that a cause of elder abuse is changing, modern society, and changing family systems. These perceptions were connected to participants’ suggestions for better rearing and education for children and youths that would teach them respect for older persons. Although not found in the reviewed perceptions articles, countering ageist and negative attitudes among the young has been promoted as a way to prevent elder abuse (McGuire and Gerber 1996). Even though attempts to change ageist attitudes would most likely require considerable time it seems to be the single most viable way of curtailing societal abuse.

As in previous perceptions research (cf. Weeks et al. 2004; Wilson 2002), participants (II and III) most often named men as abusers and those abused as women. Women as abusers were mentioned in connection to abusive actions taken during caregiving. This finding is interesting since the two major contexts for elder abuse discussed in both papers II and III were crime situations and care provision contexts such as healthcare. Since a minority of direct care providers are men two hypotheses can be put forward, (a) most male care providers are also abusers, or (b) contexts of elder abuse where males are the abusers were not discussed, e.g. elder abuse in the family. The family as a context for elder abuse was an extremely restricted area of discussion and frequent comments were made concerning resistance to getting involved in the private sphere of other people (II and III). These discussion patterns might have been
due to focus group format. Perhaps crime and healthcare were more socially acceptable topic areas for group discussion than things that go on behind closed doors.

Among participants groups, the older persons (II) showed strong gender differences in what and how topics were discussed. For example it was older women who discussed coping with elder abuse twice as much as older men in the focus groups. However, despite methodological preparedness in the study design (II), these gender differences were still only an incidental finding and not an investigatory aim. Gender differences were not noticeable in the twin study where participants discussed elder abuse as representatives of their respective organizations (III). It is not unlikely that gender differences might also have been discernable among professionals and volunteers in a study designed to include separate groups of men and women from each organization. Such a conjecture finds support in earlier perceptions research among adults (Childs et al. 2000; Weeks et al. 2004) that has shown marked differences not only in how elder abuse is perceived by women and men, but also that the participants’ age was an important factor. For example, more females than male professionals detected abuse (Weeks et al. 2004) and middle-aged women were less willing to report elderly abusers than middle-aged abusers (Childs et al. 2000). These findings can be viewed in relation to two other issues, (a) elder abuse is often detected in healthcare settings (American Medical Association 1992; Aravanis et al. 1993), and (b) front line healthcare workers are often women. These two factors in combination with the above named research results (Childs et al. 2000; Weeks et al. 2004) exposes obvious concerns for detecting elder abuse. Further research seems appropriate in regard to gendered analysis of elder abuse perceptions related to detection and coping with abuse.

One issue where there was a discrepancy between perceptions held by different groups, was seen in perceptions of professional confidentiality. Professional confidentiality was brought up by four of the six focus groups in paper III as well as in earlier perceptions research (cf. Podnieks and Wilson 2003; Saveman et al. 1992) as a major barrier to reporting and providing support. It is noteworthy that although it is within healthcare that the strictest rules of confidentiality apply, the two focus groups from healthcare in paper III did not mention confidentiality. As in earlier perceptions research (cf. Brownell et al. 2003; Krueger and Patterson 1997; Moon and Williams 1993; Podnieks and Wilson 2003; Saveman et al. 1992; Wilson 2002) there was also a difference between what older persons (II) and professionals and volunteers (III) perceived as support in cases of elder abuse. While older persons (II) spontaneously named only family and friends, participants in paper III considered themselves as potential support providers. One critical difference between these two studies was that all groups in paper III considered social services to be the most important support authority while older persons (II) never mentioned social services. This discrepancy between perceptions held by those potentially needing support and those potentially providing support could have far reaching repercussions in help seeking and intervention efforts. An initial step would be to examine the issue further with older persons and see what this “mis-perception” may be due to. Another important area for future research is to explore perceptions among social service
workers and compare these to perceptions held by older persons, other professionals, and volunteers. Investigating both the issue of confidentiality and awareness of support provision are needed areas in future elder abuse research.

Dilemmas in connection to reporting elder abuse were most directly addressed in paper III. Participants experienced frustration at abused elders’ and their families’ hesitancy to get involved or report abuse. Professionals and volunteers also expressed dissatisfaction with unclear and inefficient reporting procedures. In addition self-critical opinions were expressed about ageist attitudes among healthcare personnel together with a general lack of knowledge of elder abuse. Older persons (II) also stated difficulty getting involved in the private sphere of other people and described not reporting as part of self-protection. These problems of lack of knowledge and families not reporting are echoed in earlier perception research articles (cf. Limandri and Tilden 1996; Podnieks and Wilson 2003; Saveman et al. 1992). A common solution suggested both in papers II and III as well as in earlier research was increased education for healthcare personnel (Grafström et al. 1993a; Krueger and Patterson 1997; Limandri and Tilden 1996; Saveman et al. 1992). This solution seems logical and necessary. Keeping in mind findings from the study with the family member (IV) it can nonetheless be questioned whether receiving education will be a sufficient measure in morally demanding situations of elder abuse. For the family member witness (IV) issues of shame and powerlessness were predominant. Although knowledgeable on elder abuse and cognizant of ethical directives these were not paths she chose to follow.

Several findings in paper IV were not found in any other paper, for example that the family member witness longed for support, but did not feel she could talk to anyone since this would have meant betraying her uncle. She also expressed strong feelings of loyalty toward her family indicating her desire to protect the family. This situation put her in a position of feeling powerless, and locked in a position of passivity. She also saw the abusive situation as a direct result of an overwhelming caregiving situation. In this situation she did not view her uncle as an evil perpetrator and felt sorry for both her aunt and her uncle. What is interesting here is that these findings are very similar to those Saveman and co-workers (1992, 1993, 1996) found in their research among district nurses in Sweden. District nurses related feeling powerless, paralyzed by conflicting loyalties, and balancing between active and passive strategies (Saveman et al. 1992). These district nurses also connected elder abuse to overwhelming caregiving situations, pitied both parties in the dyad, and did not view the abuser as a villain (Saveman et al. 1993). Nurses have also been reported to have a “wait and see” attitude passively watching until abuse escalates to a dangerous level before intervening. Nurses report wanting to be sure, and not wanting to risk causing more harm (Limandri and Tilden 1996; Saveman et al. 1996; Saveman et al. 1992) which is also what the family member witness (IV) related. Was the family member witness responding as nurse, a woman, a family member, or all of these? Were the nurses in previous perception articles (Limandri and Tilden 1996; Saveman et al. 1996; Saveman et al. 1992) responding as nurses or as women in caring positions? These are intriguing questions that invite further research. The important point is
that the family member witnesses (IV) as well as potential support persons seem to share a need for support, not seeing the abuser as a bad character, and having a tendency to wait until sure before taking action. There are clear risks for the abused older person caught in the middle between two such passive agents. Provocatively it can be asked who the actual abusers are; the overwhelmed caregiver or the passive onlookers? This is a key issue for healthcare personnel and other support persons to be aware of when meeting family members potentially involved in abusive situations.

Comparison of risk indicators (I – IV)

With the exception of the risk indicator “shared living arrangements”, findings from papers I - IV supported the validated risk indicators listed in the National Research Council (2003) report. There seems to be some support for the risk indicators considered possible/plausible as well. With the exception of intergenerational transmission of violence, risk indicators considered contested in the National Research Council report were supported as much or more in the findings of papers I - IV as risk indicators considered validated in the National Research Council report. A similar pattern was evident in the perception articles reviewed earlier in this thesis. In the reviewed perceptions articles witnesses or potential witnesses to elder abuse discussed possible/plausible and contested risk indicators as much or more than indicators considered to be validated by evidence. Was this due to lack of knowledge among participants in the reviewed articles and in papers I – IV or is emphasizing quantitatively measured risk indicators (cf. Lachs and Pillemer 2004) a misguided analysis of elder abuse? As constitutive elements in elder abuse definitions risk indicators not only steer research initiatives but also policy and legislation. Yet it is most likely our perceptions that guide our actions when valuing these risk indicators and interpreting definitions and legislation. There is an apparent void between these two approaches when building an understanding of elder abuse. We are left with the question of which approach, perceptions or “evidence”, should have preferential right of interpretation in determining the viability of risk indicators as markers for an abusive situation.

There was also a notable diversity shown in the risk indicators between sample/participant groups. This diversity was especially conspicuous when considering risk indicators on the level of individual/dyad, family, or society. These findings of risk indicators on different levels are indicative of where each sample considered the main focus of the problem of elder abuse to be in society. Older persons (I) for example mentioned few risk indicators on the level of the individual/dyad and discussed elder abuse primarily as a societal human rights issue. Professionals and volunteers (III) named twice as many risk indicators on a societal level and discussed the role of larger systems in elder abuse situations. The family member witness (IV) and the risk indicators from the literature search consensus (Ia) were the most alike in that both focused on the individual/dyadic levels, while the Delphi panel (Ib) chose indicators in the family arena. Since exploring this issue was not included in the investigatory aim of the papers it can only be hypothesized why this was so. One thing is clear. It would be extremely problematic to address this diversity of
perceptions in public information campaigns or educational efforts. Yet it was exactly such campaigns and programs that were suggested as ways to address elder abuse both by participants in this thesis (papers II and III) as well as by participants in previous elder abuse perceptions research (cf. Krueger and Patterson 1997; Limandri and Tilden 1996; Saveman et al. 1992). These diverse perspectives are also indicative of the difficulties of being able to form one denotative elder abuse definition, unless one perspective is considered to have the correct interpretation and voices of other witnesses are disqualified.

Definitional difficulties are increased further by lack of research on elder abuse on a family level. In the reviewed perception articles researchers have often restrictively defined “family” as the caregiver (abuser) and care receiver (the abused). But as is pointed to by the many risk indicators on the level of the family (I - III), and made especially clear in the findings of paper IV, family members play an important role in the dynamics of the elder abuse situations with the power to expose or keep the abuse hidden. Research focusing the family as a unit could be a key area to further understand elder abuse.

**Essential elements of elder abuse**

*Endorsed risk indicators and thematic areas*

There were four risk indicators found in all five samples/participant groups that can be considered in these findings as essential elements when perceiving situations as elder abuse. Three indicators, specific for the abused, were confusion (dementia disease), isolation of the older person, and physical impairment of the older adult (see Appendix C, Table C2). One general risk indicator was endorsed by all the samples and participant groups in the findings; “Poor past relationship/poor current relationship (issues of power, control, coercion, dominance, or manipulation)” (see Appendix C, table C1). These four endorsed constituents describe elder abuse as a relationship with issues of power between two parties where the abused has no support system (isolated), is no longer mentally competent (no longer autonomous), and is no longer able to defend him- or herself physically (vulnerability). Other issues in the findings that can be considered as essential elements of elder abuse include lack of respect/ageism, victim blaming, tolerance of elder abuse, seeing the abuser as a victim of circumstances, and shame. Each of these areas will each be addressed, ending with reflections on the issues of shame, power, and compassion in connection to elder abuse.
...elderly men are less apt to make friends in proportion as they are harsher in temper, and take less pleasure in society; for delight in society seems to be, more than anything else, characteristic of friendship and productive of it. So young men are quick to make friends, but not old men (for people do not make friends with those who do not please them), nor morose men.

Aristotle, Nichomachean Ethics, (p. 176)

**Emotions in older persons and isolation of the abused older person**

It was apparent in the findings (I – IV) that emotions, e.g. shame, are a central issue in elder abuse. Yet affect research in the domain of later life is generally lacking (Gross et al. 1997). Researching affects is considered difficult in adults since affects can be radically transformed during maturation (Gilbert 1998). Gross and co-workers (1997) found that older persons experienced fewer negative emotional experiences than younger individuals. That older persons experienced fewer negative emotional experiences was not because of physiological reasons rather was due to older persons selectively managing their emotional experiences. Despite the fact that later life is otherwise associated with decreasing abilities and often ill health, there are indications that older persons can more effectively regulate their emotions. As far as emotions are concerned, it is suggested that aging can be associated with greater gains than age-related declines (Gross et al. 1997). Some have suggested that the regulation of emotions is managed by older persons through restricting their social networks of friends and family to emotionally satisfying interpersonal situations (Carstensen 1992; Carstensen 1995).

This picture of how older persons manage their social networks is intriguing. Yet there are several concerns when comparing this idea to the finding that “social isolation” as a risk indicator for elder abuse was endorsed by all participant groups in papers I - IV. One wonders what happens in situations where someone other than older person is making the choice of who is included, or more importantly excluded from social interaction with the elder. What happens in situations where the existing social network is so small that the older person has no possibility of selecting or choosing among candidates to involve in an emotionally satisfying situation? What happens when the abuser is the older person’s only “interpersonal situation”? Connections between elder abuse and how older persons manage their social networks is yet another area inviting further research.

**Issues of autonomy and vulnerability**

Participants (II – IV) described difficulties in keeping a balance between forcing help on older persons “for their own good” and letting older persons decide for themselves how much assistance they desired. The prime directive of the Swedish Health and Social Service Act is to respect the autonomy and integrity of each individual patient (Ministry of Health and Social Affairs 1982). This directive creates the dilemma of who has the preferential right of interpretation for patients with cognitive handicaps. This dilemma also occurs in issues of vulnerability. Who has the right to determine vulnerability and at what point does the vulnerability of a patient require that
personnel step in and take over? This dilemma was discussed by participants (II, III, & IV), e.g. the right of the patient to maintain their own personal standard of hygiene when refusing to take a shower. Autonomy was described as a right that was jeopardized when older persons are forced to accept care in nursing homes (II). On the other hand the principle of autonomy was also discussed as being exploited by personnel as an excuse not to provide care (IV). Such paternalistic behaviors have been described as “the belligerence of beneficence” (Rich 1996, p. 76). When does paternalistic belligerence equal elder abuse and not beneficence? This moral predicament is at least clearer when cognitive decline is not part of the picture. Describing nursing homes as the twilight of elderly autonomy, Rich maintains that new attitudes toward aging and rights of older persons are needed that support individual personhood and freedom to take risks, take chances (Rich 1996). The question is whether these new attitudes would be perceptions that would increase or decrease elder abuse.

**Victim blaming, the abuser as a victim**

Victim blaming sentiments and viewing the abuser as a victim of circumstances were evident in the findings (I - IV) and can be seen in the vignettes constructed from papers I - IV (see Figure 3). Participants described the victim as sharing responsibility for the origin of abusive situations and that as a consequence the situation created the abuser (II, III, and IV). Victim blaming sentiments could also be seen in the screening question consensus lists (I). A review of the risk indicators in the findings of all four studies shows the same tendency. Well over half of the risk indicators specific for the abused could be considered as victim blaming (for example “substance abuse” and “physical impairment”) (see Appendix C, Table C2). Victim blaming perceptions have also been reported in other elder abuse research, both in the views of older people (Minichiello et al. 2000; Moon et al. 2001), caregivers (Grafström et al. 1993a; Grafström et al. 1993b), and personnel providing support (Brownell et al. 2003). Risk indicators specific for the abuser show evidence of viewing the abuser as a victim of circumstances, for example in “lack of resources” and “forced by circumstances to provide care” (see Appendix C, Table C3). Regarding the abuser as a victim of circumstances is a recurrent theme in most elder abuse literature due to the “needy care receiver” and “overburdened caregiver” perspective prevailing in the existing elder abuse paradigm. One danger inherent in holding a victim blaming/abuser as a victim of circumstances perspective is that it leads to an ambiguity in assignment of responsibility, i.e., laying blame.

**Ageism and tolerating elder abuse**

Further complicating the situation are perceptions of ageism in society. Older persons (II) saw ageism as both a cause of and a type of abuse. Professionals and volunteers (III) agreed with this idea while simultaneously expressing ageist attitudes themselves. Such perspectives, also evident in other research (cf. Minichiello et al. 2000), easily move witnesses to a position of status quo of toleration and/or not viewing the situation as elder abuse. If this is true, witnesses, while naming the situation abusive, will perhaps avoid taking action or making the situation known, for example through
reporting. This predicament was also apparent in findings in this thesis (II, III, & IV) as well as in previous research (cf. Moon et al. 2001; Nahmiash 2002; Saveman et al. 1993; Saveman et al. 1996; Saveman et al. 1992). The stalemate position of seeing the abuser as a victim while blaming the abused provides a key to understanding why elder abuse remains a “hidden” problem. Do witnesses simply not see the situation as abuse? Or do witnesses hesitate since the requirement of culpability cannot be met? Indeed, if one considers oneself a potential abuser as did the participants in paper III, it is likely one would be less inclined to acknowledge the situation openly. Ageism, victim blaming, seeing the abuser as a victim of circumstances, and the resulting potential for tolerating elder abuse are issues that must be better understood. Studies specifically aimed to investigate these issues are currently absent in the field, yet are vital to furthering our understanding of elder abuse.

Shame and shame processes

Issues of shame were included in the findings of all four papers (I – IV) and were especially evident in the experiences of the family member witness (IV). Although the emotion shame has repeatedly been associated to both ill health and abusive experiences (Andrews 1995; Andrews 1998; Gilbert 1998; Tantam 1998) empirical investigations examining the connection between shame and abuse have been limited (Andrews 1995). Research concerning possible connections between elder abuse and shame is essentially non-existent. Only one article was located that focused on shame in connection to older persons. In this article Leeming (1998), asserts that abuse in later life is a fertile ground for feelings of shame and humiliation. These sentiments appeal to a common sense understanding of elder abuse, but no research results or references were provided for this statement. Is it so obvious that shame is part of the older victims’ experiences that we don’t need to investigate it? Or is it, in phenomenological terms, so a part of our natural world that we take it for granted? It seems in any case that we need to take a closer look at connections between emotions and emotion theory, shame processes, and elder abuse.

Klaassen (2001) has described shame as “a complicated and excruciating assemblage of self-doubt, self-directed disgust, and a strong feeling of pollution - and I have felt [italics in the original] the excruciating pain of self-doubt and self-distress which is associated with shame and have been stricken by the filthiness at the core of my self”(Klaassen 2001, p. 194). Shame is an innate potential; an involuntary, difficult to control, and unwanted experience (Gilbert 1998). Shame isolates and leads to a desire to escape or hide (Lewis 1971). Shame has also been described as a self-regarding sentiment. Cooley (1902) developed this idea as “the looking glass self” where shame is reciprocally related to pride. We feel pride when we are noticed and shame when social bonds are threatened. Shame or pride arises when we become aware of how we are seen by others. Three elements of the “looking glass self” are (a) how we imagine the other sees us, (b) how we imagine the other judges us, and (c) how we feel about ourselves. These ideas of self-feeling suggest that every word, action, and gesture delivers a message to persons about their worth (Cooley 1902). All social interaction
involves avoiding embarrassing, shaming experiences, i.e., “losing face” and obtaining deference and respect (Goffman 1967).

Shame is a relational emotion as a result of a social situation, often part of a chain of events or process (Scheff and Retzinger 2001). A number of processes involving shame are described in the literature. Tangney and co-workers (1992) describe one such process that begins when the pain of shame results in loss of self-esteem and gives rise to unfocused anger. Shame is such a sweeping affect it can be experienced as disproportionate, i.e., as unfair. Instead of being recognized as internally generated, this unfair experience is attributed to others in the eliciting situation. Shame-based anger is subsequently directed toward others (the real or imagined disapproving other). Anger then provides some relief from the shame (Tangney et al. 1992). One example drawn from the findings of this thesis and lending support to this explanation is the family member witness’s description of her uncle who lived with the shame of never having been good enough and his anger toward his dominating, provoking wife (IV).

Another process of shame and anger involves loss of status. If there is an element of arbitrariness in the loss of status, anger is aroused. If one sees oneself as the cause, shame results. If the loss of status is believed to be beyond control e.g. fate or nature, the most likely emotion is depression. Powerless persons with low or no status in a group who are dominated by others most likely do not react with anger. These persons react instead with depression, low enthusiasm, low self-assurance, low initiative, and shame. For the person with limited power, in stratified interaction, the situation leads to anger in the person. Fear is described as being the root of anger, an anticipatory emotion resulting from a belief that one can be hurt. Fear results from experiencing a great frustration as an overwhelming provocation. If one feels that this frustration must be mastered, the frustrating feeling can lead to violent expressions of anger (Kemper and Collins 1990). It is interesting to reflect on how fear was a common issue in findings of three of the papers (I, II, & III) that was focused on by women and describing primarily women’s fear. The proposition that fear is at the root of anger would help explain the seemingly contradictory risk indicators specific for the abused of being fearful, female, depressed, hostile, and aggressive (see Appendix C, Table C2).

Negative feelings associated to inferiority, shame, and powerlessness can also lead into a vicious circle that makes it impossible to carry out one’s social roles. This process paradoxically creates the conditions for inferiority. For example the negative feelings that are a consequence of abuse confirm the person’s feelings of inferiority and actually consolidate an inferior social position. Women for example in violent relationships can become so convinced of their own culpability that their own shame and self-disgust keep them oppressed (Clark 1990). In the vicious circle of shame the taboo of shame makes us fearful of becoming shamed and we are ashamed because we feel shame. We can feel so ashamed of our feelings that the feeling of shame can be almost totally repressed (Dahlgren and Starrin 2004). The family member witness (IV) perhaps experienced this feeling since she was never explicit about her feelings of
shame (cf. first interview) until the abuse situation became public and her aunt placed in residential care (cf. second interview). The family member witness experienced personnel in this residential care home as non-judgmental and understanding. Could it have been when meeting their non-judgmental attitude that the “top layer” of being ashamed of feeling shame was lifted and the family member witness could begin to recognize and face her deeper shame?

Several associations to these theoretical shame processes are visible in the findings (I - IV), for example risk indicators with connections to loss of self-esteem, status/power, and anger/depression. When considering the lists of risk indicators specific for the abused and the abuser several different patterns could be seen (see Appendix C, Tables C2 and C3). Issues of status/power and self-esteem were more common in risk indicators specific for the abuser. Issues of depression, fear, and self-blame/being blamed seem to be exclusively associated with the abused. Noteworthy is that issues of defensiveness and anger/aggression seem to be equally represented in both lists. These three patterns fit well with the risk indicator endorsed by all groups, i.e., a poor relationship characterized by issues of power.

Scheff and Retzinger (2001) have proposed a theory explaining conflict that might be fruitful to apply to elder abuse situations. This theory entails that destructive conflict is caused by dysfunctional patterns of communication, generated by unacknowledged alienation and shame. First, there is a threat to social bonds. Second, shame is evoked when these bonds are threatened but is not acknowledged. Third, anger arises in defense against an anticipated attack. This process often includes communication that is perceived as disrespect and it is this disrespect that leads into a vicious circle of disrespect - shame – anger - and more disrespect. When reflecting on essential elements of abuse in the synthesized findings (I - IV), this theory provides a way to understand elder abuse as a poor relationship with issues of power. This theory also provides keys to understanding how a “vulnerable”, handicapped elder as an agent in the relationship (described in the II, III, IV) still has power to both create and be a victim in a cycle of alienation, shame, anger and disrespect.

When viewing the findings of all four papers in light of the reviewed shame processes and theories there seems to be little risk in claiming that shame is an integral and important element of elder abuse. Many emotion theorists and researchers agree that shame is one of the most fundamental emotions in the human repertoire and calling it a “master emotion” (Scheff and Retzinger 2001). Findings (I - IV) point to many cross-linkages and connections between shame and elder abuse and reveal how issues of shame such as loss of self-esteem, loss of face, loss of status, and disrespect are tightly bound to elder abuse situations. When viewed from a shame perspective these findings could be expressed in an elder abuse description such as the following; “All social interactions lacking deference towards persons perceived as elderly, and resulting in shame.”
Relational issues of power

The concept of power can be presented in two ways. First power can be defined as “the ability to” or “to be able to”, suggesting “power-to” (Hawks 1991). For example, to be able to provide support in elder abuse situations. Second, there are definitions of power implying “power-over”, described as a source of influence, struggle for dominance, having impact, having a directive force, influencing or controlling an individual or group so that they conform or obey. “Power-over” definitions emphasize strength, control, and competitiveness as inherent in the nature of man (Hawks 1991). Max Weber’s (1962) definition of power is an example of the “power-over” genre: “By power is meant that opportunity existing within a social relationship which permits one to carry out one’s own will even against resistance and regardless of the basis on which this opportunity rests” (Weber 1962, p. 117).

Morriss (2006) has protested against a “power-over” view of power. He claims that our primary understanding of power is as “power-to” effect outcomes, not the ability to affect others, for example by domination. Although situations of “power-over” exist that do not include coercion or domination, such as the power of a mother or a teacher (May 1972; Morriss 2006) it is the power of domination and violence that seems the most palpable and evident in society. This kind of power certainly seems to be the case within the field of family violence and elder abuse. “Power-over” is a characteristic typically associated with abusers. However the endorsed risk indicator found in all four papers refers not only to a characteristic of an abuser but to issues of power in a relationship. In light of the findings in this thesis one wonders if “power-over” does not equally apply to the abuser and the abused, as well as those potentially providing support, i.e., witnesses.

The witness’s power over the abusive situation lies in his/her ability or willingness to see, or not to see, the abuse or the abuser as abusive. The power inherent in witnesses’ ignorance creates a situation where both the abused and abuser can truly be considered victims. The assignment of responsibility, i.e., culpability, considered an essential element in defining a situation as elder abuse, becomes at once more entangled. Difficulty in assignment of responsibility is seen not only in findings in this thesis (III and IV) but also in previous results from reviewed perception articles. Example of this include not perceiving the abuser as only evil (cf. papers III, IV and Brownell et al. 2003; Saveman et al. 1993; Saveman et al. 1996) and maintaining tolerant, “wait and see” attitudes allowing abusive situations to continue (cf. paper IV and Limandri and Tilden 1996; Saveman et al. 1992).

Five levels of power

Rollo May (1972) claims that power is every human being’s birthright and the source of our self-esteem. He proposes five levels of power as potentialities in human life. The first level is the power to be, given in the act of birth, as seen in the newborn infant. This power is prior to good and evil. Yet the power is not neutral and must be lived out or neurosis, psychosis, or violence will result. The second level of power is
self-affirmation, the need not only to survive but to survive with some self-esteem. Self-affirmation is especially important to humans since we are gifted with, or condemned to, self-consciousness. Self-affirmation is described as an original feeling of worth imparted in early life through parental love and experienced in later life as dignity. Indeed the root of the word dignity is the Latin *dignus*, which means “worthy” and “feeling of intrinsic worth.” When self-affirmation is blocked we try harder.

Efforts to try harder are on the third level of power. This is the power of self-assertion. One aspect of self-assertion is that humans seek out opposition in order to test limits and practice assertion. In this respect self-assertion is viewed not as pathological but as a constructive expression of the power to be. Aggression is the fourth level of power and results as a reaction to self-assertion being opposed. Aggression exists within every person as a potentiality that can become active in the “right” situation. It is in aggression that overt conflict becomes visible. Conflict is also slightly noticeable in self-affirmation and self-assertion, although on those levels it is typically directed inwards. Once again, it is interesting to go to the Latin root. Aggression comes from *aggredi*, meaning to approach or move forward. A second meaning is to move against or with intent to hurt. It is fascinating that in this meaning the opposite of aggression is not seeking peace or friendship, rather, the opposite is isolation; a state of making no contact. The fifth level of power is reached when even aggression is ineffective. At this level is the ultimate explosion of violence; an eruption of pent-up passion resulting in the desire to destroy that which is perceived as a barrier to one’s self-esteem (May 1972).

We cannot avoid
Using power,
Cannot escape the compulsion
To afflict the world,
So let us, cautious in diction
And mighty in contradiction
Love powerfully.

Martin Buber, A Believing Humanism (p. 44)

Power and love

These five levels of power are to be understood ontologically, as describing characteristics of being human where both nature (power inherent in the nature of man) and nurture (as power for the other) are rooted. Although many would claim nutrient power to actually be forms of love, May (1972) claims that a juxtaposition of love and power is an erroneous belief based on considering love only as an emotion and seeing power only as a force of compulsion. Power can be conceptualized as a continuum. Higher forms of power involve more love and lower forms on the continuum involve a minimum of love, i.e., exploitive or manipulative power.

Situations of violence show how closely connected love and power are. Violence is most likely to occur between people who share an emotional tie. It is this very tie that
makes them vulnerable to each other (May 1972). In order to inflict maximum cruelty one needs to know what that person’s sensitivities and vulnerabilities are. This is what happens in the emotional abuse of family members. Emotional abuse in the family involves using a bond without pity or compassion for another (Baumeister 1999). It is compassion that is situated opposite to violence. Compassion not only requires self-esteem, but is also the basis for contributing to the self-esteem of another (May 1972).

Self-esteem and violence

Self-esteem has been described as a “positive regard for oneself, involving a sense that one has intrinsic personal worth, or worthiness to be loved. Self esteem is sometimes viewed as synonymous with self-love, self-regard, self-respect, or self-satisfaction” (Meriwether 2003, p. 169). Self-esteem is a positive global evaluation of oneself (Baumeister et al. 1996). Low self-esteem has been one of the most frequently cited reasons for behavioral and social problems, including violence. One undebated correlation between self-esteem and violence is that victims generally show levels of low-self esteem (Emler 2001; May 1972). The traditional view that violent individuals also suffer from low self-esteem has however been questioned in several recent literature reviews (Baumeister 1999; Baumeister 2001; Baumeister et al. 1996; Emler 2001). These authors instead present arguments that high, not low self-esteem is a more plausible risk factor.

Baumeister and co-workers (1996) propose that persons with uncertain, unstable, tentative, incomplete, unwarranted, exaggerated, or ill-founded high self-esteem are more prone to respond defensively to ego threats that challenge the fragile, yet positive views they have of themselves. This idea needs to be considered in an interpersonal framework since these persons are extremely dependent on external validation. It is then the gap between how persons perceive themselves and the opinion they think others have of them that is the crucial point (Baumeister 1999; Baumeister et al. 1996). This explanation fits well with findings in this thesis, for example the family member witness’s perceptions of her uncle’s situation where he is affirmed by healthcare staff on the one hand but mocked by his wife on the other (IV). This explanation also fits with descriptions of situations where healthcare staff experience humiliation through aggressive, unacceptable behaviors of older patients (II and III). Baumeister and co-workers (1996) have proposed an explanation of the connection between threatened self-esteem and violence which emphasizes the “choice point” (see Figure 4).
Figure 4. Schematic representation of the relationship of threatened egotism to violent behavior (Baumeister et al 1996, p. 12).

Self-esteem and elder abuse

Connecting high self-esteem to violence is however more complicated when considering violence in the family. Family violence research can be interpreted as pointing to offenders as having low self-esteem. Baumeister and co-workers (1996) discuss how the choice of target is influenced by low self-esteem combined with violent tendencies. In other words, people with low self-esteem channel their aggressions on weaker, more helpless, and “safe” targets, i.e., victims who cannot retaliate (Baumeister et al. 1996). One example of this perspective is mothers who abuse young children but seldom abuse teenagers (Baumeister 1999). In cases of elder abuse this point of view could be compared to situations of a caregiver abusing a mentally or physically handicapped elder. It is also interesting to note, that the one area of violence where women and men are equally represented is in elder abuse (Baumeister et al 1996).

Research in the field of elder abuse contributes evidence that elder abuse can be connected to issues of self-esteem. Violence in caregiving situations could be dependent on issues of self esteem in both caregiver and care-receiver explaining conflicting
results in elder abuse studies that find no significant correlation between caregiving and elder abuse (National Research Council 2003). One example drawn from findings in this thesis is the family member’s story of her uncle (IV). She explains his abuse of his wife as due to the burden of having to provide around the clock care. The family member witness also perceived her uncle’s situation as one were he desperately needed the affirmation provided by home care staff in order to gain self-esteem, to be “good enough.” At the same time his wife reportedly provoked and henpecked him. Could this situation have been the result of a gap between how the uncle perceived himself and how his wife acted, that in turn led to a choice point decision resulting in situations of aggression? These explanations, caregiver burden and threatened self esteem, need further investigation in connection to elder abuse.

So where does this leave us? Is it high or low self-esteem that is the “cause” of abuse? At this point May’s (1972) five levels of power together with Baumeister and co-workers (1996) “choice point” theory provide one flexible and open explanation. However, there are troublesome circular aspects of self-esteem which remain unanswered; for example does abuse result from a basic low self-esteem or is low self-esteem a result of having abused a family member (Baumeister et al. 1996; Emler 2001), a family member one most likely feels a deep emotional attachment to. This is a circular conundrum of “which comes first” (or which is the pre-requisite of the other), love, self-esteem or abuse. When linking the concepts discussed above several things are clear; (a) abusive actions are on the low end of May’s (1972) power continuum and as such contain the least amount of love, (b) abusive actions have also been associated to threatened self-esteem (Baumeister 1999; Baumeister et al. 1996) and, in turn, (c) the crucial contributing factors to positive self-esteem are considered to be approval, acceptance, and validation (Baumeister et al. 1996; Emler 2001; May 1972). As mentioned earlier the foundation for contributing to the self-esteem of another is compassion. In other words, expressions of love (shown through approval, acceptance, and validation) and compassion should be associated with less abuse. Following this logic in the case of elder abuse means that providing support would entail more than addressing just the violence. Providing support would involve addressing the opposite of violence, i.e, compassion. Compassion is most likely a vital issue, not only for the abused, but for the abuser and the potential support provider.

Compassion requires us to be weak with the weak, vulnerable with the vulnerable, and powerless with the powerless. Compassion means full immersion in the condition of being human.
Henri Nouwen, Compassion: A Reflection on Christian Life (p. 3)

**Compassion**

Compassion is defined as “deep feeling for and understanding of misery or suffering and the concomitant desire to promote its alleviation: spiritual consciousness of the personal tragedy of another or others and selfless tenderness directed toward it” (Grove 1993). In contrast to other related words such as empathy, compassion impels people not only to acknowledge but also to take action in removing or alleviating another’s suffering (Shantz 2007). Sympathy and pity have been synonymous with
compassion but in modern usage especially pity has come to imply condescension and superiority to the sufferer (Nussbaum 2001).

In Rhetoric Aristotle describes compassion as “a feeling of pain caused by the sight of some evil, destructive or painful, which befalls one who does not deserve it, and which we might expect to befall ourselves” (Aristotle 2005, 1385b10-13). This emotion is excited by all unpleasant and painful things if they tend to destroy, are due to chance or if they are serious (Aristotle 2005, 1386a3-5). Aristotle states that it is in fact our duty to feel compassion when there is unmerited distress (Aristotle 2005, 1386b13-14). In her analysis of compassion Nussbaum (2001) agrees with these elements but qualifies and extends the requirement of similar possibilities for experiencing undeserved suffering oneself. She instead claims the requirement of a eudaimonistic judgment; that the sufferer is significant in one’s own scheme of goals and projects. She would also claim the importance of wonder and imagination, i.e., the ability to take the perspective of another, as an important part of the capability to feel compassion (Nussbaum 2001).

Nouwen (2006) questions the common assumption that compassion is a self-evident human quality. Compassion literally means “suffering with” and suffering is not something we personally desire. Therefore compassion can evoke a deep resistance (Nouwen 2006). Feeling compassion is further complicated by other strong and impeding emotions, such as feelings of shame, envy, and disgust. Resources we can call on in the struggle against this resistance include the development of love, concern, guilt, the ability to mourn a loss, and again, most importantly, the ability to take the perspective of another and see ourselves as similar to another (Nussbaum 2001). It seems increasingly tricky to demand a compassionate response to elder abuse. Can compassion be shown an abused elder if they deserved the abuse (victim blaming)? Why is compassion needed if the situation is not considered serious e.g. when viewed as a demanding caregiving situation and not an abuse situation? And it seems unlikely that we would feel compassion for someone we judge as very different from ourselves (ageist sentiments).

**Compassion and community**

Compassion is generated through our recognition of community, i.e., recognition of our common humanness and that we are all part of the human experience. Community also arises out of communication and through communication we rediscover the “we-ness” of being human. We communicate when we consider the other as worth the effort (May 1972). Public policy and support is what we do for, to, and with each other as a community. We need to accept our personal responsibility to take action to deal with elder abuse as members of our community (Murray 1996). Findings in this present thesis (II, III, and IV) support these views that communication and community are requisite when addressing issues of elder abuse. One envisions the support provider as a compassionate person who values and supports self-esteem, both of the abuser and the abused, thereby providing support to involved persons who are threatened and struggling at the “choice point” in an abusive situation.
Could then providing support entail communicating non-judgmental affirmation in order that this might jury-rig a fragile, threatened ego? One way to achieve such a goal is through the power of consolation and the “power-to” console. This perspective is timeless. The fifth century philosopher Boethius described when one has been seen, heard, respected and considered worthy one will find consolation and be consoled (Boethius 1999). But is this perspective the answer? Can jury-rigging self-esteem through affirmation and consolation be connections between elder abuse and power, violence, love, compassion, community? This conclusion is doubtful until one has the moral courage to depend on others in one’s community. Depending on the community was something the family member witness longed for, namely, support she could trust but felt powerless to reach for (IV).

It seems we have come full circle where everyone is a victim of circumstances. What has happened to assigned responsibility, considered an essential element of defining elder abuse? Is no one culpable? Once more we must reflect on the situation described by the family member witness (IV). Her uncle is affirmed by healthcare workers and most often by his niece, yet he continued to refuse to depend on outside assistance. The family member witness described him as “not in touch with his feelings” and lacking empathy. Reflecting on this in conjunction with the discussion of power issues it is now possible to describe elder abuse as; “Egotistical, self-serving acts lacking in compassion and experienced as demeaning to the self worth and dignity of an older person.” Emphasis is not on the actions or the experience of the abused. Emphasis in this description is on the abuser’s actions, self-serving and lacking in compassion, as roots of the abusive action, intentional or not.

**Elder abuse or Abuse of older people**

In the findings of this thesis experts focused on aspects of individuals and the dyad while societal abuse due to ageism was highlighted by older persons. Professionals, volunteers and the family member witness tended to expand discussions from the individual to societal levels as an interwoven context of abuse involving older persons. When generalizing witnesses’ perceptions in this thesis there remains a tenacious uncertainty; were participants describing (a) elder abuse as a concept, or (b) perceptions concerning abuse of human beings who happen to be elderly? What factors determine elder abuse as constituting something conceptually different from abuse of people in other (age) groups? Child abuse is delimited by age. Domestic abuse is defined by a marriage or marriage-like relationships with written or unwritten contract between individuals. Dating violence is also determined by the nature of the relationship. But elder abuse as it is defined today leaves definition of “old” hanging free to be adjusted to an available research sample or current retirement age. In addition elder abuse is perceived as involving a myriad of “relationships” both within the family as well as on a societal level.

Relationships of trust have been specified in the most recent elder abuse definitions. But does there need to be trust? For example, is trust a prerequisite when there is a violation of human rights between an older person and an organization or system?
There is for example no relationship of trust between older persons and youths who steal purses and specifically choose to target older persons in a population. Yet participants (II & III) discussed this as elder abuse. The only reasonable assumption at this juncture is that elder abuse can be any situation where an older person is being abused. Then we have returned to the question; is it “elder abuse” or abuse of older persons? What is really at the heart of the problem “elder abuse”? Findings in this thesis point to certain areas of agreement that seem to be essential elements of situations of elder abuse such as curtailed autonomy, isolation, and vulnerability in the abused elder, and poor relationships with issues of power. Findings and reflections also indicate the importance of issues such as shame, pride, dignity, and respect.

Two elder abuse descriptions have been suggested in the previous discussion. The first echoes the voices of older persons (II) and the second the voice of the family member witness (IV). Here can be added a third variation that interprets the professionals and volunteers (III).

- “All social interactions lacking deference towards persons perceived as elderly and resulting in shame.”
- “Egotistical, self-serving acts lacking in compassion and experienced as demeaning to the self worth and dignity of an older person.”
- “Those actions unnecessary for the good of the older person and not leading to improved quality of life.”

Synthesizing these three suggestions the description of elder abuse becomes; “Self-serving acts, lacking in compassion or deference, which are unnecessary for the improved life quality of persons perceived as elderly or as demeaning to the self worth and dignity of an older person.” Implicit in this description is a goal for how older persons should be treated, that is, with deference. This description creates room within which to escape shame and instead culture pride and respect. This is a room where human rights are protected from any self-serving act whether it is on the level of society or between individuals.

Once more we must return to our original question, is it elder abuse or abuse of older persons? In the incorporated description “persons perceived as elderly” and “older person” carry the only remaining definitional keys specifying that this is “elder abuse”. The meaning of “old” must first be conceptualized. Yet age and aging are concepts so tightly bound in culture and tradition that they defy global definition. It seems that in order to generate a global description of “elder abuse” we must accept the conjecture upon which earlier definitions of elder abuse have been founded, i.e., that older persons are a homogenous group and as such are vulnerable, helpless, and need protection. Yet this idea in itself is the ultimate ageist presumption lacking in deference and respect. Until a definition of elder abuse is based on “violation of the right to be respected as a human being” and stops being defined from a deficit perspective of needs and vulnerability of fragility it seems there is a definitional impasse impossible for all stakeholders to truly recognize his or her perceptions.
Building on the ideas contributed by the findings, and reflections on key elements constituting elder abuse (I - IV), abuse can be viewed as a vulnerability to the power of being shamed that leads to conflict and/or isolation. It is not exclusively the vulnerability due to mental or physical handicaps or a general vulnerability of belonging to a certain age group as in current elder abuse definitions (see Appendix A for examples). Seen in the light of vulnerability to the power of shame it becomes understandable why anyone can become a victim and how hard it is to take action. In light of the findings, synthesized findings, reflections, and the suggested alternative descriptions of elder abuse a perceptions-based “elder abuse anti-definition” is now proposed:

Self-serving acts, lacking in compassion and unnecessary for improved life quality, that violate the right of the older person to be respected as a human being.

It is “elder abuse” when the rights of older human being have been incontestably violated through disrespect. It is the spirit of the action (self-serving, lacking in compassionate, and unnecessary) not its consequences that defines the abuse. The consequence of the abuse, i.e., the violation of the right to be respected, can be stated so plainly, that the experience of the abused individual need not be categorically sought. The message is simply that no one has the right to show older persons disrespect; a lack of respect that leads to shame and feelings of unworthiness. The responsibility for the abuse is placed squarely on the shoulders of the abuser leaving no loophole to blame the abused (by claiming “needs” or “vulnerability”). Elder abuse in this anti-definition includes both a wife slapping her elderly husband when he refuses to eat and personnel avoiding caregiving responsibilities by exploiting laws for self-determination. It includes both a grandchild’s theft of pension funds and societal eldercare budget cuts. This anti-definition does not need a third person to authorize it as “abuse”. The actors have the right to claim themselves abused or abusers. Neither is a “relationship of trust” a factor. The key that unlocks this definition is the ability to see a situation as if we were in it ourselves, experiencing the potential for disrespect, shame and unworthiness inherent in the act. The key to unlocking elder abuse is the ability for compassion.

Compassion gives us a basis for arriving at the humanistic position which will include both power and love. Compassion occupies a position opposite to violence; as violence projects hostile images on the opponent, compassion accepts such daimonic impulses in one’s self. It gives us the basis for judging someone without condemning him. Although loving one’s enemies requires grace, compassion for one’s enemies is a human possibility (May 1972, p. 252).
CONCLUSIONS

Findings revealed a great diversity in perceptions of elder abuse, a diversity that most likely is extremely problematic to address in areas such as research, policy, education and, as exemplified in this thesis, defining elder abuse. An important question raised by these findings is how we are to come to grips with these divergent perceptions, value them, without granting one perspective the preferential right of interpretation and thereby disfranchising the voices of other potential witnesses.

One palpable conclusion drawn from the findings is that tolerance for abusive situations is an important issue. The family member witness described how she tolerated escalating abuse out of loyalty to the abuser and in order to protect family. She also described how healthcare personnel tolerated the abusive situation as well, seeming either not to see the abuse or accepting it as part of a demanding caregiving situation. The family member witness connected healthcare personnel’s accepting attitude to their advocating individual patient’s right of autonomy and self determination. She described personnel as exploiting the principles of autonomy and self-determination it in order to avoid having to provide care themselves. How much abuse are we as healthcare providers willing to accept in the name of protecting patients’ autonomy? Or are we protecting ourselves? How willing are we to advocate the rights of self-determination for our patients when a caregiver has “crossed the line” between care and abuse, even if it means having to provide care ourselves to patients perhaps both unable and unwilling to accept care? How can we protect both ourselves and our patients’ rights without crossing the line ourselves from beneficence to “paternalistic belligerence?” Contemplating these questions and the findings in this thesis hopefully elicit self-reflection on our own behaviors as care providers and on our own caring practice. But self-reflection is not enough. We must also be prepared to take action, action grounded in compassion.

A second conclusion that can be drawn from the findings is that shame is an essential element in elder abuse situations. Findings pointed to the effects of shame on all parties; not only the abused and the abuser but also for witnesses to the abuse. When meeting family members potentially involved in abusive situations it is vital for healthcare personnel and other support persons to keep this key issue of shame in mind. It is also imperative to remain aware that family members, entrapped by shame, may not offer information or take action though they are longing for non-judgmental understanding and support that reaches past thwarting shame. Feelings of shame together with toleration for abuse situations can lead to a passivity among support persons and create an extremely dangerous situation for the abused person caught in the middle between passive agents. We must ask ourselves who the actual abusers are; overwhelmed caregivers or passive onlookers? Perhaps most important is that as potential support persons we need to maintain an awareness of our own
vulnerability to shame and how this affects our actions, or more ominously in cases of elder abuse, our inactions.

Reflections on the findings brought to light that also compassion is most likely a vital issue, not only for the abused, but also for both the abuser and for the potential support provider. Compassion is the ability to see a situation as if we were in it ourselves, experiencing the potential for disrespect, shame and unworthiness inherent in the abusive act. A key to unlocking elder abuse is the ability for compassion. Envisioned in these findings is a compassionate support provider who values the self-esteem of both the abuser and the abused and, through the power of consolation and the “power-to” console, creates a non-judgmental room for understanding those threatened and struggling in an abusive situation. This is a person who has the moral courage to depend not only upon herself but upon others in her community.

Community is the group in which I can depend upon my fellows to support me; it is partially the source of my physical courage in that, knowing I can depend on others, I guarantee that they also can depend on me. It is where my moral courage, consisting of standing against members of my own community, is supported even by those I stand against (May 1972, p. 248).

Recommendations for further research

- Further research is suggested in regard to gendered analysis of elder abuse perceptions especially in relation to detection and coping with abuse.
- Research focusing the whole family as a unit could be a key area to understanding elder abuse, studying systems and hierarchies as well as how families and larger systems interact.
- Ageism, victim blaming, seeing the abuser as a victim of circumstances, and the resulting potential for tolerating elder abuse are issues that must be better understood. Studies specifically aimed to investigate these issues are currently absent in the field, yet are key to furthering our understanding of elder abuse.
- Further investigation of self-esteem in connection to elder abuse and caregiver burden is suggested.
- Investigating both the issue of confidentiality and awareness of support provision are needed areas in future elder abuse research, including exploration of perceptions of elder abuse among social service personnel.
- Further research exploring connections between emotions and emotion theory, shame processes, and elder abuse is especially recommended.
- Personally I am convinced that the most viable way forward in elder abuse research is through interviewing people involved in elder abuse situations, listening to their stories, and creating a compassionate environment for narration.

Det övergripande syftet med avhandlingen var att fördjupa förståelsen av övergrepp mot äldre genom att utforska och jämföra uppfattningar bland experter, äldre personer, företrädare för organisationer med potentiella stödfunktioner, och familjemedlemmar i familjer där övergrepp ägt rum.

I paper (I) undersöks experternas perspektiv på övergrepp mot äldre. Inledningsvis granskades expertliteratur om övergrepp mot äldre. Riskindikatorer (N = 563) och screeningfrågor (N = 67) identifierades. En internationell panel av experter på övergrepp mot äldre besvarade sedan en enkät baserad på de funna indikatorerna och screeningfrågor. De riskindikatorer som var vanligaste förekommande i expertliteraturen sammanställdes i en konsensuslista (n = 48). Likaså sammanställdes en konsensuslista över de indikatorer som valdes av Delphipanelen (n = 42). Samma process genomfördes för screeningfrågorna, dvs. de vanligast förekommande frågorna i expertliteraturen (n = 13) och frågor utvalda av Delphipanelen (n = 9). Skillnader fanns inte bara mellan konsensuslistor för expertliteraturen och expertpanelen, utan fanns också inom Delphipanelen, mellan representanter från utvecklade länder och utvecklingsländer.

I papers II och III intervjuades deltagare i fokusgrupper angående deras uppfattningar om övergrepp mot äldre. Transkriberade intervjuer analyserades med innehållsanalys. Äldre personer (II) (N = 37 i sex fokusgrupper) uppfattade övergrepp mot äldre som en följd av att samhälle och familjssystem har förändrats och att barn inte längre uppföras att respektera äldre personer. Övergrepp mot äldre uppfattades framförallt som brott, åldersdiskriminering, vanvård inom äldreomsorg och övergrepp på en samhällelig nivå. Förövaren uppfattades som en främling eller sjukvårdspersonal. Rädsla beskrevs som en betydande konsekvens av övergrepp mot äldre, speciell rädsla hos kvinnor. Utsatta personer ansågs själva bära ansvaret att söka hjälp. Vittnens motvillighet att bli involverad beskrevs också. Olika sätt att hantera övergrepp mot äldre diskuterades, t ex utbildning av barn och sjukvårdspersonal såväl som förbättringar i samhället. Förutom vänner och familj förekom få spontana förslag
på hjälp-/stödinstanser i samhället. De förslag som förekom inkluderade sjukvård, polis, kyrkan och frivilliga organisationer.

I paper III intervjuades representanter från de föreslagna organisationerna (N = 31 i sex fokusgrupper) Uppfattningar kring orsaker till övergrepp mot äldre liknande de som diskuterades av de äldre personerna (II). I paper III framkom fyra teman; goda intentioner i övergreppssituationer, äldre generationens ansvar för övergrepp mot äldre, svikande rapportering av övergrepp mot äldre och förebyggande av övergrepp mot äldre. Deltagarna (III) uttryckte åldersdiskriminering, skuldbelade de utsatta, och antydde en tolerans för övergrepp mot äldre. Deltagarna uppfattade att vem som helst kunde bli provocerad att bli förövare och att förövaren själv kan anses vara ett offer i en övergreppssituation. Sekreteress beskrevs som ett hinder i rapporteringsförfarandet. Deltagare identifierade ett behov av att uppostra barn att respektera äldre.

I paper IV intervjuades en vuxen familjemedlem angående hennes upplevelser av att bevittna övergreppssituationer mellan hennes morbror och hans fru. Transkriberade intervjuer analyserades med narrativ analys. Medan den intervjuade strävade att försvara och förbli lojal med sin familj upplevde hon en maktlöshet där hon tolererade morbrorns övergrepp mot hustrun. Den intervjuade längtade efter stöd hon kunde lita på men var låst i passivitet bl a på grund av de skamkänslor hon hade för att det var en släktande till henne som var förövare. Samtidigt upplevde den intervjuade att sjukvårdspersonalen endast uppmarcksmade de svårigheter hennes morbror hade som anhörigvårdare i en ansträngd situation. Den intervjuade upplevde också att personalen utnyttjade autonomiprisippen för att undvika att ge vård till hennes moster som ansågs vara en mycket besvärlig patient.


Avhandlingen visar på många och varierande uppfattningar om övergrepp mot äldre i samhället idag och som innebär utmaninger vad gäller bemötande och intervention i övergreppssituationer. Speciellt bland vårdande personal i mötet med personer involverade i övergreppssituationer betonas vikten av självreflektion och ett fördomsfritt bemötande som är grundat i medlidande.
ACKNOWLEDGMENTS

This thesis has been carried out at the Department of Nursing, Umeå University and with economic support from the School of Human Sciences, University of Kalmar.

I would like to gratefully acknowledge the many people who have contributed to this thesis through their expertise, support and friendship.

Firstly I would like to acknowledge my three thesis advisors. Britt-Inger Saveman, Professor, University of Kalmar, my head advisor, for her encouragement, guidance and support, and belief in my abilities. Sture Åström, Associate Professor, Umeå University, my co-advisor, for his enthusiasm for my doctoral project and well founded advice. Sharon Carlson, Professor, Otterbein College, USA, my co-advisor, for her heartwarming support that has lifted and guided me to make my own discoveries. She should never underestimate the effects of her encouragement or the long lasting sustenance of her comments.

In addition I would like to acknowledge my co-author Agneta Berg for helping me take my first steps towards becoming a researcher.

I would also like to thank teachers of my doctoral courses who have “made a difference” in my growth both as a researcher and as a person. I would like especially to name Astrid Norberg, Anders Lindseth, Catherine Riessman, and Karin Dahlberg. You have opened for me the worlds of philosophy and narrative, may those doors never close.

I am also grateful to my colleagues in Umeå as well as in Kalmar, for your helpful discussions, creative criticism, and mutual supportive attitudes.

A special thanks to my colleague and friend Margaretha Hagberg, my unofficial “advice-er” and mentor. You have unflaggingly provided wisdom, listened with patience, consoled and encouraged, especially during the many hours of commuting together back and forth between Öland and Kalmar.

My greatest thanks go to my family. My parent’s and sibling’s love is always with me as internal scaffolding providing the strength to believe in myself. I have done this project for you as much as for myself. Jeff, I wish you could have lived to see this! And naturally I am incredibly proud and thankful to and for my husband Bengt and our children, Styrbjörn, Karin, Signe, Thorulf, Hjorleif, Shannon, and Julie, who have continuously supported me with the staples of life, i.e., popcorn, foot-rubs, humor, consistent love, and curiosity. Thank you all!
REFERENCES


Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. Sociology of Health and Illness, 16, 103-121.


Appendix A
Overview of elder abuse definitions

Elder abuse is conceptualized as self- or other-inflicted suffering unnecessary to the maintenance of the quality of life of the older person. (Amended 1991): [...] older person] by means of abuse or neglect caused by being overwhelmed.

All cases of abuse and neglect can be thought of as inadequate care, defined as the presence of unmet needs for personal care....we define elder abuse as actions of a caretaker that create unmet needs for the elderly person, such as for food, shelter, supportive relationships, or medical care. We define neglect as the failure of an individual responsible for caretaking to respond adequately to established needs for care.

Elder mistreatment: Destructive behavior that is directed toward an older adult; occurs within the context of a relationship connoting trust; and is of sufficient intensity and/or frequency to produce harmful physical, psychological, social, and/or financial effects of unnecessary suffering, injury, pain, loss, and/or violation of human rights and poorer quality of life for the older adult.
Elder abuse: Aggressive or invasive behavior/action(s), or threats of same, inflicted on an older adult and resulting in harmful effects for the older adult. Elder neglect: The failure of a responsible party(-ies) to act so as to provide, or to provide what is prudently deemed adequate and reasonable assistance that is available and warranted to ensure that the older adult’s basic physical, psychological, social, and financial needs are met, resulting in harmful effects for the older adult.

Abuse is a social act with at least two actors, where one actor violates the personal boundaries of another. This act is abuse if interpreted and valued as illegitimate by a third person, the witness.

5. Action on Elder Abuse (AEA), (1995):
A single or repeated act or lack of appropriate action occurring in any relationship where there is an expectation of trust, which causes harm or distress to an older person.

Defines abuse as a violation of an individual’s human and civil rights by any other person or persons and may consist of a single act or repeated acts. It may be physical, verbal or psychological, it may be an act of neglect or an omission to act, or it may occur when a vulnerable person is persuaded to enter into a financial or sexual transaction to which he or she has not consented, or cannot consent. Abuse can occur in any relationship and may result in significant harm to, or exploitation of, the person subjected to it.

have adopted the same definition as AEA

8. National Research Council (NRC), (2003):
Elder abuse is defined to refer to (a) intentional actions that cause harm or create a serious risk of harm (whether or not harm is intended) to a vulnerable elder by a caregiver or other person who stands in a trust relationship to the elder or (b) failure by a caregiver to satisfy the elder’s basic needs or to protect the elder from harm.

Definitions from the USA (#1, 2, 3, and 8), Norway (#4), the UK (#5, and 6), and international organizations (#7)
# Appendix B

## Reviewed articles with content on perceptions of elder abuse from witnesses’ perspectives

<table>
<thead>
<tr>
<th>Sample</th>
<th>Author</th>
<th>Publ. year</th>
<th>Country</th>
<th>Title (Journal)</th>
<th>Aim</th>
<th>Participants/Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>FCG &amp; OP</td>
<td>Anetzberger, Korbin, &amp; Tomita</td>
<td>1996</td>
<td>USA</td>
<td>Defining elder mistreatment in four ethnic groups across two generations (J. of Cross-Cultural Gerontology)</td>
<td>Examined perceptions of elder mistreatment across ethnic groups and generations</td>
<td>European-American, African-American, Puerto Rican, and Japanese-American in two generations (elder and &quot;baby boom&quot; caregiver) Focus groups/Manifest content analysis</td>
</tr>
<tr>
<td>OP &amp; Pro</td>
<td>Brownell, Berman, Nelson, &amp; Fofana</td>
<td>2003</td>
<td>USA</td>
<td>Grandparents raising grandchildren: the risks of caregiving (J. of Elder Abuse &amp; Neglect)</td>
<td>To identify and compare perceptions of grandparents raising grandchildren and child welfare workers on: prevalence and types of grandchildren's behaviors toward grandparents associated with elder abuse; available services that may be useful to grandparents coping with abusive grandchildren, and services that may be helpful but are not currently available.</td>
<td>Custodial grandparents and child welfare workers Focus groups/Content analysis</td>
</tr>
<tr>
<td>Gen Pub</td>
<td>Childs, Hayslip, Radika, &amp; Reinberg</td>
<td>2000</td>
<td>USA</td>
<td>Young and middle-aged adults' perceptions of elder abuse (Gerontologist)</td>
<td>To examine the impact of (a) respondent age, (b) age and gender of perpetrator and victim, and (c) history of experienced violence on perceptions of elder abuse</td>
<td>Middle-aged and young adults Questionnaire/Descriptive statistical analysis</td>
</tr>
<tr>
<td>Gen Pub</td>
<td>Gebotys, O’Connor, &amp; Mair</td>
<td>1992</td>
<td>Canada</td>
<td>Public perceptions of elder physical mistreatment (J. of Elder Abuse &amp; Neglect)</td>
<td>To determine the public perception of labeling a situation as physical abuse</td>
<td>General public Questionnaire to measure public attitudes towards elder physical mistreatment/Descriptive statistics and factor analysis</td>
</tr>
</tbody>
</table>

FCG = Family care giver, OP = Older Persons, Gen Pub = General Public, Pro = Professionals, SO = Significant others
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Reviewed articles with content on perceptions of elder abuse from witnesses’ perspectives

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<th>Title (Journal)</th>
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<th>Participants/Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pro</td>
<td>Harrell, Toronjo, McLaughlin, Pavlik, &amp; Dyer</td>
<td>2002</td>
<td>USA</td>
<td>How geriatricians identify elder abuse and neglect (American J. of Medical Science)</td>
<td>To learn how practicing geriatricians define, diagnose, and address abuse and neglect to provide some guidance to general internists regarding this complex issue</td>
<td>Geriatricians Interviewed with standardized set of open-ended questions/“quantitative and qualitative analysis”</td>
</tr>
<tr>
<td>OP, SO &amp; Pro</td>
<td>Hirst</td>
<td>2000</td>
<td>Canada</td>
<td>Resident abuse: An insider’s perspective (Geriatric Nursing)</td>
<td>To understand the meaning of the term resident abuse as those who live and work within long term care institutions use it.</td>
<td>Older residents, Significant others, Registered nurses, Non-professional staff Focus groups, individual face-to-face interviews Ethnography/Constant comparative method</td>
</tr>
<tr>
<td>Pro</td>
<td>Hudson</td>
<td>1991</td>
<td>USA</td>
<td>Elder mistreatment: A taxonomy with definitions by Delphi (J. of Elder Abuse &amp; Neglect)</td>
<td>To enlist elder mistreatment experts to inductively derive a taxonomy of elder mistreatment concepts and precise definitions of all the categorical concepts.</td>
<td>63 elder mistreatment experts Delphi technique</td>
</tr>
</tbody>
</table>

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<tbody>
<tr>
<td>Gen Pub</td>
<td>Hudson</td>
<td>1994</td>
<td>USA</td>
<td>Elder abuse: Its meaning to middle-aged and older adults Part II: Pilot results (J. of Elder Abuse &amp; Neglect)</td>
<td>Goals were to: 1. Compare expert’s definition of elder abuse to middle-aged and older adults residing in a culturally diverse area 2. Identify demographic variables that show significant correlation with specific population groups’ definitions of elder abuse, including experience with abuse as an abused person and/or abuser 3. Compare the types of elder abuse that the public recognizes with those in the experts’ taxonomy 4. Identify the types of elder abuse that the public believes warrant professional intervention 5. Develop a taxonomy of elder abuse that incorporates the public’s and experts’ perceptions of its components 6. Develop a definition of elder abuse that includes the public’s and experts’ perceptions of its essential characteristics</td>
<td>Community-dwelling adults ages 40 to 91 years Interviews using vignettes and Elements of Elder Abuse Scale/Descriptive statistics</td>
</tr>
<tr>
<td>Pro</td>
<td>Kreuger &amp; Patterson</td>
<td>1997</td>
<td>Canada</td>
<td>Detecting and managing elder abuse: Challenges in primary care. (Canadian Medical Association Journal)</td>
<td>To determine family physicians’ perceptions of barriers and strategies in the effective detection and appropriate management of abused elderly people</td>
<td>Active non-specialist physicians who reported seeing elderly patients in their practices Questionnaire survey/Descriptive statistics</td>
</tr>
</tbody>
</table>

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</thead>
<tbody>
<tr>
<td>Pro</td>
<td>Limandri &amp; Tilden</td>
<td>1996</td>
<td>USA</td>
<td>Nurses’ reasoning in the assessment of family violence. (Image: Journal of Nursing Scholarship)</td>
<td>To explore factors influencing clinicians’ choice to intervene and to compare the reasoning used by various health professionals (reported elsewhere).</td>
<td>Nurses: Surveys &amp; interviews/descriptive statistics and thematic content analysis</td>
</tr>
<tr>
<td></td>
<td>Moon, Tomita &amp; Jung-Kamei</td>
<td>2001</td>
<td>USA</td>
<td>Elder mistreatment among four Asian American groups: An exploratory study on tolerance, victim blaming and attitudes toward third-party intervention (J. of Gerontological Social Work)</td>
<td>Examines the degree to which 4 Asian American ethnic groups (1) tolerate elder mistreatment, (2) blame the victim, and (3) are likely to report it to agencies and law enforcement. The study also explores variations in responses (ethnicity, degree of acculturation, or adaptation to the dominant American culture).</td>
<td>Chinese Americans, Japanese Americans, Korean Americans, and Taiwanese Americans: 14 statements/Descriptive statistical analysis</td>
</tr>
<tr>
<td>OP</td>
<td>Moon &amp; Williams</td>
<td>1993</td>
<td>USA</td>
<td>Perceptions of elder abuse and help-seeking patterns among African-American, Caucasian American, and Korean-American elderly women (Gerontologist)</td>
<td>To examine 1) how various potentially abusive situations are perceived by three groups of the elderly; 2) whether and to what extent the elders’ perceptions of situations are correlated with their decisions to seek help; and 3) group similarities and differences in where to or to whom they could turn for help in given situations.</td>
<td>African-American, Caucasian American, and Korean-American elderly women: Interviews based on scenarios/Descriptive statistical analysis</td>
</tr>
</tbody>
</table>

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<th>Participants/Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>OP</td>
<td>Pablo &amp; Braun 1997 USA</td>
<td>Perceptions of elder abuse and neglect and help-seeking patterns among Filipino and Korean elderly women in Honolulu. (J. of Elder Abuse &amp; Neglect)</td>
<td>Examined views about elder abuse and help seeking behavior.</td>
<td>Asian-American groups Interview based on scenarios/ Descriptive statistical analysis (Same design as Moon &amp; Williams 93)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pro</td>
<td>Podnieks &amp; Wilson 2003 Canada</td>
<td>An exploratory study of responses to elder abuse in faith communities (J. of Elder Abuse &amp; Neglect)</td>
<td>To gain an understanding of faith leaders’ perceptions of elder abuse, to ask how faith leaders respond to elder abuse in their communities, to determine what barriers they experience, and to find out what resources faith leaders would find helpful in meeting the needs of their congregants regarding elder abuse.</td>
<td>Faith leaders (Protestant, Roman catholic and Jewish) Face-to-face or telephone survey/Descriptive statistics and content analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pro</td>
<td>Saveman, Hallberg, &amp; Norberg 1992 Sweden</td>
<td>The problems of dealing with abuse and neglect of the elderly: Interviews with district nurses (Qualitative Health Research)</td>
<td>To discover how district nurses dealt with approaching, recognizing, and intervening in cases of elder abuse.</td>
<td>District nurses Interviews/Content analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pro</td>
<td>Saveman, Hallberg, &amp; Norberg 1993 Sweden</td>
<td>Identifying and defining abuse of elderly people, as seen by witnesses (J. of Advanced Nursing)</td>
<td>To analyze how Swedish district nurses identified and defined abuse of elderly people in practice</td>
<td>District nurses Interviews (Same interview material as in Saveman et al. 1992)/Content analysis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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<th>Sample</th>
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<th>Publ. year</th>
<th>Country</th>
<th>Title (Journal)</th>
<th>Aim</th>
<th>Participants/Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pro</td>
<td>Saveman, Hallberg, &amp; Norberg</td>
<td>1996</td>
<td>Sweden</td>
<td>Narratives by district nurses about elder abuse within families (Clinical Nursing Research)</td>
<td>To interpret narratives of district nurses’ cases of elder abuse concerning the abusive situations and the nature of the relationship between the abused and the abuser</td>
<td>District nurses</td>
</tr>
<tr>
<td>Pro</td>
<td>Weeks, Richards, Nilsson, Kozma, &amp; Bryanton</td>
<td>2004</td>
<td>Canada</td>
<td>A gendered analysis of the abuse of older adults: Evidence from professionals (J. of Elder Abuse &amp; Neglect)</td>
<td>To identify contextual variables, with a particular focus on gender, that may be related to the abuse of older adults through the analysis of professional perceptions of abuse cases.</td>
<td>Abuse cases, as described by 121 professionals</td>
</tr>
<tr>
<td>Pro</td>
<td>Wilson</td>
<td>2002</td>
<td>UK</td>
<td>Dilemmas and ethics: Social work practice in the detection and management of abused older women and men (J. of Elder Abuse &amp; Neglect)</td>
<td>To look at ideas and understandings rather than ‘facts’ about social work practice and elder abuse</td>
<td>Social workers</td>
</tr>
</tbody>
</table>

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### Appendix C

#### Table C1. Overview of general risk indicators (I – IV)

| Found in sample: | Therapeutic failure  
Prolonged interval between injury and medical treatment  
Inadequate food supply  
History of doctor hopping |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Delphi panel consensus (Ib)</td>
<td>Evidence of unusual family stress/ recent family crisis</td>
</tr>
</tbody>
</table>
| Older Persons (II) | Wrong priorities on governmental level  
Healthcare budget cuts  
Understaffing in police force and healthcare  
Policies allowing for increased immigration  
School system not preparing youths to be good citizens  
Changing family structure/Unstable family systems  
Parents’ lax attitudes/Children’s’ poor upbringing  /New technologies for banking and communication |
| Professionals & volunteers (III) | Relationship problems in the family  
Delegating nursing tasks to uneducated healthcare personnel  
Mass media conveying a picture of a legal system that does not prosecute elderly wife abusers  
Confidentiality between organizations/agencies/health care  
Unclear and inefficient reporting procedures |
| Family witness (IV) | Dirty home  
Healthcare personnel discuss integrity/autonomy in connection with care provision |
| Ia & Ib | History of family violence (violence normal response to stress)  
Drug or alcohol addiction in family |
| Ia & IV | Noncompliance |
| II & III | Ageism and/or a general lack of respect for older persons  
Changing, modern, more lax society  
Generations segregated in society |
| III & IV | Too little time for healthcare personnel to provide patient care |
| Ia, Ib & IV | Reports of being left in an unsafe situation |
| Ia, III, & IV | History of untreated psychiatric problems in elder or caregiver |
| II, III, & IV | Uneducated/incompetent/unknowledgeable personnel in institutional and home care  
Absence of social stimulation  
Societal budget restraints on care provided to the elderly |
| Ia, Ib, III, & IV | Excessive dependence of elder or caregiver |
| Ia, Ib, II, III, & IV | Poor past relationship / poor current relationship (issues of power, control, coercion, dominance, or manipulation) |
Appendix C
Table C2. Overview of risk indicators specific for abused elders (I – IV)

<table>
<thead>
<tr>
<th>Found in sample:</th>
<th>Risk indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delphi panel consensus (Ib)</td>
<td>Victim of past abuse, Substance abuse (alcohol or drugs)</td>
</tr>
<tr>
<td>Older Persons (II)</td>
<td>Opening doors to strangers, Lending money to children, Not speaking up for themselves</td>
</tr>
<tr>
<td>Professionals &amp; volunteers (III)</td>
<td>Elders who are mentally retarded/have mental impairment, Elder repeatedly visits healthcare, Elder runs out of medicine extra quickly, Older women remaining in abusive relationships, Wandering, Not keeping up with new technology, Women failing to protect their purses, Lonely/longing for social contact even from unknown persons, Experiencing guilt and shame, Being unwilling to risk losing social contacts, Accepting abuse as a part of elderly life experiences</td>
</tr>
<tr>
<td>Family witness (IV)</td>
<td>Being very old, Being difficult/Troublesome, Being demanding, Being angry, Being dominant, Being a complainer, Speaking poor Swedish or mother tongue with a strong dialect, Not being properly tested/diagnosed for dementia diseases</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ia &amp; III</th>
<th>Withdrawal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ia &amp; IV</td>
<td>Poor hygiene, Living with relatives</td>
</tr>
<tr>
<td>II &amp; III</td>
<td>Older persons who voluntarily isolate themselves, Elders refusing help or making excessive requests for help, Carrying too much cash, Changing routes/choosing a dangerous route</td>
</tr>
<tr>
<td>Ia, III, &amp; IV</td>
<td>Symptoms of depression, Acute and chronic health problems</td>
</tr>
<tr>
<td>II, III, &amp; IV</td>
<td>Increased suspicion, Hostile behavior/aggression/ initiating violent encounters, Being female</td>
</tr>
<tr>
<td>Ia, Ib, II &amp; III</td>
<td>Exhibiting fearful behavior, Fear, of robbery or caregiver</td>
</tr>
<tr>
<td>Ia, Ib, II, III, &amp; IV</td>
<td>Confusion (dementia disease), Isolation of elder, Physical impairment of older adult/suffered stroke</td>
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## Appendix C

### Table C3. Overview of risk indicators specific for the abuser (I – IV)

<table>
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<th>Found in sample:</th>
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<td><strong>Literature search consensus (Ia)</strong></td>
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<td>• Has mental illness</td>
</tr>
<tr>
<td>• Poor finances</td>
</tr>
<tr>
<td>• Being a blamer</td>
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<tr>
<td>• Loss of job</td>
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<tr>
<td>• Poor health</td>
</tr>
<tr>
<td><strong>Delphi panel consensus (Ib)</strong></td>
</tr>
<tr>
<td>• History of violence, abuse, neglect, or exploitation</td>
</tr>
<tr>
<td>• Current violence towards family members or pets</td>
</tr>
<tr>
<td>• Is forced by circumstances to care for the patient who is unwanted</td>
</tr>
<tr>
<td>• Aggressive</td>
</tr>
<tr>
<td>• Dependent on the abused</td>
</tr>
<tr>
<td><strong>Professionals &amp; volunteers (III)</strong></td>
</tr>
<tr>
<td>• Personnel delegated nursing tasks although not educated for the tasks</td>
</tr>
<tr>
<td><strong>Family witness (IV)</strong></td>
</tr>
<tr>
<td>• Holding back information</td>
</tr>
<tr>
<td>• Low self esteem</td>
</tr>
<tr>
<td>• Henpecked</td>
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<tr>
<td>• No contact with own feelings</td>
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<tr>
<td>• Limited empathy</td>
</tr>
<tr>
<td>• Refusing healthcare/home care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>&amp;</th>
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</thead>
<tbody>
<tr>
<td><strong>Ia &amp; Ib</strong></td>
</tr>
<tr>
<td>• Financially dependent on elder</td>
</tr>
<tr>
<td><strong>Ia &amp; IV</strong></td>
</tr>
<tr>
<td>• Depression</td>
</tr>
<tr>
<td>• Ill prepared to give care</td>
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<tr>
<td>• Frustrated</td>
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<tr>
<td>• Poor knowledge of patient’s medical problems</td>
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<tr>
<td>• Denies access to client</td>
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<tr>
<td><strong>Ib &amp; IV</strong></td>
</tr>
<tr>
<td>• Lack of resources, e.g. time, money, energy</td>
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<tr>
<td>• Intolerance of the older person’s behavior</td>
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<tr>
<td><strong>III &amp; IV</strong></td>
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<tr>
<td>• Dominating communication with others</td>
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<tr>
<td><strong>Ia, Ib &amp; IV</strong></td>
</tr>
<tr>
<td>• Hostility toward elder/healthcare</td>
</tr>
<tr>
<td><strong>II, III, &amp; IV</strong></td>
</tr>
<tr>
<td>• Lack of education</td>
</tr>
<tr>
<td>• Ageistic attitudes</td>
</tr>
<tr>
<td><strong>Ib, II, III, &amp; IV</strong></td>
</tr>
<tr>
<td>• Perception of stress as a load to heavy to bear/overwhelmed</td>
</tr>
<tr>
<td><strong>Ia, Ib, II, &amp; IV</strong></td>
</tr>
<tr>
<td>• Substance abuse (alcohol and drugs)</td>
</tr>
<tr>
<td><strong>Ia, Ib, III, &amp; IV</strong></td>
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<tr>
<td>• Gives vague, implausible, inconsistent or no explanations for elder’s injuries</td>
</tr>
</tbody>
</table>
### Appendix C

**Table C4. Overview of risk indicators for physical, sexual, and financial abuse (I – IV)**

<table>
<thead>
<tr>
<th>Found in sample:</th>
<th>Indicators of physical abuse</th>
<th>Indicators of sexual abuse</th>
<th>Indicators of financial abuse</th>
</tr>
</thead>
</table>
| **Literature search consensus (Ia)** | ◆ Malnourishment  
◆ Bruises in various stages of healing  
◆ Contractures  
◆ Absence of hair  
◆ Broken nose or teeth | ◆ Bleeding  
◆ Bruising on inner thigh | ◆ Evidence that personal belongings of elder are being taken without elder’s consent  
◆ Unexplained loss of social security/pension checks |
| **Delphi panel consensus (Ib)** | ◆ Injuries or traumas inconsistent with reported causes  
◆ Multiple injuries  
◆ Signs of hair pulling (hemorrhaging below scalp)  
◆ Slap marks  
◆ Previous similar injuries  
◆ Fractures in unusual locations  
◆ Marks left by gag  
◆ Injuries in unusual locations  
◆ Black eyes  
◆ Bruises not consistent with a fall | | |
| **Family witness (IV)** | ◆ Sores in mouth | | |
| **Ia & Ib** | ◆ Fractures in various stages of healing  
◆ Friction from ropes or chains  
◆ Dehydration  
◆ Unexplained burns  
◆ Cigar/cigarette burns | | |
| **Ia & IV** | ◆ Decubitis | | |
| **Ib & III** | ◆ Unexplained injuries | | |
| **Ib & IV** | ◆ Suspicious falls or injuries | | |
| **Ia, Ib & IV** | ◆ Injuries in shape of object that inflicted them | | |
| **Ia, III, & IV** | ◆ Unexplained bruises | | |