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Perspectives on Elder Abuse in the Netherlands



Yuliya Mysyuk

Perspectives on Elder Abuse in the Netherlands

Yuliya Mysyuk

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Perspectives on Elder Abuse in the Netherlands

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Promotoren: Prof. dr. R.G. J. Westendorp
Prof. dr. S. Biggs (Melbourne University, Australia)

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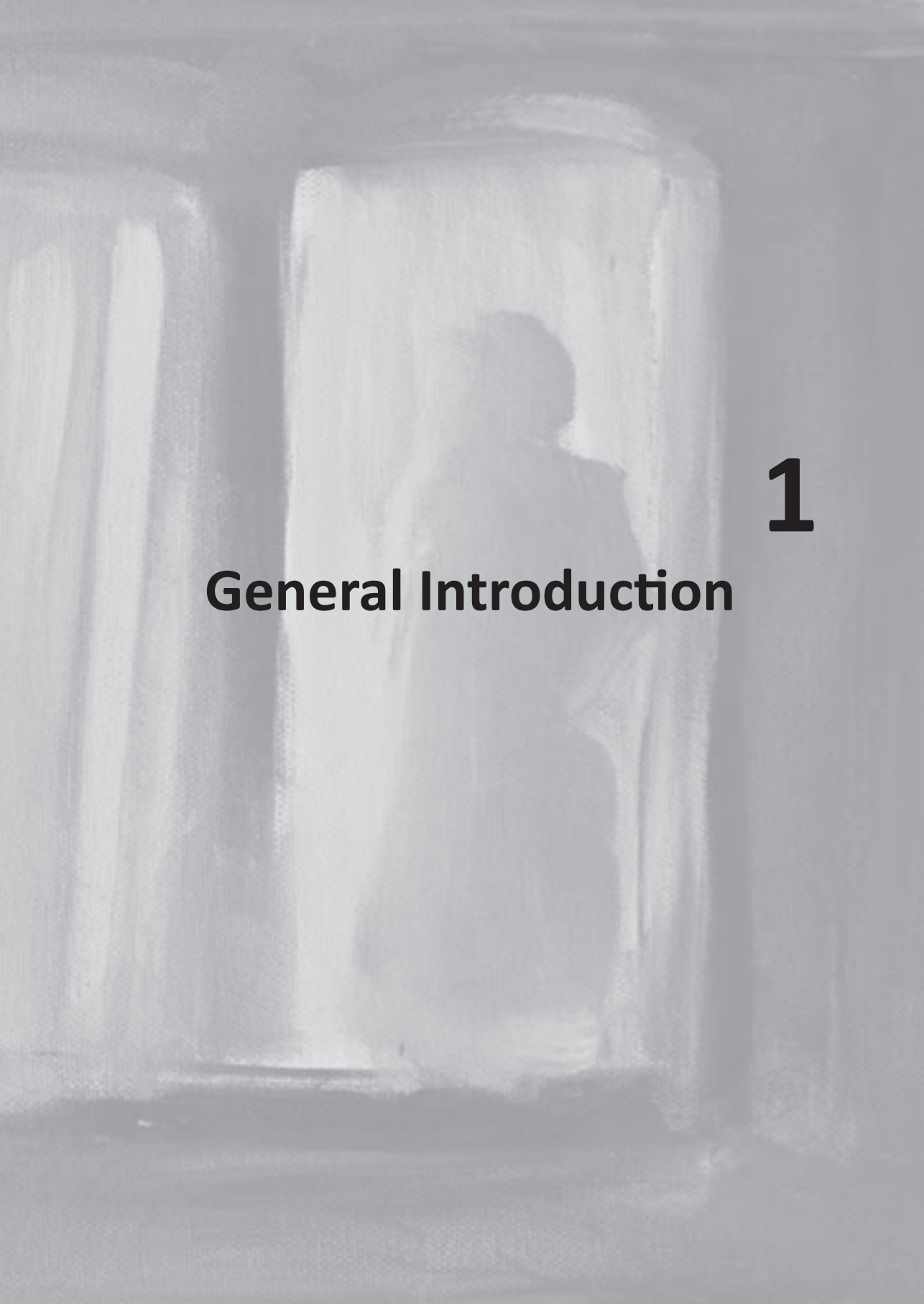
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Prof. dr. R. C. van der Mast
Prof. dr. A.M. Pot (University of Amsterdam)

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1

General Introduction

Actieplan Ouderen in veilige handen [Action plan The elderly in safe hands]

Ministry of Health, Welfare and Sport

30-03-2011

[State secretary Marlies Veldhuijzen van Zanten wants to put a stop to abuse. In the next few years she will allocate an annual sum of 10 million euro to the issue: elder abuse. The state secretary wants to stop the violence as quickly as possible by early detection, reporting and support of victims.

With the Action plan “The elderly in safe hands” Veldhuijzen van Zanten wants to combat violence and abuse committed not only by professionals but also in the home setting].

Meer ouderenmishandeling gemeld [More elder abuse reported]

NOS News

10-06-2014, 21:07

[Last year there were increased cases of abuse reported over the previous period. In 2013 there were 1703 cases of abuse reported to the Support Centre of Domestic Violence. This is an increase of 66 % in comparison to 2012 as was reported by the National Platform to Combat Elder Abuse. The number of reports has steadily increased since 2010. Women become victims of abuse three times more often than men. Two-thirds of the reported cases involved psychological abuse of women. Financial exploitation (39%) and physical abuse (38%) were also often reported. Patterns indicate that most perpetrators are children, grandchildren or (ex-) partners. More than three-quarters of the victims live alone or with a partner. In 9% of the cases an older person lives in a health care institution. The amount of reports by victims themselves or their family members was low: the majority of reports were filed by police, social workers and professionals from health care institutions].

During the past few years, more attention has been paid to the issue of elder abuse. This interest appears to be more widespread as it is discussed in the media, scientific publications and has resulted in several policy documents and programs (information campaign “Safe at home”, prevention of financial exploitation, “Volunteers against elder abuse”). For example, the Dutch government has launched an action plan “The elderly in safe hands” which is targeted against abuse, exploitation and neglect of older persons and aims to improve prevention of elder abuse, victim support and firm action towards offenders, all to be achieved through the joint efforts of the government, municipalities and professional organizations (Ministry of Health, Welfare and Sports, 2011). Elder abuse is now more often discussed in the news, where attention is focused upon the increase in reporting of abuse: types of abuse reported, perpetrators involved, frequent reporters.

Attitudes and perceptions towards elder abuse have changed throughout history. From being barely acknowledged in the 70's and 80's it has developed by being defined and recognized as an important social phenomenon and problem in the last two decades.

The wider relevance

Public attention for elder abuse coincides with the growing numbers of older individuals in our society. Concerns have been raised about how we ought to care for older people and whether we will be able to do so in a good way. Questions have been raised whether our individualized, "western" societies have resulted in decreased respect for our older generation, as their value waned with the growing reliance on IT and technological innovation. Nevertheless, elder abuse is a worldwide phenomenon, not one isolated to European or North-American countries, not a phenomenon merely present in OECD countries. It is a global social issue that requires attention and actions that need to be taken to prevent and eliminate it. Studying elder abuse will help us understand the position of older persons in our society: how can we understand these abusive situations? Are they a sign of our times, or rather an incident that is unrelated to the demographic changes in our society? Is it related to transformed values and norms of current society?

Current knowledge on elder abuse

Not only in the Netherlands but also worldwide, elder abuse is becoming a high priority issue on the agendas, however there are still numerous aspects that have been left unexplored. Elder abuse is a complex issue with continuous controversies regarding its definition (as shown in chapter two of this thesis). Currently there is not an unambiguous consensus on the definition of elder abuse. Different academics, practitioners and policy makers use different definitions. The first question that this thesis therefore answers is how is elder abuse defined? This is done through a systematic review (chapter two) and later in other chapters of this thesis by exploring the definitions of those involved in the field of elder abuse. Nevertheless, one of the most commonly used definitions is the WHO definition that emphasizes the nature of the relationship between the older person and the perpetrator and the notion of trust is at the center of this definition (WHO, 2002). Another definition that is commonly used in the Netherlands diverts from the WHO-definition and uses the age limit of 65 for being considered as an older person (Comijs, 1999). We discuss the development of elder abuse definitions over time and which purposes they (could) serve in public and scientific domain.

Although there are discussions and debates about the exact definition of elder abuse, most of the studies distinguish the various types of abuse: physical, psychological, sexual, financial and neglect.

Lack of agreement about the definitions, makes it difficult to determine the extent of the problems of elder abuse. Prevalence rates vary in different countries. For example, prevalence rates of 4-6 % have been found in Canada, Great Britain,

and in Finland rates vary between 1-10% (Griffin, 1994; Pillemer & Finkelhor, 1988). In the Netherlands, a prevalence rate of 5.6% was found (Comijs, Dijkstra, Bouter, & Smit, 2000; Comijs, Pot & Jonker, 1998; Comijs, 1999). Prevalence rates of abuse can range between 1% and 35%, depending on definition, methods and techniques used (Pillemer & Finkelhor, 1988; Yan & Tang, 2001). Despite the variation in prevalence rates, these studies shed light on the extent of elder abuse. That elder abuse happens is beyond doubt, and since it affects older persons it warrants attention. The prevalence rates also raise further questions: what is behind these numbers? Why are these older individuals abused and not the others?

Part of the answer to this question can be found in risk factor studies. We can categorize these risk factors for elder abuse as ones related to the victim, ones related to the perpetrator and those attributable to the environment. Among the characteristics of the victim are social isolation, dependency, vulnerability, loneliness, age and gender. The possible characteristics of the perpetrator that can contribute to the occurrence of abuse are psychopathology of the abuser, substance abuse, a history of violence, stress and dependence on older person. Risk factors in the environment can be, for instance, ageism, negative attitudes towards old age and cultural norms (Anetzberger, 2004; Comijs, 1999; Kosberg & Nahmiash, 1996; Pillemer, 1986; Podnieks, Penhale, Goergen, Biggs & Han, 2010). Still the question about what is behind the numbers is not entirely answered. Risk factors, despite their indispensable value, are associations, and do not prove a clear cut answer as to why and how abuse occurs. The second question this thesis answers is how older individuals experience and explain the process of abuse, how do those abused see the chain of events? And relate the risk factors to how they experienced the abusive situation? These questions are addressed in chapter five.

Even though attention to the research on elder abuse is increasing, there is still a lack of studies on perspectives of various groups involved in elder abuse, this is particularly the case for older persons' perceptions and victims' views on elder abuse. The majority of current studies still focus on risk factors of abuse, definition and forms of abuse, and its prevalence (Anetzberger, 2004; Bennett, Kingston, & Penhale, 1997; Biggs, Phillipson, & Kingston, 1995; Comijs, 1999; O'Keefe, Hills, Doyle, McCreadie, Scholes Constantine, Tinker, Manthorpe, Biggs & Erens, 2007; Penhale, 2008; Peshevska, Sethi, & Serafimovska, 2014).

There are few studies that focus upon researching older victims' perspectives and older persons who do not have any experience with abuse (exceptions are for instance, Chen, Dolinsky, Doyle, & Dunn, 1981; Comijs, Pot, Smit, Bouter, & Jonker, 1998; Erlingston, Saveman, & Berg, 2005; Naughton, Drennan, Lyons, & Lafferty, 2013; Hightower, Smith, & Hightower, 2006; Hurme, 2002; Taylor, Killick, O'Brien, Begley, & Carter-Anand, 2013; Pillemer & Prescott, 1989; Pritchard, 2000, 2001; Thomas, Scodellaro, Dupree-Leveque, 2005; Yan & Tang, 2001, 2004). Therefore we delved into the exploration of these perspectives on elder abuse as they enable understanding abuse in the way older persons and older victims see and experience it therewith contributing to a conceptualization of elder abuse that allows a closer

convergence between the views of those involved in elder abuse and those investigating abuse.

Methods

This is a short discussion of methods used in the current study. For more detailed description of methodology and methods we refer you to Appendix F.

Given that the questions raised are primarily questions about the process and explanation of abuse, this thesis was based primarily on a qualitative study on elder abuse. Qualitative research allows one to explore and understand the phenomenon, which was the aim of this study. It allows the participant's story to emerge and enables answering the questions about the "what", "how" and "why" of elder abuse.

The data gathered through the diverse methods (see details below) were analyzed following a hermeneutic approach that helped to understand, explain and interpret the phenomenon of elder abuse from diverse perspectives.

The primary methods of data collection were in-depth semi-structured interviews and focus groups (for further details see also the chapters of this thesis). We also performed a systematic review on definitions of elder abuse.

The qualitative study was conducted among older persons, men and women age 63 and over, professional groups and experts involved in elder abuse. 35 in-depth interviews with non-abused ten older men and 25 older women (between the ages of 65 and 85 years) and 17 interviews with six older men and 11 older women (age range from 63 to 90 years) who experienced abuse. For non-abused older persons we adhered to the age limit of 65 years and for abused older persons we did not have the age limit (for more details see Appendix F). Additionally 35 expert interviews (six males and 29 females) who are currently working in the field of elder abuse were also conducted. All interviewees were contacted through reference of residential care facilities and the support center of domestic violence. In addition, older individuals, professionals and experts were contacted using a snowball sampling technique. Finally, abused older persons were also called upon via advertisements in freely distributed local newspapers in the larger region of the Randstad, the Netherlands. All the interviews were conducted between April 2012 and December 2013.

Interviews with older individuals lasted between 1,5 and 3 hours, with older victims of abuse between 2 to 4 hours, and with professionals between 1 to 1.5 hours.

We also held eight focus groups that involved experts, policy makers, managers, interest organizations of older persons, physicians, professionals from intramural and extramural care and older people themselves. Each focus group included one of these groups. The list with potential participants for the focus groups was made on the basis of known organizations in the Dutch field of elder abuse. Then, persons from different organizations who are involved in the field of elderly care were added to the list and asked for further referral and potential

participants. Following this, all the potential participants were contacted via e-mails and phone calls and invited to take part in a particular focus group based on their position, expertise, experience and skills. Older persons were contacted via interest groups for older persons. In total 42 participants were included in these focus groups. Focus groups were held in the period between February and March 2012 and lasted on average 1 to 2.5 hours.

Confidentiality and anonymity were guaranteed through signing an informed consent form or having an explicit oral agreement. With the permission of the participants, the focus groups and interviews were recorded.

For interviews and focus groups topic lists with main questions were used (see Appendices A, B, C). The list of topics and questions were first developed on the basis of existing research literature on elder abuse and also taken from the pilot interviews with older persons conducted before the study and adjusted while interviewing in order to be understandable and clear to our respondents.

Focus groups and interviews were transcribed verbatim. Verbatim transcripts were comprehensively and systematically analyzed using NVivo, a software program for qualitative analysis. The approach used for analyzing data was primarily inductive, in which analytical concepts are derived from the data through a coding technique based on a grounded theory approach (Glaser and Strauss, 1976). The key points were indicated with the codes, then the codes were grouped into concepts from which main categories were developed that were used as the basis for exploring and discussing the perceptions, ideas and experiences of the respondents.

For the focus groups and interviews with older persons, older victims and experts, we developed codes that totaled to 702, 886, 338 and 405 respectively. From these codes 5, 2, 4 and 3 corresponding main categories were derived.

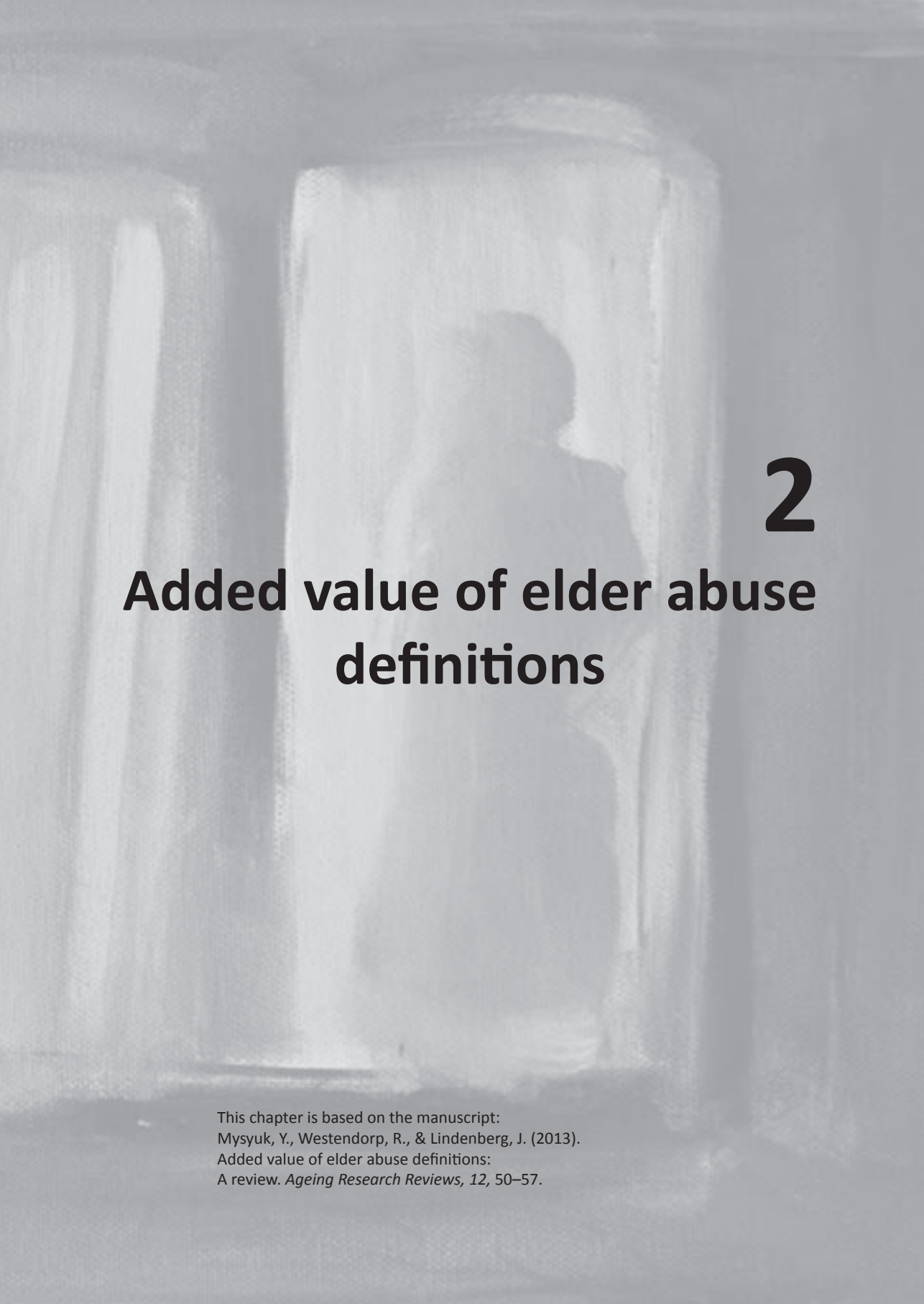
Outline of the thesis

In the **second chapter** of this thesis, definitions of elder abuse and their developments are reviewed. **Chapter three** explores different perspectives on the etiology of violence in later life. **Chapter four** discusses older persons' definitions of and explanations for elder abuse. **Chapter five** explores older victims' ideas about the causes and effects of abuse, the ways of coping with abuse and how they currently feel about it. In the **sixth chapter**, the framing of elder abuse as a social and a health problem is addressed, with attention to the factors that influence societal context and the health care system. **Chapter seven** raises the debate about the distinction of system abuse as a separate form of elder abuse. Finally, key findings of this thesis on perspectives on elder abuse are summarized in **chapter eight** of this thesis.

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2

Added value of elder abuse definitions

This chapter is based on the manuscript:
Mysyuk, Y., Westendorp, R., & Lindenberg, J. (2013).
Added value of elder abuse definitions:
A review. *Ageing Research Reviews*, 12, 50–57.

Abstract

Elder abuse has devastating consequences for older persons such as a poor quality of life, psychological distress, and loss of property and security. It is also associated with increased mortality and morbidity. Elder abuse is a problem that manifests itself in both rich and poor countries and at all levels of society. It is timely to discuss one of the basic problems that has hampered the study, detection and intervention of elder abuse as the variety of definitions that exist now produce a definitional chaos for researchers, practitioners, and policy makers. In this article we trace the elements of “how to define elder abuse” and situate them in their socio-historical context. We also analyze the purposes of these different definitions to assess their appropriateness in different settings concerned with elder abuse. Our analysis shows that elder abuse mirrors the societal arrangements which gave rise to them. It also highlights that it is a complex problem that is difficult to define. The central question is whether we need a common definition of elder abuse or different definitions that can be used in different settings. By evidence of our analysis we can see that there is a need for a sufficiently broad and flexible definition in order to cover different behaviors that can constitute abuse and the various settings in which it may occur. On the other hand, the definition needs to be specific and concrete to be useful in professional contexts. To take a further step forward for both research and practice of elder abuse, we propose to consistently adhere to the WHO-definition that leads the enquirer towards a better understanding of the problem and helps to distinguish it from other phenomena; and to a simplified definition for professional practice that sets boundaries to the phenomena and is appropriate for effective prevention and intervention measures.

Key words: elder abuse, definition, purpose

Introduction

Elder abuse remained hidden and taboo until quite recently. After child abuse and domestic violence were discussed publicly in the 1970s, elder abuse emerged as a form of family violence. During the early 1980s more public and professional interest was given to the issue of elder abuse (McCreadie, 1996; McCreadie, 2003; Pritchard, 1995). What exactly constituted elder abuse, however, was at that time less at the center of attention. Despite the fact that the problem of elder abuse has gained more public attention and quite some research was conducted, global statistics are still lacking, in many instances health care professionals still ignore it, and even now not enough action is taken to protect the individuals subjected to abuse. Moreover cases are often not recorded and unreported (Perel-Levin, 2008). Part of this underreporting is due to the complexity of and unequivocality inherent in the phenomenon itself: abuse can take place in a whole range of settings, including hospitals, nursing homes, residential care homes, day centers and even the person's own home, perhaps the one place where the older person might feel safest (Abbey, 2009; Ansello & O'Neill, 2010; Arai, 2006). Family members, adult children, or spouses are implicated in 90% of the cases of elder abuse. Other abusers include care professionals such as health or social workers, friends, or neighbors. Sometimes the abusers do not recognize what they are doing as a form of abuse; they, and at times their victims, do not know what constitutes abuse and what not, different organizations and professionals still use different terminology, adhere to different definitions and thus perceive abuse differently. This causes significant issues for research as it makes it more difficult to compare the outcomes of various reports as the result of the inconsistencies in the definitions of elder abuse (Pillemer & Wolf, 1986; Pillemer & Prescott, 1989; Newton, 2010).

Lack of agreement about the definition and its parameters has made the assessment of prevalence and incidence problematic from an empirical perspective (Harbison & Morrow, 1998). It makes it especially difficult to determine the extent of the problem of elder abuse. Prevalence rates of elder abuse of between 4-6 % were found in Canada, Great Britain, Finland and a prevalence rate of between one and ten percent was estimated in the USA (Griffin, 1994; 1979; Pillemer & Finkelhor, 1988). In the Netherlands one prevalence study on elder abuse showed a 5.6% prevalence rate (Comijs, Dijkstra, Bouter & Smit, 2000; Comijs et al., 1998; Comijs, 1999). Inadequate knowledge and training in how to detect abuse and a lack of staff awareness of what constitutes abuse can lead to underreporting of cases of abuse, underestimation and imprecise prevalence rates (Anetzberger, 2004; Griffin, 1994; Kivela, Kongas-Saviaro, Kesti, Pahkala, & Ijas, 1992; Ogg & Bennett, 1992; Podnieks, 1992). Some prevalence studies include only one form of elder abuse, such as solely physical abuse and others more than one, for example, physical and psychological abuse. As a result, prevalence rates are inconsistent and incomparable. On top of this, the studies involved provide different interpretations of elder abuse, this makes it confusing to analyze and understand the phenomenon

in a comparative way and it also has an impact on further research, and thus for the development of policies, prevention and intervention programs.

As a first step towards further developing the field of elder abuse in a comparative way, this article reviews definitions of elder abuse taking into account different aspects of these definitions and effects they can have on research and professional practice. The purpose of this analysis is to come to an understanding of the development of research and practice in elder abuse. By enabling comparative understanding it hopes to contribute to a comprehensive approach towards elder abuse.

Methods

Identification of studies

Studies were identified by searches of 11 databases (PsycINFO, PubMed, EMBASE, Web of Science, CINAHL, Academic Search Premier, ScienceDirect, Wiley, LWW, HighWire, Taylor&Francis/Informa) The search strategy consisted of the AND combination of two concepts: “elder abuse, “definitions”. For these concepts, all relevant keyword variations were used, not only keyword variations in the controlled vocabularies of the various databases, but the free text word variations of these concepts as well (such as: elder neglect, elder mistreatment, terminology, concepts, ontologies). Searches were restricted to papers published in English. The bibliographies of relevant original and review articles were screened aimed to include all published studies that provide information about the phenomenon of elder abuse, definitions of elder abuse, problems in defining elder abuse, the development of definitions, comparison and analysis of different definitions. The titles and abstracts of all articles identified by the search were screened and potentially relevant articles were retrieved and assessed. Additional relevant articles were identified through Pubmed, Google Scholar and other relevant search engines. Relevant books and chapters of the books were also included to the review.

Inclusion and exclusion criteria

The studies which provided information about the phenomenon of elder abuse, definitions of elder abuse, problems in defining elder abuse, the development of definitions, comparison and analysis of different definitions or any information were included in the review. The articles that did not contain necessary and relevant information were excluded from the review.

Results of the search

The PsycINFO yielded 113 hits, the PubMed yielded 77 hits from which 52 were unique (not found in other databases), the MEDLINE yielded 80 hits (0 unique), the Embase yielded 35 (12 unique), the Web of Science yielded 56 hits (17 unique), the CINAHL yielded 84 hits (36 unique), the Academic Search Premier yielded 42 hits (0 unique), the ScienceDirect yielded 4 hits (1 unique), the Wiley-Blackwell yielded

12 hits (0 unique), the LWW yielded 96 hits (76 unique), the Taylor & Francis yielded 38 hits (19 unique) and the COCHRANE yielded 0 hits.

Screening of titles and abstracts identified potentially relevant papers; then the papers were thoroughly studied and 12 studies which met the inclusion criteria are addressed in this review. Other relevant studies which were identified from references lists, authors and additional search engines were also included in the review (see Figure 1).

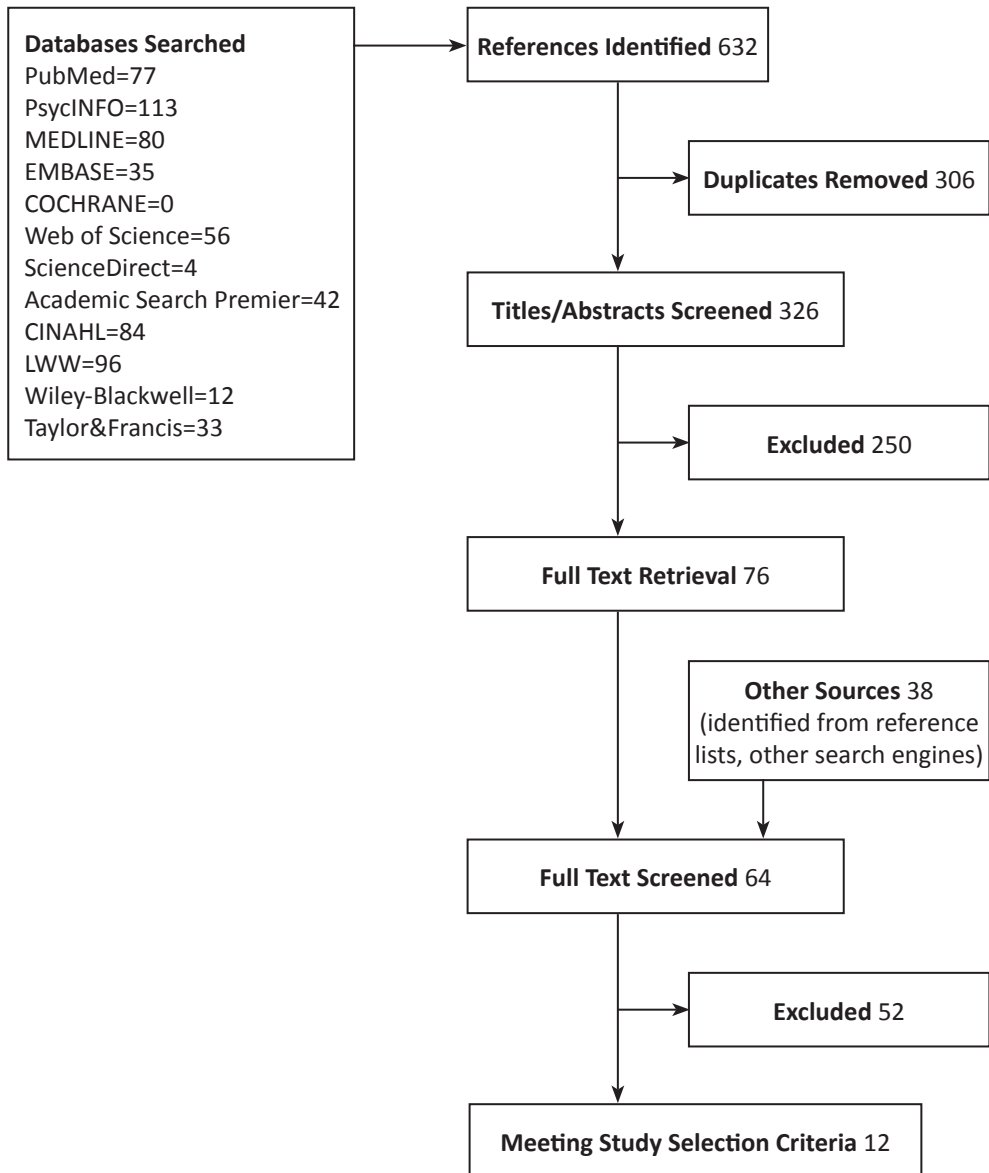


Figure 1. Literature search results flow chart

Information obtained during the symposium “Elder abuse in context” (Leiden, 2011), interviews, exchanges and meetings with professionals, experts, older people also contributed to this review.

Classification of definitions

To explore definitions of elder abuse, we will first discuss what kinds of definitions are commonly distinguished and which purposes they serve, as a comparative starting point for our analysis of elder abuse definitions. This will be the first starting point for our analytical framework for these definitions.

In a long history of definitions, many strands have become tangled together, so that “definition” has implicitly come to mean many different things to many people, often in ways that are inconsistent (Cregan, 2005). As a first step, Robinson (1950) distinguished two types of definitions: lexical (or also dictionary) and stipulative.

Lexical definitions are used when we need to explain the existing meaning of an old word or term; that is, a word/term that is already in use in the community, but unfamiliar to the person wanting the explanation. Lexical definitions seek to pinpoint what was meant by some word to someone at some point in time (Belnap, 1993).

If one might wish to explain a proposed meaning for a new word, stipulative definitions will be used. The purpose is to specify that a certain term will be used only to mean a certain precise thing within a given context (Belnap, 1993; Ierodiakonou, 1993). This may be a broadening or narrowing of an existing sense of a term; a completely new usage of an existing term; or may involve the creation of a totally new term. It is a specification of how the author intends to use the term in the future within a particular work or context, and binds the author to making good on that intention (Zalta, Nodelman, Allen, & Perry, 2009).

However, besides the two types that Robinson (Gulpa, 2008) distinguished, there are also many cases not exhibiting either one of these types, including perhaps most distinctively philosophical definitions; in these cases one wants both to rely on an old, existing meaning and to attach a new, proposed meaning, they try to explain the circumstances of elder abuse without necessarily being a full sum-up of the conditions that make it count as elder abuse. For this purpose a third type of definition, here called explicatory, is used in which analyses or explications expounded.

The three broadly distinguished types of definitions- lexical, stipulative and explicatory-discussed above can be identified in definitions of elder abuse as well. These types will be used as a conceptual framework to analyze elder abuse definitions in this review.

The incongruity between different interpretations and definitions of elder abuse also have their impact on the understanding of the consequences of the phenomenon. To explain the impact of elder abuse, we need to have a clear idea of what that phenomenon entails. Clear definitions serve several important purposes:

- As pointers towards the social problem in question which guide towards a clearer understanding of the issue;

- Clear and consistent definitions are necessary for permitting effective intervention and prevention strategies (Biggs, 1995).
- The three purposes can be identified in elder abuse definitions as well and that is the second tool in our analysis of elder abuse definitions. The overview of our analytical framework comprising the different types of definitions and the purposes that they serve is shown in Table 1.

Table 1
Types of definitions and their purposes

Type of definition	Semantics	Purpose
Lexical	Existing meaning of an old word/term	Better understanding of phenomenon; Focus on the problem under study
Stipulative	Proposed meaning for a new word	Effective prevention and intervention strategies
Explicatory	Both existing and proposed meaning	Better understanding of phenomenon, explaining causal mechanisms

Results

The development of elder abuse definitions

Despite that the recognition of elder abuse provoked quite a lot of debate, there was little attempt to place the phenomenon in some form of conceptual framework for some time. There is no common vision on definitions of elder abuse. In this article the evolvement of definitions of elder abuse in historical perspective will be analyzed. A critical analysis is insightful because it can enlighten our understanding in elder abuse and enable a step-forward in the conceptualization and understanding of the problem.

The definitions of elder abuse changed and developed considerably over time: from “granny battering”, “granny bashing” to “elder mistreatment” and “elder abuse” (1970s-2000s). Some of them were rather similar and had shared intentions, other ones introduced new and different elements. An overview can be found in Figure 2.

Females and physical assault

In the 1970s the focus of early definitions of elder abuse was on physical assault of older women with the use of the terms “granny battering”, “granny bashing” and “granny battering syndrome”. Part of the explanation for the attention for elder abuse at that exact point in time can be linked to larger developments in society.

Properties					General developments
Definitions	Rationale	Forms	Circumstances		
Granny battering ² (Bakker, Burston)	– “Ill treatment” of older people – Parallel with “baby battering”	– Physical assault	– Family crisis – Stressed caring daughter – Vulnerable women – Ageist negative assumptions	Females and physical abuse 1975-1977	
Elder abuse ¹ (O’Malley et al.)		– Physical pain, mental anguish	– Dependence of older person – Intention of harm by caregiver – Deprivation by caretaker of service – Relationship caregiver-caretaker		
Elder mistreatment ¹ (Beachler)				Risk factors and widening of actions 1979-1982	
Battered elder syndrome ² (Block & Sinnott)	– “Labeling”: syndrome, disease – Powerless and sick older people	– Physical, psychological and economic			
Granny battering ² (Eastman)	– “Systematic physical abuse of an elderly person by a relative” (p. 23)		– Importance of the quality of relationships – Females		
Old age abuse ¹ (Eastman)	– Applies to older people, not just grannies – A new term “maltreatment” – Narrowing the settings	– Physical, emotional, financial	– Care-giving relative	Widening of victims 1984	
Elder mistreatment ¹ (Comijs)		– Physical, psychological, material damage	– Acts or lack of actions – Personal or professional settings	Widening of perpetrators 1998	
Elder abuse ¹ (WHO)	– Excludes random acts of violence or criminal behavior – Reduces specificity but increases the territory covered by the problem		– Focus on trust relationship	Widening of context 2002-2003	
Elder mistreatment ³ (Bonnie & Wallace)	– Excludes cases of self-neglect, and victimization of elders by strangers – Ambiguous terms “harm”, “trust relationship”; intentional actions		– Vulnerable elder-caregiver		

Figure 2. Development of elder abuse definitions

¹ lexical, ² stipulative, ³ combination

The Industrial Revolution set the stage for reshaping the status older persons occupy in our society and their associated values. Through this revolution, men generally gained position in the upper tiers of societal hierarchy, predominantly controlling decision-making and resources. Having power to control resources put them into visible roles in society, maintaining the status quo. Those individuals lacking power and visibility, such as women and children, were less valued. This was reflected in the social movement of feminism that developed in response. The attention for females (weak, powerless, vulnerable) in definitions of elder abuse can be seen as mirroring these developments. At the same time we can identify an ongoing, increased incidence rate of abuse, not only of women and children, but also of the elderly (with the special accent on elderly women) generally considered the most invisible and least valued of all (Baron & Welty, 1996). The term “granny battering” was used in the UK as an euphemism for the ill-treatment of older people (Baker, 1975).

The terminology of child abuse was adopted, and doctors concerned with the elderly saw “baby battering” to have its parallels for their older patients (Burston, 1975). In Baker’s (1975) article, the term included the risks to older people’s health and well-being, as well as overmedication and general misuse of drugs, and physical abuse. The “granny battering syndrome” was quickly adopted as a model for social and health care workers, featuring a stressed or burnt-out daughter caring for her physically disabled and slightly confused mother (Eastman 1982; Cloke, 1983; Whitehead 1983; Schlesinger, 1984).

Besides the focus on vulnerable females, another focus that can be identified in these definitions was the one on physical assault. Case examples were cited to suggest that those at risk were living in three generations families: “the domestic situation may well be linked to a pressure cooker” (Burston, 1977). The term “granny battering” itself revealed the often ageist assumptions that lay behind its labeling, where elderly victims are seen as passive recipients of care and therefore a burden to their family.

In a later definition of elder abuse by O’Malley, Segel and Perez (1979, p.13) attention was again given to physical abuse. They defined it as: “the willful infliction of physical pain, injury or debilitating mental anguish, unreasonable confinement or deprivation by a caretaker of services which are necessary to the maintenance of mental and physical health”. This definition broadened the context of physical abuse in comparison to previous definitions. The abuse was also considered as intention of harm. The relationship between caregiver and caretaker was introduced. In spite of these new elements, this definition still describes elder abuse quite narrowly; the terminology used in the definition is difficult, and not fully unambiguous. It can be considered a lexical definition; elements require definition by themselves. It applies the label of abuse only if there is the relationship “caregiver”-“care-receiver/caretaker” and when the caregiver intends to do harm. It also assumes that the older person is dependent. This assumption effectively excludes independent elderly who, as we know from

prevalence studies (Griffin, 1994; 1979; Pillemer & Finkelhor, 1988; Anetzberger, 2004; Griffin, 1994; Kivela et al., 1992; Ogg & Bennett, 1992; Podnieks, 1992), may also be the victim of abuse.

In the early definitions of elder abuse one can thus observe similar elements. The emphasis of these definitions was on vulnerable and unprotected women who were dependent on other people and elder abuse was only associated with physical battering. These definitions were also more clinically oriented.

Risk factors and widening of actions

The focus of later elder abuse definitions shifted to risk factors and different types of abuse. For example, Beachler in his definition of “elder mistreatment (McMullen, 2004)”, focused on risk factors of abuse such as: dependency, developmental disorder of abuser, situational crisis of abuser, or victim and long-term environmental conditions). Beachler tried to determine the underlying associated factors of elder mistreatment and what actions should be taken. His work was never published, but it reflected the tendency of that period; it was focused on more than just physical assault and moved away from the term ‘battering’ that denotes a physical emphasis. Elder abuse was put in a wider context. Thus changes in the tendencies in society such as reshaping the status of older persons and their values, maintaining status quo of men, social movement of feminism were reflected in the definitions of elder abuse.

Around the same time another definition appeared; the “battered elder syndrome” (Block & Sinnott, 1979). The battered elder syndrome included types of abuse instead of the incorporation of risk factors as Beachler for instance had done. Three major categories of abuse were distinguished: physical, psychological, and financial. Physical abuse included both bruises as well as lack of supervision and proper care that can lead to injuries. In the category of psychological abuse, threats and isolation were included. Stealing or cheating the elderly out of their own funds and possessions constituted material or economic abuse. Abuse was further defined in terms of verbal and emotional factors (Block & Sinnott, 1979). It was a step forward in defining elder abuse as forms of abuse were distinguished more clearly and it went beyond physical abuse, although “battered” still connoted physical abuse. In spite of this fact, the term “battered elder syndrome” is kind of a label that has a definite physical association. It seemed from this definition that abuse is a disease and it needed treatment and older people are those who were seen as patients; powerless and sick. As the early definitions of elder abuse this definition also focused on unable, sick, susceptible elderly.

Mervyn Eastman, a practicing social worker from London in a similar trend, defined “granny battering” as “the systematic physical abuse of an elderly person by a relative” (p. 8). Eastman pointed out that ageist attitudes could result in a denial by professionals that physical abuse existed. The problem of abuse was conceptualized in terms of care-giving and emphasis was again put on the dependency and vulnerability of the older person, arising from their physical and mental frailty and

on the stress entailed in caring. By implication, the key persons in this situation, both older person and caring relative, were females following the still prevalent tendency of that time (McCreadie, 1993).

Two years later Eastman (1982) widened his definition: “granny battering is defined in general terms as the abuse, either physical, emotional or psychological of the elderly by a care-giving relative on whom that elderly person is dependent” (Eastman, 1982). The types of abuse that were mentioned were physical assault, neglect, financial exploitation and abandonment of an older person by a relative. He later added sexual abuse to this list (McCreadie, 1993). This definition widened the context of abuse, showed it in a different, and wider perspective, a similar tendency as we have observed in Block and Sinott (1979). The importance of the quality of relationships was emphasized, while stressing that the relationship was one between the elderly and their caregiver. Moreover the addition of the word “systematic” added an emphasis on the continuity of this relationship (Eastman, 1982). A new accent in the definitions of elder abuse was given to victims; assuming that the victims of elder abuse could be all older people thereby changing the widespread belief that older females (“grannies”) are the only possible victims of abuse. Eastman’s definition of “old age abuse” is a good illustration of this new shift.

Widening of victims

Two years later, Eastman defined old age abuse as “the systematic maltreatment, physical, emotional or financial, of an elderly person by a care-giving relative” (Eastman, 1984, p.23). Eastman pointed out that terms such as “granny battering” and “granny bashing” were unsatisfactory since “battering” and “bashing” are suggestive of the actions of hooligans and thugs, while “granny” is expressing sweet innocence. Therefore the term “old age abuse” makes clear that abuse applies to older people, not just “grannies” showing heterogeneity within the older group. It also suggested a link with the concept “child abuse” placing elder abuse firmly within the family context (Eastman, 1984). Two things about this definition can further be noted: firstly, that systematic maltreatment was introduced as a criterion of abuse and secondly, that care-giving was considered an intrinsic part of the phenomenon, thus limiting elder abuse only to a care-giving situation. Although the strength of this definition is that different types of abuse were again highlighted, at the same time it limits the scope for what counts as abuse and who can be involved. Eastman also mentioned that it was difficult to define precisely what emotional, financial or physical abuse was, because of the different ways people live and deal with things. This was an important point as the complexity of the phenomenon was pointed out and possibilities for further research were opened. This thus brought new views in comparison with his other definitions. Despite of its positive aspects, this definition introduced a new term “maltreatment” which also needed further conceptualization. It also narrowed the settings in which elder abuse can occur to a family setting and by a care-giving relative.

Widening of perpetrators

The continuous widening of the circumstances under which a certain action can be considered elder abuse persisted in the definitions that followed in the 1990s. An example can be Comijs (1998, p. 11) proposed definition of elder mistreatment; “all acts or the refraining from acts towards persons over 65 years of age, by those who have a personal or professional relationship with the older person, leading to (repeated) physical, psychological, and/or material damage”. Her definition sets the boundary for being an elderly at 65 years. On the one hand this can be seen as an advantage since a cut-off point for defining an older person was introduced, but on the other hand, it can also be a limitation since people who are under 65 that have experienced abuse due to age-related processes will be excluded in this definition. Defining elder abuse by stipulating a chronological age can have consequences for who counts, and who does not count. While the definition of Comijs is somewhat arbitrary, it is based on the age at which one can begin to receive pension benefits in the Netherlands.

Some developed countries have accepted the chronological age of 65 years (the entitlement age for pension benefits in a number of countries) as a definition of “elderly” or “older” person, but this, for example, does not adapt well to the situation in Africa. Although there are commonly used definitions of old age, there is no general agreement on the age at which a person becomes old and it is questionable whether in practice a chronological age is suitable in this context. The common use of chronological age to mark the threshold of old age assumes equivalence with biological age, yet at the same time, it is widely accepted that these two are not necessarily synonymous (Thane, 1978; WHO, 2002; 2011). It shows that there are also problems with defining “older/elderly person” that should be addressed when defining elder abuse comprehensively.

Besides the inclusion of a threshold in chronological age, Comijs also widened her definition in several ways. Abuse could occur in personal or professional settings, forms of abuse were distinguished and it was pointed out that abuse can be “repeated”. Therefore, in line with definitions in that period, it broadened the possible situations and included the frequency of behavior as a condition for elder abuse.

Widening of context

The definition of Comijs resembles the definition of the WHO, which is probably the most well-known and widely used currently. The WHO-definition can be considered a lexical and explanatory definition: “Elder abuse is a single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person” (WHO, 2002). It is important to note that elder abuse in this definition, as with Comijs’ her definition, excludes random acts of violence or criminal behavior against older people. The harm of elder abuse overlaps with, but is not necessarily synonymous

with, criminal acts. A trusting relationship between the abused and the abuser – such as partners, children, in-laws, grandchildren, nurses, social workers and home helps – is at the heart of the issue. In this definition elder abuse is seen as a betrayal of trust. This new focus on trust is derived from the occurrence of elder abuse within different kinds of relationship. Rather than detailing different forms of abuse, the definition cites “single or repeated acts” and “lack of appropriate action”. As with “any relationship”, each reduces specificity, but widens the context covered by the problem (Brammer & Biggs, 1998). It enables a wider range of inclusion and therefore runs a lower risk of unnecessary exclusion but simultaneously increases the chance of ‘false-positives’.

The Panel to Review Risk and Prevalence of Elder Abuse and Neglect in the USA (Bonnie & Wallace, 2003) developed a definition of elder mistreatment which included a number of conditions we identified in the two last definitions: a) intentional actions that cause harm or create a serious risk of harm, whether or not intended, to a vulnerable elder by a caregiver or other person who stands in a trust relationship to the elder; b) failure by a caregiver to satisfy the elder’s basic needs or to protect the elder from harm. “Mistreatment” here conveys two ideas: that some injury, deprivation or dangerous condition has occurred to the elder person and that someone else bears responsibility for causing the condition or failing to prevent it (Bonnie & Wallace, 2003). Two features of this definition merit emphasis. First, the term “mistreatment” was meant to exclude cases of self-neglect. Self-neglect was seen as a separate domain of elder protection, not as a component of mistreatment. Second, elder mistreatment, as defined by the panel, excluded victimization of elders by strangers, as this was seen as a kind of criminal behavior, not as a component of the domain of elder mistreatment that also signals the integration of elder abuse in the field of family violence. The definition of the Panel is an example of a combination of lexical and stipulative definitions. As in the definitions of Comijs and the WHO the stress in this definition was put on the nature of the relationship between the older person and the perpetrator. This definition shows some more striking similarities and differences with the definition of the WHO. As the WHO-definition it also focuses on a trust relationship, harm, it also brings attention to intentional actions that can cause harm to an older person. On the other hand, this definition introduced more ambiguous terms than it gave demarcating explanations. Concepts as “elder”, “vulnerable elder”, “trust relationship”, “caregiver”, “harm” were mentioned, thus, they also needed to be defined. This made it more complicated, but at the same time it is more comprehensive and fitting to reality because elder abuse is a complex phenomenon involving many variables and it is not easy to define it in a simple way.

Discussion

Currently the definitions of elder abuse that are widely used are those developed by WHO, the Panel to Review Risk and Prevalence of Elder Abuse and Neglect, and in the Netherlands the definition developed by Comijs. Some of them are old

definitions that were modified and others are new ones that were developed lately, reflecting developments and changes in the society.

We can identify from this overview that stipulative definitions, i.e., which explain existing meaning of an old word/term, are usually used in a professional context such as the starting definitions of Eastman, as they need to be concrete and specific. These kinds of definitions enable the observation of elder abuse under specific conditions, by summing up different characteristics. They are useful for this context because they help to indicate the problem clearly and analyze it more precisely, taking into account special features of the particular setting. They also enable specific prevention and intervention on the given conditions.

For research purposes however lexical definitions, i.e., which explain proposed meaning for a new word, are more often applied as they can lead the way towards understanding and explaining the phenomenon without setting too many limiting conditions that would lead to “missing values”.

It appears from this review that pure explicatory definitions, i.e., which explain both existing and proposed meaning, are not common in elder abuse definitions. This could be related to the position that the field of elder abuse has within the scientific community, only limited attention is paid to it. As a result there is still a lack of understanding in numerous issue related to elder abuse. It is therefore explainable why this type of definitions is as of yet not really present.

A continuous shift in a wider focus can be found in this overview of definitions. The focus of early definitions was on physical assault and vulnerable and unprotected older women. Later the focus shifted to the forms of elder abuse and abuse applied to all older people, not only females. The context of elder abuse definitions also changed (trust relationship, different settings), and new tendencies appeared. These shifting definitions reflect the socio-historical developments at the time and similarly mirror developments in the field of elder abuse.

It was shown in this review that purposes of definitions, as identified in the first part of this review, are often mixed in elder abuse and that this mixture goes together with the combination of kinds of definitions. However, whether lexical, stipulative or explicatory, it is important to realize that the content of definitions of elder abuse has its implications for research and practice and as a result impacts people's lives directly.

It is crucial to recognize that elder abuse is a very complex issue with diverse definitions and terms. A variety of definitions including use of the interchangeable conceived terms such as “abuse” and “mistreatment” produce a definitional chaos for researchers, policymakers and practicing professionals. Many researchers might have underestimated the problem of elder abuse because they fail to define or operationalize the terms in a clear and objective way. Moreover comparative efforts face difficulties as they might be discussing from a different starting point. It makes it not easy to deal with the problem of elder abuse, differentiate it from other phenomena, to implement intervention and prevention strategies; it can provoke difficulty in analyzing the results from previous studies on elder abuse and the development of research and effective policy are frustrated.

On the one hand, we can conclude from this overview that there is a need for a sufficiently broad definition in order to cover different behaviors that can constitute abuse and the setting in which it may occur, to provide improved legal protection, and to develop appropriate multi-disciplinary responses. Such kinds of definitions may be useful and appropriate for academia and policy makers. This definition needs to be comprehensive and uniform, covering quite a wide variety of cases while at the same time guide us towards understanding the phenomenon. A well-developed lexical definition may be the most suitable for this purpose. As an example of this type of definitions the WHO definition can be used. This definition is in line with two important purposes of definitions that were mentioned in the introduction. It can serve as a pointer towards better understanding of elder abuse. It also helps to distinguish elder abuse from other phenomena. It is however does not correspond with third purpose of definitions as the definition used by professionals should be more specific and concrete in order to permit effective prevention and intervention strategies. On the other hand, it is necessary for a definition to be specific and concrete in some settings. It is especially important in (professional care) practice, as the definitions that are used by practitioners and professionals need to be context specific and enable them to work with and clearly identify elder abuse. They need to guide professionals and to help to understand the characteristics of a particular setting. These definitions should be adapted to these settings and include the features of the conditions, be flexible and reflect the empirical reality. Stipulative definitions that are narrow and specific would meet these objectives.

Conclusion

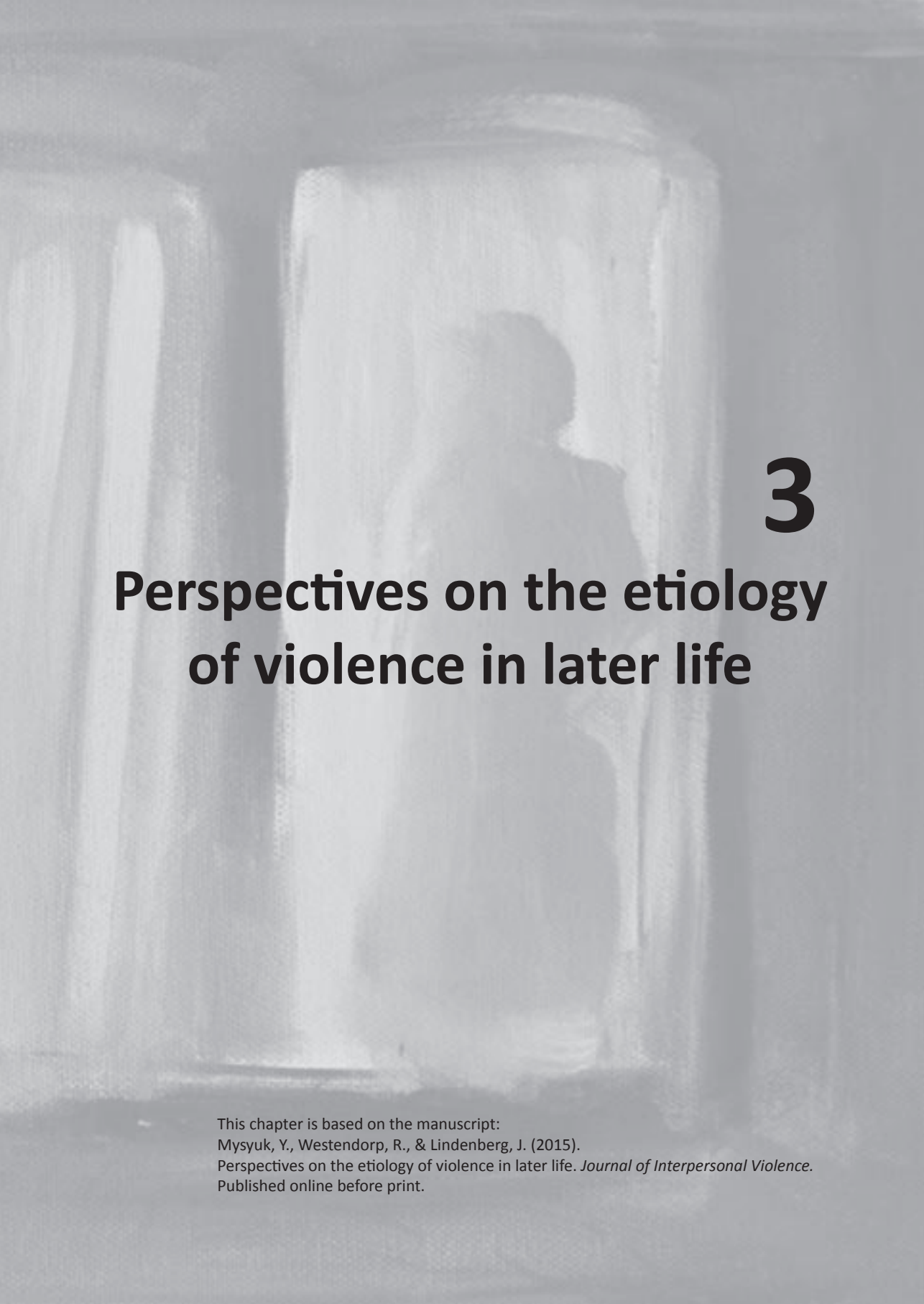
The problem of defining elder abuse cannot be easily solved, but it is clear that more attention should be paid to it; it is after all the starting point of our practice and research. The question of defining elder abuse remains open. Do we need a common definition of elder abuse or do we need different definitions that can be used in different settings? Considering the overview of definitions that was discussed above it is clear that definitions, especially those of a social problem like elder abuse, are set in a social surrounding. They are not timeless and change with the currents of socio-historical changes that influence the inclusion and exclusion process of what counts as elder abuse. It is the challenge now, however, to take a further step forward in both practice and research of elder abuse. One such step, albeit a very basic one, we propose here: for research purposes a lexical definition such as the WHO-definition should be consistently used. As it was shown earlier this type of definition follows the main purposes of definitions: it leads the enquirer towards a clearer understanding of the problem and helps to differentiate it from other phenomena. For professional practice, however more use can be found in a stipulative definition that set boundaries to the phenomenon and fits with the cultural and social context of that practice. Since lexical definitions do not serve this purpose, they are not appropriate for these particular settings. However, we

argue that as scholars we can nevertheless set a first step by choosing one lexical definition that we will all follow in our research. Since it is already widely used we propose to follow the WHO-definition “elder abuse is a single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust that causes harm, distress to an older person”. One definition might not be enough for the social problem we are dealing with, but it could be a helpful and necessary starting point to enable further understanding of and research on elder abuse.

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3

Perspectives on the etiology of violence in later life

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Abstract

This article focuses on the development of a conceptual framework for explaining the etiology of violence in later life by various groups involved in the field of elder abuse. In this study we explore this through eight focus groups with different professionals involved in the field of elder abuse and older persons themselves and in interviews with 35 experts in the field. Our findings show dependency, vulnerability, power and control, social isolation, stress and care burden play a central role in their explanations for the occurrence of violence in later life. The role of a history of violence in violence in later life is equivocal. The complexity and ambiguity of dependency and vulnerability, the notion of mutual dependency, and diverse attitudes and expectations towards them that arise with the ageing process are distinct features of violence in later life that were found.

Key words: elder abuse, etiology, dependency, vulnerability

Introduction

Explanations for the occurrence of violence in later life that are often described in the literature focus on individual characteristics, interpersonal interactions and relationships, and factors related to the environment. Indeed, variables such as mental problems of the perpetrator including substance abuse, and dependency, social isolation, stress and overburdening, power and control dynamics are important explanatory variables have been identified (Anetzberger, 2004; Biggs, Phillipson, & Kingston, 1995; Burnight & Mosqueda, 2011; Phillips, 1986; Pillemer, 1986).

Violence in later life is differently viewed and experienced by various groups involved in the field of elder abuse. This raises the question how violence in later life is understood and explained by those groups. By exploring the etiology of violence in later life through empirical data from expert interviews and focus groups of diverse stakeholders we come to a conceptual model for explaining the etiology of violence in later life from the perspectives of the groups involved in elder abuse.

In this article, elder abuse refers to violence perpetrated by anyone in the environment of an older individual that is trusted by this individual and follows the definition of the WHO¹. We do not use the age limit and instead adhere to the principle that abuse arises as a result of circumstances connected to age-related problems. The prevalence rate of elder abuse in the Netherlands was estimated at 5.6 % with 3.2 % for the prevalence of verbal aggression, 1.4 % for financial exploitation, 1.2% for physical aggression and 0.2 % for neglect accordingly (Comijs, Pot, Smit, & Jonker, 1998).

Health care in the Netherlands

Our study was conducted in the Netherlands, a country known for having a rather elaborate social welfare system that includes quite an extensive amount of formal care for older individuals. This might impact the explanations of abuse we delve into. To situate our findings, and the way our participants explained abuse, we first give a brief introduction into the circumstances of older individuals in the Netherlands. Particular attention is given to care and support, because this played an important role in the explanations of our participants.

Over the past sixty years in the Netherlands, there was a shift in responsibility for care of older persons from familial and informal care to institutional care (van Bodegom et al., 2010). Long-term care in the Netherlands is provided both in institutions (residential care) and in communities (home care). The residential care sector includes nursing homes and residential homes. Residential homes provide housing, care, help and support for persons who cannot live independently. Nursing homes are principally for people with more severe conditions who require continuous care. However, the care provided in residential care facilities has become more complex over the years and nowadays the services between nursing homes

¹ Elder abuse is a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.

and residential homes often overlap. In addition to residential and nursing homes, semi-residential care settings such as day care centres and short stay care centres provide care to individuals who still live in their own homes, but who have limited access to informal care (OECD, 2011; Schäfer et al., 2010). Older women more often live in institutional care facilities than men because the average life expectancy of females is higher, but also because they traditionally marry men who are several years older (van Bodegom et al., 2010). Another form of care for older persons in the Netherlands is home care that includes home help, personal care and nursing care at home which is provided by different home care organizations or residential and nursing homes. To illustrate, in 2008 approximately 6.7% of the Dutch population over the age of 65 received long-term care in an institutional setting, while 12.9% of this population received long-term care at home (OECD, 2011).

Informal care is an important form of care in the Netherlands and can involve informal caregivers and volunteers. The number of individuals providing informal care has remained remarkably stable in the last decades; between 12-13% of Dutch above the age of 18 provide informal care. The acknowledgment of the care and contribution these informal caregivers provide seems limited in the Netherlands (de Boer, 2005) and this is perhaps best illustrated with the 'informal care compliment' which is a token of appreciation of the Dutch government for informal caregivers amounting to 200 euro annually. About 7% of those caregivers are heavily to very heavily burdened by the care they provide (de Boer, 2005, p. 127). In addition, there are indications that due to demographic changes and the labor participation of females the supply of informal care will not be sufficient for the demand of informal caregivers in the future. Both emotional and instrumental support (helping with housework, administration) are provided by caregivers. Emotional support rather than instrumental support seems to play an important role in the Netherlands among family members. Informal helpers are – in order of number of hours of informal care given according research in the SHARE study (Bonsang, 2009) – partners, children, other family members and friends. Older persons who live at home but also the ones in care institutions receive informal care. Approximately 40% of older people receive informal care (de Boer & de Klerk, 2013; van Bodegom et al., 2010). About 4% of older individuals live with their children in one house (de Boer, 2005).

Methods

A qualitative study on the meaning, perceptions, ideas and views on elder abuse was conducted among older persons, professional groups and experts. The methods of data collection were focus groups and semi-structured interviews. The aim of focus groups was to capture options and views of different groups on elder abuse to be able to understand how these groups define and explain elder abuse. Expert interviews were held in order to show how experts in the field, people who work with the problem, frame abuse. The interviews added to the knowledge obtained by conducting focus groups. Confidentiality and anonymity were guaranteed through an explicit oral agreement.

Focus groups

Eight focus groups were conducted. The topics that were discussed were defining elder abuse and actions that could be performed to reduce its occurrence. We conducted separate focus groups with experts (7 persons: 5 females and 2 males), policy makers (6 persons: 5 females and 1 male), managers of health care organizations (7 persons: 3 females and 4 males), interest organizations of older persons (3 persons: 2 females and 1 male), physicians (4 persons: 3 females and 1 male), professionals from institutional (4 persons: 4 females) and home care (4 persons: 4 females) and older people themselves (7 persons who had no experiences with abuse: 4 females and 3 males). In total 42 participants were included. The focus groups lasted 1 to 2.5 hour; by and large this seemed to depend on the number of participants. The groups were homogeneous in professional background, however heterogeneous in gender and age, except for the focus groups of institutional and home care. During the focus groups a protocol was followed that included the introduction of the purpose of the focus group, the main rules, starting and leading of discussion, the main questions and how to deal with challenging moments (see Appendix A for the protocol). The list with potential participants for the focus groups was made on the basis of known organizations in the Dutch field of elder abuse. Then, persons from different organizations involved in the field of elderly care were added to the list and asked for further referral and potential participants. Recruitment of older persons was through senior citizen organizations in the Netherlands. Pre-screening of older persons regarding their experiences with abuse was done by telephone. Following this, all other potential participants were contacted via e-mails and phone calls and invited to take part in a particular focus group based on their position, expertise, experience with abusive situations and skills. This was checked in a telephone conversation preceding the focus groups. All participants were informed of the purpose of the focus groups. Before the start of the focus groups permission was asked for recording. The focus groups took place between February and March 2012 and were transcribed verbatim.

Interviews

35 expert interviews (6 males and 29 females) with diverse professionals who work in the field of elder abuse were conducted. The experts included academics, managers of health care facilities, professionals from public health services and support centers for domestic violence, elderly advisors and case managers and police officers. The experts in the field were identified through different organizations in research, elderly care and elder abuse fields. Furthermore they were approached through contact persons via a snowball sampling technique. The experts were considered as such based on their experience with elder abuse, and/or special knowledge and expertise related to the field of elder abuse. During the interviews, the discussion focused on how cases of abuse were identified, assisted and followed-up. The semi-structured expert interviews were held by guidance of a topic list. The topics and the questions of the topic guides were developed based on existing research literature on elder

abuse and also with help of pilot interviews with some experts conducted before the study, as well as discussions and debates with experts and professionals.

The topics and the questions of the interview guide were developed based on existing literature on elder abuse and on findings obtained from the focus groups. The topics of the interview guide included background and meaning of elder abuse, profiles of victim and perpetrator, collaboration and network, perspectives of wider society and necessary actions to deal with elder abuse (see Appendix B). The expert interviews lasted 1 to 1.5 hour. The interviews took place between December 2012 and April 2013. All interviews were transcribed verbatim for analysis.

Analysis

Verbatim transcripts of the interviews and focus groups were comprehensively and systematically analyzed using the computer software NVivo. The approach used for analyzing data was primarily inductive, in which analytical concepts and perspectives are derived from the data through a coding technique based on a grounded theory approach (Glaser and Strauss, 1976). First the text was divided in segments that discussed the same theme (content analysis). Second, through interpretative analysis concepts were indicated with codes, then the concepts that emerged from the codes were used to develop the main categories that served as the basis for exploring and discussing the views and experiences of the respondents. Such an approach allows exploring the ways in which respondents explain their own experiences and also permits unexpected topics, issues and thoughts to emerge.

Results

We identified the following concepts that play a role in explaining the etiology of violence in later life and its associated factors according to our participants: dependency, vulnerability, power and control, social isolation, stress and burden and history of violence.

Dependency

Loss of autonomy and increasing dependency in old age are seen by experts as the most important issues that can influence the occurrence of violence. Experts and professionals usually meant relying on other people for assistance or care when they referred to dependency of older persons, this could be in the physical, economic, social, or psychological domain. Older persons can become dependent on their children or other family members. Different forms of dependency that are present in later life put older persons even more at risk of violence. A similar opinion was expressed by one of the participating professionals:

Dependency is often present. Dependency on the perpetrator, and this can be dependency because of housing, financial dependency, emotional dependency, dependency on care and help... In my opinion dependency plays a role in abuse, it is a risk factor for abuse. (Focus group "Institutional care")

Professionals, especially in the group of physicians and home care, pointed out that not only the victims are dependent on their abusers, but often also the perpetrators can be dependent on their victims. One professional from extramural care stated it as follows: “In my experience, very often abusers are dependent on the older persons, they do not have their own house, normal job and means of living”. Our participants saw mutual dependency as a common and determining feature of elder abuse.

Vulnerability

A concept that was discussed as important in several focus groups and interviews was the notion of vulnerability. Similar to dependency, vulnerability was seen as having different forms. One of the participating policy makers described:

You can observe different types of vulnerability, for example, psychological or physical. In a case of financial abuse the person is not able to do his or her own administration and somebody else has to do it for him or her, this makes this person per definition vulnerable.

Thus an inability to perform daily tasks or limited opportunities to remain autonomous and independent poses potential risks to become exposed to stressful situations in which abuse can occur. According to expert opinions dependency and vulnerability are distinct but interrelated concepts:

[...] we see older people as vulnerable and dependent, they go together, they are connected. If we think about older persons the first idea that comes to our mind is that the elderly are fragile, weak and dependent. That's the image that a lot of people have about older persons (Interview, expert public health sector).

Older people shared this notion of vulnerability and dependence. For them being vulnerable leads and at the same time is a consequence of being dependent and they are afraid of losing their independence as one older participant formulated it: “You are vulnerable when you are dependent on others” (Focus group “Older persons”).

At the same time, however, we obtained contradictory results from the focus groups, showing that older people themselves sometimes refrain from using the word “vulnerable” to describe a situation that in other groups would be described as such. Rather, older people see vulnerability as a concept that has a negative connotation putting them in a dependent position and presenting them as incapable, weak and impaired. Older persons describe that you can be vulnerable only when you yourself feel vulnerable and fragile; otherwise it is just the perception of other people. They argued that often other people see and present older persons as frail and vulnerable, in spite of the fact that according to older people they would not consider themselves as being so (Focus group “Older persons”). Older persons sometimes see vulnerability as a social artefact, something that is imposed on them by the outside world basically because they have aged. At the same time experts see vulnerability as something related to older persons and to the occurrence of abuse, making vulnerability an especially contested and ambiguous concept.

The conceptualization of vulnerability becomes more complex as professionals often saw this concept as something that can be applied to different age groups, as one expert from the local government phrased it: “We can all be vulnerable at different times in our life (Interview expert local government)”. It seems that our participants viewed the condition of vulnerability as neither age-specific or age-related; everyone can be seen as vulnerable to some degree.

Social isolation

The concepts of dependency and vulnerability were often mentioned together with the role that social isolation played in cases of elder abuse. Professionals, especially in the group of experts and policy makers, voiced assumptions and ideas about social isolation as a contributor to circumstances in which abuse can occur. Social isolation was seen as a lack of support from family, friends or neighbors and a lack of established social networks. One of the experts stated this as follows: “Social isolation is a basis for abuse. Being alone, having no social contacts, no social networks can eventually lead to abuse”. One of the interviewees pointed out that there is an association between social isolation and loneliness: “I think that loneliness plays a big role, older people are lonely and isolated. What I often see and observe is loneliness, isolation and dependency”. Other respondents shared this idea. Thus social isolation is often linked to loneliness and financial or psychological dependencies.

Experts in the focus groups not only discussed the idea of isolation as a contributor to abuse, but also as a consequence of abuse. They described that as a result of the experienced abuse, some people do not want to go out or socialize, and as a result withdraw from their community and become isolated and feel lonely. One of the experts pointed out that “elderly are often isolated, they are alone with the abuser since the abuser is someone whom they know and the other contacts are just excluded”. It makes it more difficult to detect abuse and to change such a situation: “It seems like older people are locked in a vicious cycle, not seeing other opportunities and ways out (expert from non-profit organization)”. Social isolation is therewith at the same time a cause and a consequence of violence in later life.

Stress and burden

Besides the web of dependencies sketched above, both professionals and older persons mentioned many issues of stress and burden experienced by the perpetrator. These included lack of time, lack of privacy, difficulties in relationships, and decreases in financial recourses. Stress and burden seem to be conceptualized as pre-dependency issues. Some of the interviewees pointed to a combination of different factors that can lead to stress and eventually accordingly can lead to violence. Possible contributors that were mentioned in this context were unemployment, substance abuse, and problems in the family that could each contribute to the development of stress. One of the respondents from the focus group “Physicians” phrased it as: “Stress and overburdening are very common, in particular when one person is caring for another one. It can be overburdening to provide care” and from the findings of de Boer et al.

(2005) we know that – at least – for 7% of the caregivers in the Netherlands, the care provision is indeed considered a heavy to very heavy burden. The findings from the focus groups and interviews show that the predominant image of elder abuse is one of a dependent older person, who becomes a difficult burden to her or his adult child and who abuses or neglects the older person in response to stress and frustration.

Power and control

Through the multiple losses of power that can occur during the ageing process, older persons can feel that they are burdening others. One of the older persons phrased it as “older persons feel powerless, they do not wish to bother others”. These shifts in power combined with dependency and vulnerability increase the feeling of older persons that they are disturbing others and makes them feel redundant. The powerlessness they experience also has its impact on the experience of power and control feelings of the perpetrator.

Professionals from different focus groups pointed out that there are different reactions of an older person to a lack of power, such as acceptance and adaptation, or denial and resistance. The decrease in power they experienced in the relationship with the abuser and their reactions to this loss of power seemed to be influenced by older persons’ perspective of being unnecessary for society, especially in the case of adaptation and acceptance. Some of these reactions may cause frustration to an older person and to a perpetrator and these were seen as perhaps bringing on (further) violence on the side of perpetrator. These ideas of professionals come close to the views of older persons. “A lot of older people just do not react to an abusive situation, they just ignore or accept it” stated one of the participants in the focus group “Older persons”.

Loss of power is an important factor in violence in later life; experts felt that this was not only the case for older persons, but also for perpetrators. Respondents from the focus group of policy makers described that: “Powerlessness and incapacity can lead to abuse, the abuser is trying to increase his or her power and control by using abuse.” One of the experts saw the issues of power and control imbalance as follows: “He [perpetrator] is going to abuse because of a lack of power, incapacity and inability to cope with the situation. This is self-evident.” Accordingly, abuse can occur as a response to a lack or loss of power of the older person, but also of the perpetrator in which case there is dependency of the perpetrator on an older person. A perpetrator uses violence in order to gain power and control, and dominance in the relationship. Thus, the participants in our study viewed the feelings of powerlessness or powerfulness of the perpetrator in the relationship with the victim as one of the crucial explanations why perpetrators start using violence and saw this mainly as an effort to restore or enhance power and control.

History of violence

Professionals and experts who work in the field of elder abuse expressed the opinion that violence is learned behavior. An expert from the local authorities described it

as follows: “Experiences of violence during childhood or being raised in a situation of family violence or being familiar with violence can be a risk factor for violence in later life”. Participating experts explained violence in later life as a learned behavior that was transmitted from one generation to the next.

The opposite opinion was expressed by some of our participants. One of the experts from the research field doubted whether violence is transmitted from generation to generation. The concerned expert said: “It is not evident whether violence is learned behavior. I would rather argue that only in some cases this is true. [But], we know about different studies that prove the opposite”. Other respondents agreed to that, pointing out that violence in later life is occurring mostly without prior history of violence during childhood. These two opposite views expressed by our respondents – in particular experts and professionals – show that the contributory role of a history of violence in the explanation of elder abuse is still debated.

The etiology of violence in later life

All the concepts discussed above have interrelationships according to our participants, thus making the picture of violence in later life as envisioned by our respondents rather complex. In figure 1 we have portrayed these interrelationships to provide a model for understanding violence in later life from the perspectives of older persons, experts and professionals.

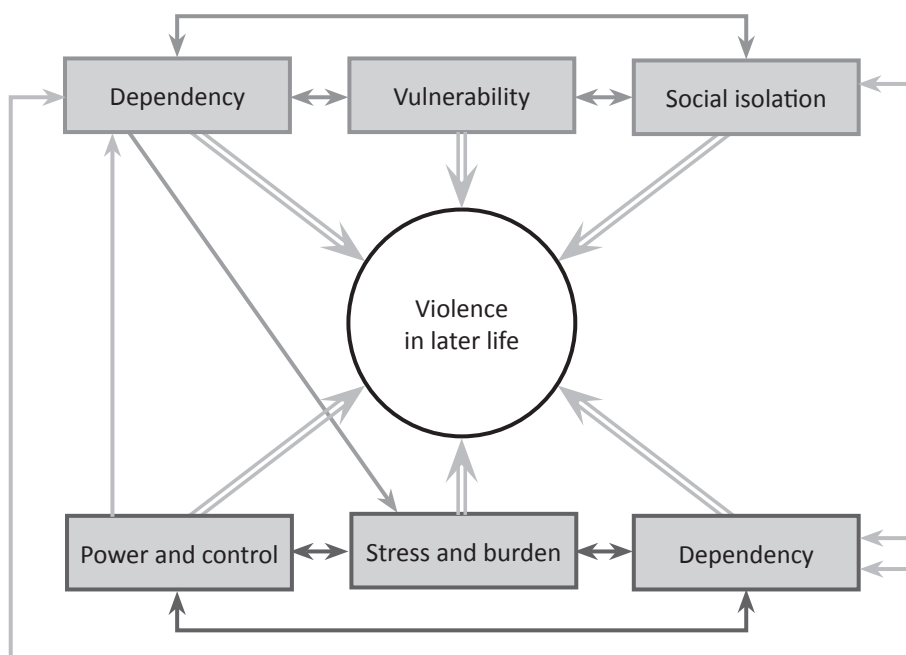


Figure 1. Relationships between concepts

— Concepts related to victim
 — Concepts related to perpetrator

The complexity becomes especially vivid for the concepts of dependency and vulnerability; their different forms are linked together, their occurrence influences each other and at the same time the two seem to complement each other. Concurrently, vulnerability can cause dependency, which can cause violence. Caregivers who care for a vulnerable and dependent older person or who themselves are dependent on an older person are not always able to manage their responsibilities and cope with stress in an effective way. In a lot of cases a victim is isolated by a perpetrator from the outside world, feeling lonely and socially excluded (Bennet, Kingston, & Penhale, 1997; Biggs, Phillipson, & Kingston, 1995). Hence isolation and loneliness are important (interrelated) circumstances for the development of violence in later life. Social isolation, in addition, may not only be a cause, but also a consequence of dependency of either the victim or the perpetrator, which again can be the result of vulnerability. The dependency of victim and perpetrator, vulnerability and social isolation of a victim and caregiver's stress are closely related to power and control inequalities, which determine the imbalance experienced in the victim-perpetrator relationship.

It is important to mention the way our participants tied different factors together in their explanations of the occurrence of abuse, namely the web of dependencies and its relationship with the ageing process and the ambiguity expressed by older participants about dependency and vulnerability.

Discussion

Through our empirical data we have explored different perspectives on the etiology of violence in later life by the groups involved in elder abuse. We established that the main concepts presented above were discussed by all the groups included in our study as important in explaining the etiology of violence in later life, with the exception of a history of violence, which was mainly mentioned in the professional focus groups and in the interviews with experts. According to our participants several concepts, dependency, vulnerability and social isolation, were interrelated and influenced each other. Thus we identified that all groups in elder abuse shared a similar understanding of the etiology of violence in later life. There is however some ambiguity around the conceptualization of vulnerability and the role of a history of violence.

Dependency

The views of the participants in the focus groups of professionals, older people and experts about the dependency of older persons on their abusers is confirmed by some studies that suggest that older people who are dependent on their caregivers, family members, other relatives or friends seem to be at greater risk of becoming victims of violence (Pillemer, 1986; Douglass, Hickey & Noel, 1980). Some studies also show that reverse dependency (perpetrators on their victims) can exist, such as also proposed by some of our participants. It is argued that abusers can be dependent on older persons for financial, emotional or social support (Pillemer, 1985; Kosberg & Nahmiash, 1996). It is however also posited that dependency takes the form of

mutual dependency, where perpetrators are dependent on older persons and in turn older people are dependent on their abusers. These multiple dependencies may cause an imbalance in rewards and control, meaning that older persons are less able to contribute to the relationship in any positive way, increasing the stress of the caregiver and the costs of relationship and maximizing the risks of violence to occur (Pillemer, 1985; Phillips, 1986).

Dependency is generally seen as a crucial factor in violence in later life, but it is not yet clear who is depending on whom in these abusive relationships. We establish that dependency in later life is a complex concept that can have different bases (psychological, physical or economic dependency) and causes; it can be related to the victim or the perpetrator creating mutual dependency. More importantly dependence seems to have negative connotation, as older individuals are expected to be mature, independent adults, while at the same time bodily decline during the ageing process often puts them inescapably dependent on others. These characteristics of dependency, which seem related to specificities of the ageing process, makes violence in later life distinct from dependency in other stage of life in which family violence can occur.

Vulnerability

The perceptions of experts and older persons about the interrelation between dependency and vulnerability are in line with some literature findings on elder abuse that state that there is a relationship between dependency and vulnerability, especially for older persons (Roberto, Teaser & Duke, 2004; Stevenson, 2009). Moreover, from the findings of study it emerges that older persons see vulnerability as hazardous, because it can contribute to dependency. They also consider vulnerability to have a negative connotation that is sometimes imposed on them by society. Different studies confirm the view of the experts from our study, older people seem to be more susceptible to specific challenges (in terms of health, income and social roles) and vulnerability entails that they have reduced capacity to respond to them (Grundy, 2006).

The ambiguous feelings around the meaning of vulnerability and in particular its meaning for older persons as described above in the empirical data, the existence of different forms of vulnerability and its relationship with dependency are important elements that have to be taken into account when we discuss violence in later life. The general concept of vulnerability seems to have a specific meaning in the context of elderly in which vulnerability occurs because of increasing physical frailty associated with aging (Slaets, 2006). More importantly, the ambiguous feelings around the meaning of vulnerability as imposed by others and in particular its meaning for older persons as described above are aspects that should be taken into account and are important considerations in which elder abuse is quite different from family violence at other stages of life.

Social isolation

The views of professionals about the role of social isolation in violence in later life are confirmed by some studies that show that social isolation is a characteristic of

families in which child, spouse, and elder abuse occurs (Pillemer, 1984; Pillemer & Finkelhor, 1988). Social isolation of an older person and caregiver is associated with increased risk for elder abuse (WHO, 2002).

One of the crucial features of social isolation is that it can be at the same time a cause and a consequence of violence in later life. Based on the views of experts and professionals it is generally argued that the concepts of social isolation, loneliness, lack of support are related to each other and influence each other. However, theoretically it has been argued that violence in later life causes social isolation (Pillemer, 1986).

Stress and burden

Besides the other variables discussed above the respondents also mentioned the issues of stress and burden. Our findings from interviews and other studies outline that stress can occur due to internal or external factors and accumulation of stresses can lead to overload which can result in abuse (Block & Sinnott, 1979; Galbraith & Davison, 1985; Bennet, Kinston & Penhale, 1997). Some studies even show that actual stress may be a less important predictor of violence than the caregiver's perception of stress (Steinmetz & Amsden, 1983; Zarit, Reever & Bach-Peterson, 1990). The ideas expressed in focus groups and interviews that stress and overburdening are common in caregiving situations and can lead to abuse are also present in the literature. Indeed, violence in later life is often considered as a result of an inability to cope with stress occurring from caring for an older person. Therefore caregiving is often seen as a burden that is not possible to bear (Wolf, 2000; Burnight & Mosqueda, 2011).

The issues of stress and burden are closely related to the perpetrator. Stress and overburdening of the caregiver can lead to abusive situations (Hyde-Nolan & Juliao, 2012; Bennett, Kingston & Penhale, 1997). The concepts of dependency and vulnerability of both victim and perpetrator are interrelated and influencing the possible occurrence of stress and the possible resultant abuse.

Power and control

The views of professionals and experts in our study about possible reactions of compliance and acceptance to abuse which older persons can demonstrate are confirmed by findings in the literature showing that some older people experiencing violence can react to a situation of abuse by becoming more compliant and this can sometimes provoke more abuse. In the literature this phenomenon is described as "learned helplessness" (Miller & Seligman, 1975, p.228). Seligman mentions that helplessness produces emotional distress. There is no motivation to respond to the situation if the individual feels nothing can be done to affect the outcome (Quinn & Tomita, 1997).

The ideas about the attempts of perpetrator to restore his or her power and control by using violence that were expressed by different experts are in line with other studies that described that perpetrators may use various tactics to gain lost

power and control of their victims, one of which is abuse (Bancroft, 2002; Biggs & Haapala, 2010; Biggs, Phillipson & Kingston, 1995). Abusers' thinking patterns lead them to believe their needs are more important than others and that they can use any method necessary to get what they want and desire (Bancroft, 2002). Pillemer (1986) suggests that the feeling of powerlessness experienced by an adult child who is dependent on an elderly parent(s) may be critical, because it is against society's expectations and norms that believes that adults should function independently and be autonomously. In these abusive situations the individual may use violence and act out of weakness. Again, the importance of powerlessness and loss of control is interrelated with issues of dependency and vulnerability.

History of violence

In our study we have found that a role of a history of violence in the occurrence of elder abuse is quite equivocal. Most of our informants, in particular, the experts from academia, did express ideas about elder abuse occurring mostly without prior history of violence. These opinions resemble the findings of some studies within the field of elder abuse that family history plays a less central role in the occurrence of elder abuse than, for instance, in family violence at other stages of life. These studies suggest that violence in later life occurs at best only in a minority of cases due to learned behavioral patterns in the context of the family (Pillemer, 1986; Korbin, Anetzberger, & Austin, 1995; Thornberry & Henry, 2013). These views are also congruent with the results from a study conducted by Pillemer (1986), who found no association between being abused as a child and becoming an abuser later in life (Pillemer, 1986; Korbin, Anetzberger, & Austin, 1995; Thornberry & Henry, 2013).

The opposite perspective suggesting that abusive adults learned violent behavior as a result of being the victims of or witnesses of such behavior as children elder abuse may occur due to previous history of violence in the family was also expressed by some of our participants, in particular by some older persons and experts. This view that individuals who are abused in childhood grow up to become abusive parents and violent adults has been discussed extensively within the family violence field (Gelles, 1980; Starr, 1988; Burgess, Hartman & McCormack, 1987; Straus, Gelles & Steinmetz, 1980; Walker, 1984; Boden & Horwood, 2006). Some studies also suggest that violence in later life is more common in families with established patterns or histories of violent behavior and violence may be a consequence of learned responses (Kosberg & Nahmiash, 1996; Fraser, 1996; Owen & Straus, 1975; Nadien, 1995).

Thus based on our data and insights from prevalence studies it appears that there is not unequivocal evidence for the hypothesis that violence in later life occurs through a modelling of behavior that was observed earlier in life. Thus still divergent views exist about violence as learned behavior that is passed on through generations.

Limitations

In this study we used different qualitative methods of data collection. Nevertheless, the results from this study were based on a non-representative sample. Consequently, some of the findings cannot be generalized to the whole population. However, our primary aim was to explore the perspectives on the etiology of violence in later life of diverse groups involved in elder abuse and therefore a qualitative research design to explore these explanations was more suitable for the purpose of the study.

For future studies, we recommend that the current study will be extended and a systematic review on the theoretical perspectives of elder abuse and family violence will be added in order to establish how they differ and how particular theories are used in explanation of violence at different stages of life.

Conclusion

Our findings show that our participants explain elder abuse as a complex problem in which the variables dependency, vulnerability, social isolation, stress and burden, power and control and history of violence play a central role in why abuse happens. The identified variables are interrelated. The role of a history of abuse in the occurrence of elder abuse appeared equivocal. Our study provides insights in the understanding of the etiology of elder abuse from the views of different groups involved in the field of elder abuse. We also established that different degrees and reversed issues of dependency and vulnerability, the notion of mutual dependency, and diverse attitudes and expectations towards them are distinctive features in the explanations of violence in later life.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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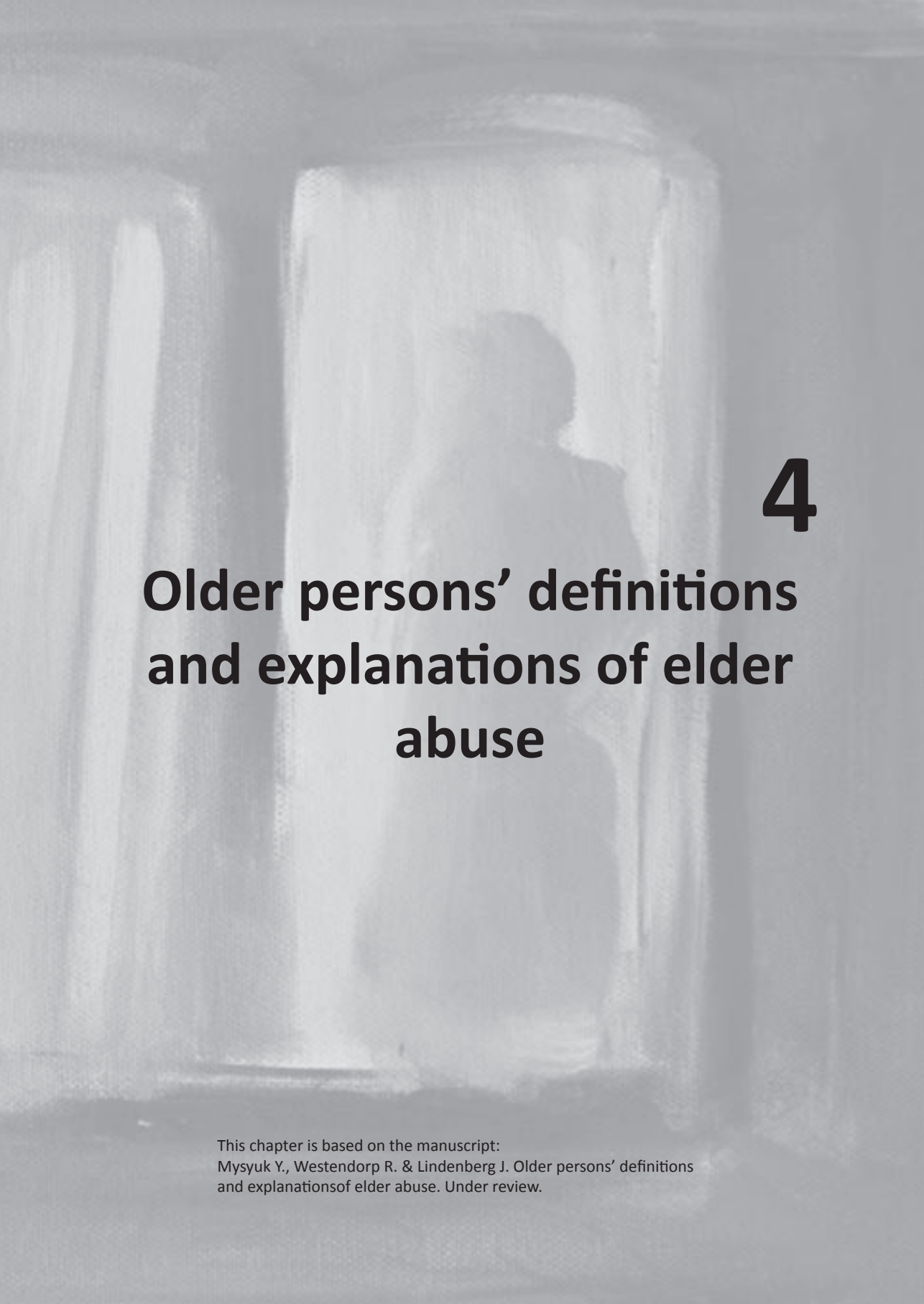
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4

Older persons' definitions and explanations of elder abuse

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Mysyuk Y., Westendorp R. & Lindenberg J. Older persons' definitions
and explanationsof elder abuse. Under review.

Abstract

In this article we explore older persons' definitions of and explanations for elder abuse by means of interviews with older persons. A qualitative study was conducted based on semi-structured interviews with 35 older persons who had no experience with abuse. Our findings show that older persons participating in our study define elder abuse foremost as physical violence that is performed intentionally. Older individuals in this study explain elder abuse as a result of the dependency and vulnerability of older persons, of changing norms and values, and of changes in the position of older persons in society, which result in disrespect toward older persons and a lack of social control and responsibility. The older persons' explanations for the occurrence of abuse mainly focus on societal changes; older persons seem to regard elder abuse primarily as a societal problem. This understanding of, and explanation for elder abuse may influence their detection and reporting behavior, as they may tend to acknowledge only severe cases of intentional physical violence that leave clear and therefore physically detectable evidence.

Key words: elder abuse, older persons, definitions, explanations, detection, reporting

Introduction

In the past decade we have seen an increased awareness of the diverse groups involved in elder abuse. Despite this, only a limited number of studies have been conducted from the perspective of older persons, and most of these studies focused on older persons with a history of abuse (Dixon et al., 2010; Nandlal & Wood 1997; Podnieks, 1992a; Pritchard, 2000, 2001, Griffin, 1994; Hudson & Beasley, 1999; Moon & Williams, 1993; Pablo & Braun, 1997; Ploeg Lohfeld, & Walsh, 2013; Tatara, 1999). However, some notable exceptions have paid attention to older persons' views on the meaning of abuse, possible causes of elder abuse, types of elder abuse, and consequences of abuse (see for instance Erlingsson, Saveman, & Berg, 2005; Naughton, Drennan, Lyons, & Lafferty, 2013; Taylor, Killick, O'Brien, Begley, & Carter-Anand, 2013; Tsukada, Saito, & Tatara, 2001; WHO, 2002). In the present article, we pay further attention to the views of older persons on elder abuse by focusing on the views of non-abused older individuals, as potential victims or witnesses and reporters of abuse. Thus far, this is the first study on the subject of elder abuse in the Netherlands which includes the perceptions of non-abused older persons.

In the Netherlands, as in other European countries, such as Sweden, the UK and Belgium, the sustainability of the welfare state is under pressure. Health care, long term care and social security are undergoing profound changes that have resulted in a "participation" state in which individuals are in principle responsible for their own lives, while the government plays a facilitating role. In the Netherlands, this development was validated on January 1, 2015 by passing the participation law (Ministry of Social Affairs and Employment, 2015). According to this law, the provision of care now falls onto the shoulders of the citizens. One of the most immediate consequences is that others are increasingly expected to take care of, and keep a watchful eye on those who run the risk of abuse. Logically, older individuals will play a vital role in this process.

In this article we explore the perspectives of non-abused older persons and their definitions of and explanations for elder abuse by means of interviews. The views and perceptions of non-abused elderly are important as they provide professionals with a fuller understanding of potential victims and possible reporters in a "participation society", in which the role of elderly citizens is increasingly important. The results will help to set appropriate targets for prevention of and intervention in elder abuse.

Methods

We conducted a qualitative study on perspectives on elder abuse among older persons in the Netherlands who had no experience with being abused. Given the known literature on perceptions of older persons on abuse, we were guided by the question of how non-abused older persons explained the occurrence of abuse. In our analysis, we identified which explanations older persons had for why abuse

occurred, and which variables played a role according to them. Since the topic of elder abuse is a sensitive one and older persons often do not feel comfortable discussing this subject nor sharing their ideas and thoughts about it, we chose semi-structured in-depth interviews to allow interviewees to express their thoughts freely. At the same time – as little is known about the rationale of older persons concerning abuse – this method of data collection allowed the researcher to adjust the in-depth questions to each informant's viewpoints when discussing details about elder abuse. We held 35 interviews with 10 older men and 25 older women between the ages of 65 and 85 years. We adhered to the age limit of 65 years, it was the age from which older persons in the Netherlands start to receive the state pension. Nineteen of them were living independently and 16 of them were living in residential care facilities and nursing homes in large cities in the Netherlands (the Hague, Leiden, Rotterdam, Amsterdam, Utrecht). Participants were recruited through convenience sampling and snowball sampling (Polit & Hungler, 1999) and via contact persons (coordinators of volunteers and welfare managers) in residential facilities and nursing homes.

Since in-depths interviews consume a lot of time, we had to restrict our research to a limited sample. To maximize the inclusion of a heterogeneous sample, we included participants with a broad age range and diverse living situations and geographic placements. The heterogeneity in our sampling was also necessary to develop, after comparative analysis, a differential expression of variables that play a role in our participants' ideas regarding elder abuse.

To enhance comparability while not compromising the individual participants' freedom to express their views in their own terms, the semi-structured interviews were guided by a topic list that only included the larger themes. We developed the topics and the questions of the interview guide based on existing research literature on ageing and elder abuse - in particular on perceptions of older persons, both abused and non-abused, the definitions of elder abuse, risk factors for abuse, theoretical frameworks of elder abuse and other studies on perceptions on elder abuse. After analyzing this relevant literature, we developed an interview guide, which we tested in pilot interviews with seven participants. Subsequently, some of the questions were modified and adjusted. The main topics of the interview guide for older persons were: demographic and social background; health status and daily life; risk and protective factors; meaning of elder abuse; perceptions, attitudes towards elder abuse; experiences with elder abuse; and social life (see Appendix C). The interviews lasted between one and a half to three hours; an average interview took about two hours. The interviews took place between April 2012 and March 2013.

Participation in the study was voluntary. The respondents were told that they would receive a small gift (notebook) after participation in the interviews. Prior to the interview, the purpose of the study was explained to each participant. All the participants were considered to be cognitively intact and to have the capacity to consent to involvement in the study. Confidentiality and anonymity were guaranteed

through an explicit oral agreement. With the permission of the participants, the interviews were recorded. To ensure anonymity, participants are cited in this article using pseudonyms.

We did not ask for permission from the medical ethical committee because it did not concern patients, but we did adhere to the ethical standards as subscribed by the designated professional associations of anthropologists, in particular American Anthropological Association (AAA) and European Association of Social Anthropologists (EASA).

Analysis

Interviews were transcribed verbatim for analysis. We then comprehensively and systematically analyzed verbatim transcripts of the interviews using NVivo, a qualitative data analysis software package. Data were analyzed using a primarily inductive approach, in which concepts were derived from the transcribed data through a coding technique based upon the grounded theory approach. First, the texts were segmented based on their content. Secondly, key points were marked with codes, which were then grouped into main categories that served as the basis for analyzing and discussing the views of the respondents. Such an approach provides leeway and more flexible, alternate means for respondents to explain their own experiences; it also allows for the expression of unexpected or neglected topics, thoughts and ideas (Glaser & Strauss, 1967).

As the aim of this study was to explore participants' perceptions of elder abuse, we did not adhere to a definition of elder abuse prior to the study, but post analysis we compared participants' definitions of elder abuse with the WHO definition of abuse: "Elder abuse is a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person." For the purpose of comparative analysis, we followed the Dutch Ministry of Health, Welfare and Sports in distinguishing between the following types of abuse: physical abuse, psychological abuse, financial abuse, neglect and sexual abuse (Institute for Social Research, 2014).

Results

Defining elder abuse

First, we explore the definitions that older persons hold in regard to elder abuse and the elements that they include in these definitions to clarify what they would identify and report as abuse. These primarily included physical violence and intentional harm, and in some cases other types of abuse. Notions such as physical violence and intentionality were mentioned and discussed by respectively 28 and 30 out of the 35 interviewees. In addition, other types of abuse were also considered, such as psychological abuse (nine interviewees), financial abuse (seven interviewees) and neglect (five interviewees), but they were less immediately identified as abuse than physical abuse.

Physical abuse

Our findings show that the strongest focus of our participants was on physical abuse. For a majority of the participants, 28 out of 35 interviewees, the first thing that came to mind when asked what “abuse” meant to them was some physical act, which would manifest in different forms, such as hitting, punching, kicking, pushing, pulling, or being trussed. Elder abuse was perceived as the use of physical force against an older person. Numerous participants said in diverse ways what Lisa (70 years) said: “Mistreatment means hitting someone.” Other interviewees also understood abuse as physical violence. One of them mentioned: “Hitting and kicking, I think these violent actions can be seen as abusive (Henk, 79 years)”. Another participant stated:

Abuse is when you are tying an older person to a bed or a chair, for instance, tying the legs or arms of older man to the bed and they sit or lie like that the whole day or till someone is going to visit them. It is happening in the nursing homes. (Anne, 81 years)

In line with this view, these Dutch older individuals seemed to reason that abuse is related to something that you can see, something that leaves signs and can be proven.

Other types of abuse

The participants also discussed other types of abuse, but these were not immediately raised and not as widely discussed as physical abuse. For instance, nine of the interviewees mentioned psychological (or emotional) abuse, emphasizing the importance of its possible causes and its effects on older persons: “You can abuse somebody physically, but you can also abuse someone verbally, with words, these words can be unpleasant and painful...they can have a big impact on older persons and cause them great emotional distress and other problems (Anette, 79 years)”. For other interviewees who talked about psychological abuse, it included verbal aggression, giving insults, being manipulative and using a threatening tone:

Teasing, insulting and manipulating, isolating from the outside world. I know that older persons feel afraid because they do not know how to deal with all these manipulations and offences. Older persons are often left alone in their homes, without any contact with the outside world, not having the opportunity to communicate with others. (Ingrid, 71 years)

Another interviewee described psychological abuse as follows:

Treating people as inferior, forcing them to do things they do not want or are not willing to do, not even asking the elderly whether they are happy doing these things. Not even caring about this. It is emotional abuse that is really bad. (Karel, 82 years)

Some participants argued that psychological abuse was more severe and harmful than physical abuse, and unlike various other participants, they did not think that psychological abuse could be considered less serious than physical abuse.

Psychological abuse was perceived as emotional harm to an older person that was inflicted on purpose. "I would say that psychological abuse is worse and can be more harmful than physical abuse, and it is very often intentional. You cannot abuse someone without the intention to do so. You do it on purpose (Peter, 74 years)". Although only six of the interviewees expressed this idea, it does show that some older persons in the Netherlands acknowledge the occurrence of psychological abuse and the impact it can have on an older person.

Another type of abuse, which was mentioned by seven interviewees, was financial abuse. This involved issues of illegal or unauthorized use of a person's property or money: "Stealing money, using an older person's bankcard, transferring money. For example, using money of an older person for your own needs: to buy furniture, electronics or to go on holiday (Ward, 77 years)". Participants who identified financial abuse thought it was fairly common, yet the majority of participants did not recognize this type of abuse.

Another type of elder abuse that was mentioned by our participants was the issue of neglect; five participants discussed this type of abuse. By neglect older persons meant depriving an older person of food, clothes or care. "If you do not give enough food and drink to an older person, I think this is a real abuse. The fridge is empty for days or even weeks." (Gerda, 69 years) For these participants, neglect was perceived as the failure to meet older people's basic needs.

Intentionality

From the findings above we can already infer, to a certain extent, that older persons in our study viewed elder abuse foremost as intentional behavior. Thirty out of thirty-five participants expressed this opinion. Indeed, one of the participants said: "Things that you do with intention and regularly that hurt older persons, that is abuse. I understand it as such (Tereza, 66 years)". Intentionality was (implicitly or explicitly) a prime focus of the participating older persons and was perceived as a precondition in their views on elder abuse: "For me, the word 'abuse' means doing something on purpose, intentionally (John, 76 years)".

A majority of the older participants understood abuse as something premeditated and done on purpose; the word signals to them that the abuser wishes to control them, and intends to hurt them. Fifteen of the interviewees shared the idea that the word "abuse" itself already had a purposeful connotation, implying "a bad purpose, a kind of evil intention (Ellen, 75 years)" (abuse in Dutch is "mishandeling" which literally translates as "mistreatment").

Older persons' definitions and current definitions of elder abuse

In the literature, elder abuse is defined in various ways, but there is no strict consensus on a common definition. Still, the different definitions do include some common elements, such as the types of abuse that are distinguished, the different settings, the expectation of a trust relationship, and the infliction of harm (Bonnie & Wallace, 2003; Comijs, 1999; Mysyuk, Westendorp, & Lindenberg, 2011; WHO,

2002). The most commonly used definition is the WHO definition, which we use as a reference in this study. For our comparison, we therefore consider elder abuse as violence perpetrated by anyone in the environment of an older person who is trusted by this person.

The older persons in our study expressed an understanding of elder abuse that had some key elements in common with the current definitions. Our participants mentioned the infliction of harm, but also – similar to for instance the definition of the US National Research Council – they stress that this harm was inflicted intentionally. As is clear from the above, our older participants distinguished different types of abuse, although only a minority did so. The distinctive features in our participants' understanding of elder abuse were the strong emphasis on physical violence and the highlighting of intentionality, both of which are not prominent in the definitions of abuse given by the WHO or the definition often used in the Netherlands (WHO, 2002a; Comijs, 1999). This shows that older persons perceive abuse differently than it is described and defined in current literature and by professionals in the field of elder abuse. The emphasis on physical violence and the centrality of intention seem to be part of a rationale in which visible evidence plays a prominent role. Both the premeditation as well as the use of physical violence result in clear categories of abuse in which boundaries are clearly crossed and the evidence is palpable, making the occurrence of elder abuse beyond doubt.

Explanation of elder abuse

We also asked participants to identify key factors that would explain the occurrence of abuse. Twenty-five participants attached importance to individual factors, such as dependency and vulnerability, and used these to explain abuse. Furthermore, 27 out of 35 participants mentioned changing norms and values as important explanations for the occurrence of abuse. A majority (26) of our participants perceived abuse as resulting from a changed position of older persons in today's society, a position that they described as marginalized and disadvantaged. Moreover, 27 of our participants attributed the occurrence of abuse to a lack of respect for older persons. In addition, 12 older interviewees mentioned that elder abuse was contributed to by a general lack of social control and responsibility in modern society.

Dependency and vulnerability of older persons

In the perception of our participants, the most important threat to their well-being and successful ageing was becoming dependent and vulnerable. Twenty-five out of the 35 participants described that being dependent on others for care created opportunities for older people to be abused. One of the respondents stated this as follows:

Older person are very much dependent on others. They are dependent on their children, on other relatives or friends... They can be dependent on them for care, help, or other things. This creates risks. They can easily become victims of violence. (Petra, 79 years)

The participants emphasized the possible role of dependence and vulnerability in the occurrence of elder abuse. "I think the dependence and vulnerability of older persons are crucial factors in abuse (Adrienne, 75 years)". Autonomy, independence and taking one's own decisions seemed essential issues, as mentioned by 18 interviewees. They also believed that remaining independent as long as possible, and self-reliant, would protect them from abuse. Illustrative are these two statements of interviewees: "I would like to be independent, to be my own boss. It is really essential for me as I can feel good and satisfied" (Bert, 80 years) and "my independence is really important to me; I do not want to be dependent. I think that independence can also be a protective factor against abuse (Gerda, 71 years)".

Changing norms and values

The perceived threats of dependence and vulnerability as described by our participants were mainly related to ideas that participants had about current society. According to our respondents (27 out of 35 mentioned this in some way) norms and values have changed in Dutch society, which has caused changes in family values, resulting in a situation that might be more prone to abuse. As one interviewee stated after being asked how she would explain the occurrence of abuse: "The norms are changing, nowadays, family members no longer share the same values and principles. This can lead to conflict situations in families, which can develop into abuse." (Enna, 77 years) Our participants explained that contemporary society is focused mainly on productivity, individualism, personal responsibility, efficiency and functionality. In such a society, dependent, unproductive and vulnerable older persons are not of great value. One of the interviewees described this as follows: "Nowadays there is only a need for efficiency, and older persons cannot fulfill this need, as they can be vulnerable and fragile. They are not seen as an important part of society. They are kind of redundant (Karel, 73 years)". Therefore older persons often felt ignored, misunderstood and out of place: "There is no consideration for the problems of older people, older persons feel unhappy and misunderstood (Ineke, 75 years)". In a society in which values, norms and principles are redefined in such a way that older persons are at a disadvantage by the impact of the very process of ageing, abuse accordingly becomes more permissible.

Position of older persons

According to our interviewees, the changing norms and values in society have led to, but are also a result of a change in the position of older persons in Dutch society. Twenty-six interviewees expressed that they felt that in the past, old age was often highly regarded, while in present society the position of older persons had changed to a rather disadvantaged one. One of the participants phrased this as follows: "Earlier older people were considered wise teachers, now this has changed. People used to ask older people for their advice and wanted them to share their knowledge (Emma, 79 years)". According to our participants, older persons used to represent a source of knowledge and experience. Nowadays, they felt, Dutch society tends to

exclude older people, and their status declined as the views on the contribution of older persons have changed. This opinion is illustrated by the words of one of the participants: "I hear very little positive things about older people and ageing, it is a rather negative image (Jan, 82 years)". This changed social position of older persons has led to marginalization and isolation of older persons, which in turn created an increased risk for the occurrence of elder abuse.

Disrespect

According to 27 of our participants, the decline in status of older persons has resulted in a general lack of respect and consideration for older persons. One of the interviewees stated this as follows: "In other cultures, people are respected as they grow older, but in our culture that is not always the case, sometimes older people are just forgotten and not understood... People do not care much about the elderly (Pim, 80 years)". Moreover, participants felt that older persons are not approached and treated in the way they themselves once treated the older generation when they were young in the Netherlands. For instance, Miriam (78 years) said: "In the past older persons were approached with respect and reverence, we were taught to respect the elderly and to care for them ...now it is completely different. Now, younger generations have different values and priorities." Disrespect and having a sense of little worth as an older person were prominent notions in our respondents' explanations for the occurrence of violence in later life.

Lack of social responsibility and control

Besides these perceived changes in social norms and values and in the social position of older persons, another societal factor that was mentioned by 12 of our participants as an explanation for elder abuse was a general lack of social responsibility and social control in the Netherlands. The words of Maria (75 years) exemplify this rationale: "People are not responsible for each other, they do not feel socially responsible...older persons are expected to be responsible for themselves, there is less social control." Some concerns were expressed regarding changes in present society in general, its lack of care for others, and its failure to protect older persons in particular. Berta (70 years) said: "Society is not doing much to secure a normal life for older persons. It should do so, it should try to protect the elderly."

Our older participants felt that in the past, social control and responsibility were "protecting" older persons, as other people could intervene in alarming situations and thus prevent abuse. Nowadays, the decrease of social solidarity and a focus on individualism and personal autonomy has reduced social security, protection and social control, and this may have contributed to the increase in the occurrence of abuse.

Discussion

The aim of this study was to explore the perspectives of non-abused older persons and their definitions of and explanations for elder abuse by means of

semi-structured in-depth interviews. Our findings show that the occurrence of elder abuse is perceived and understood by our participants as a result of individual risk factors of dependence and vulnerability in combination with changes in values and norms at the societal level in the Netherlands. Together, these factors are perceived as increasing the susceptibility of older persons to abuse. For our participants independence had an important value. This might be typical for the Dutch context, because studies have shown that independence is highly valued among Dutch older individuals (von Faber et al., 2001). However, our participants' ideas on the role of dependence in abuse is confirmed in international studies on risk factors of abuse (Anetzberger, 2004; Pillemer, 1986).

Our findings demonstrate that our participants distinguish between different types of abuse, but at first instance they consider abuse to mean intentional physical harm, while other types of abuse are only considered on second thought. In addition, some of the types of abuse commonly recognized in elder abuse, are only identified as abuse by a minority of our interviewees, while others, such as sexual abuse, were not mentioned at all.

Our participants perceived the role of society as crucial, as they emphasized that society creates the circumstances for abuse. Their reasoning is that these circumstances have become more prevalent due to the importance that is attached to individualism, personal freedom and responsibility, self-reliance and independence. These principles are expressed in numerous policy changes in the Netherlands, and they are likely of influence as well in other European countries that undergo similar changes. The principles seem founded on neoliberal starting points – taking neoliberalism here foremost as an ideology (Ferguson, 2009). In the Netherlands, as in other countries, neoliberal starting points have entered into elder care and health care at large through the introduction of soft market incentives, such as privatization and market competition, and their impact is now actually felt by older persons. Moreover, new programs and policies in the Netherlands, but also elsewhere in Europe, focus on citizens taking responsibility, participating and contributing, and thereby emphasize the importance of self-reliance and self-responsibility. Following the rationale of our participants, this might have caused a decrease in social control and social responsibility, putting older persons at a higher risk of abuse.

Remarkably, our interviewees did not mention other common explanations of abuse that are often discussed in current literature. For example, our participants did not mention intra-individual characteristics of the abuser, such as social isolation, mental problems or substance abuse, nor did they relate elder abuse to the dynamics of interpersonal relationships, such as a history of family violence, stress issues, power and control inequalities or sociocultural factors (Anetzberger, 2004; Biggs et al., 1995; Burnight & Mosqueda 2011; Phillips, 1986; Pillemer, 1986). Our participants' explanations of abuse emphasized societal changes, placing responsibility for the occurrence of abuse in a wider contextual field and considering elder abuse foremost as a societal problem. This focus suggests that it may be vital to take wider societal issues into account in future research on the causes of elder abuse.

That the Dutch situation is not exceptional in this regard is shown by Taylor et al. (2013), who found that a sample of 58 older persons in Northern Ireland and the Republic of Ireland also mentioned issues of respect and the vulnerability of older persons as possible explanations for abuse. The importance of structural-societal factors in elder abuse was acknowledged earlier in a study of the WHO (2002), which focused on issues of disrespect and ageist attitudes. A Swedish study of Erlingsson et al. (2005) confirmed these findings. In their study, the possible causes of abuse were societal changes, family structures, and individual determinants. However, quite in contrast to our study, they found that older persons defined elder abuse as an act of robbery and/or assault, focusing on violence in the streets. Thus incidental criminal behavior was considered abuse. Nevertheless, these findings do, as in our study, show a focus on intentional, premeditated and purposeful acts of abuse. A study among older persons by Taylor et al. (2013) found that abuse also included notions similar to our study, such as vulnerability of older persons and intention of the perpetrator. Also in line with our findings, Naughton et al. (2013) established that while there was a relatively high level of awareness of the term elder abuse, quite a number of participants did not readily associate this term with abusive behaviors in their personal lives. In line with our findings, this indicates that older individuals possibly do not identify risk factors of abuse in their own lives, or in that of their peers. To shed more light on this interaction, future research should take into account both the individual susceptibility and social changes in societies and focus on how perceptions of older individuals in different countries are influenced by changes at the societal level.

The focus on physical violence and intentionality in the definitions of our participants seems to be part of an argumentation in which visible evidence plays an important role. The implied relevance of visible evidence of abuse seems to be related to our participants' perception that their social position was rather marginalized. A large majority of the older persons in this study felt that they are not valued, that their voices are not heard and that they are excluded. In line with findings in other countries (Erlingsson et al., 2005; WHO, 2002), it might be that they fear not to be taken seriously, which may motivate them to look for evidence beyond reasonable doubt. It seems possible that older persons in the Netherlands need irrefutable and clear proof before they have the confidence to speak up. This might not only influence older persons' definition of abuse, but also their reporting behavior. There are two possible consequences of their views on the role of society in abuse that might have a detrimental effect on older individuals' reporting behavior in the Netherlands. First, older persons may not report abuse at all, if they believe that they are not an important part of society and that their opinions and ideas might not be heard or taken seriously. Second, their reporting behavior might decrease, as they do not believe that they are significant enough to contribute and have a legitimate say.

These findings show that if we hope to increase the involvement of older citizens in the detection of abuse, a different approach is needed rather than simply

calling upon them to participate. It might be a questionable assumption that we can rely on others to care and that we can trust that individuals who are able to do so will keep an eye on the more vulnerable in our society. Our results show that the perceived disadvantaged position of older persons in society should be taken into account when calling upon them to participate in identifying and reporting abuse.

Implications and recommendations

Research on elder abuse mostly focuses on the characteristics of the perpetrator and the victim, and on the interpersonal dynamics within the family. Currently, there is also an emphasis on pathology and psycho-pathology, such as the relationship of elder abuse with substance abuse and cognitive disabilities (Anetzberger, 2004; Biggs et al., 1995; Burnight & Mosqueda, 2011; Phillips, 1986; Pillemer, 1986). As a result, elder abuse continues to be regarded as an interpersonal or family problem, rather than being viewed as a general societal phenomenon. The role of society in elder abuse has therefore often been underestimated and disregarded in research (WHO, 2002).

As our findings indicate, it is important to change this exclusive focus on the role of individual and interpersonal characteristics in the occurrence of elder abuse. We need to broaden our perspective in research and practice to ensure that not only the established factors, but also the rationale behind them and the way this might influence prevention and reporting of abuse stays in view in the field of elder abuse. Professionals who are working in the field of elder abuse can use the results of this study to pay more attention to older persons' rationale and motives for reporting or not reporting abuse. The way older persons understand and explain elder abuse may influence their reporting behavior. Indeed, in our study only actions involving physical violence or those clearly performed intentionally were immediately considered to be abuse and might thus be reported. These perceptions of older persons on abuse might limit their identification of risk factors and their reporting behavior, as they will probably only report severe cases of abuse that are unequivocal and evident. As a consequence, older persons may underestimate and overlook the risk of other types of abuse for themselves or for someone in their environment.

The findings of this study are a first step towards understanding why some cases of abuse are reported by older persons and others not, and what ideas influence older persons' reporting behavior. They will then lead to further understanding of under-detection and underreporting of elder abuse and of the role our participants attribute to the perceived marginalized position of older persons in society. Similar considerations might play a role in other countries, which calls for paying attention both to individual risk factors and to the social context of these factors.

In practice, we recommend involving older persons in the decision-making process concerning elder abuse, including education and training, to enable their active participation, inclusion and contribution in the total process of risk detection and case management. Furthermore, we need to encourage and empower older

persons, which could possibly increase their reporting behavior. Measures may include, for instance, organizing specific training sessions and workshops on elder abuse for older persons, focusing on the more subtle signs of elder abuse, including older persons in teams that review cases of abuse, or initiating community volunteer groups of older persons. Another recommendation is that older persons first need to understand what abuse is, since this is crucial for defining a situation as abusive and reporting it accordingly. This also means including the older persons' societal explanations of elder abuse in the instruments that are currently used for detecting abuse. The emphasis on intentional and detectable harm has to be taken into account. This means adapting questions related to elder abuse and its possible experiences, and including questions on specific behaviors that may be considered abusive while visiting older persons at their homes, during GP visits or in health care facilities.

A key finding of our study is that older individuals in this study perceive elder abuse in the Netherlands as a general societal phenomenon. To do justice to this finding, we recommend an approach that is directed at general changes in society, namely changes in attitudes and behavior as well as in perceptions of old age and older persons and their position in society. This can be achieved by promoting a positive image of older persons, for instance by using role models, social media campaigns and by increasing the social involvement of older individuals. Another strategy can be to increase the understanding of the ageing process and of issues of vulnerability and dependence by providing more information on the ageing process to the general public.

Limitations

In this study we used a single method of data collection, namely semi-structured interviewing. It would have been more comprehensive to use additional methods (data triangulation) that would have enabled us to check and establish the validity of our results by analyzing a research question with multiple data collection methods. While triangulation is a useful method, it was not possible to use this in our study because of the sensitivity of the topic and the specificity of the target group. To enhance external validity, we intentionally included participants from different settings: individuals living independently, in residential care facilities and nursing homes. In this way we ensured the participation of older individuals from diverse social backgrounds, with different health statuses and living arrangements. As a result, we were able to capture the diversity of opinions and views of various groups of older persons, even though we may not necessarily have covered all perspectives. Our heterogeneous inclusion also imposed a limitation on the method of data collection; due to physical and mobility limitations of our respondents, we visited our participants at home, which precluded the use of other methods. It is, however, important to point out that our hermeneutic approach using in-depth interviews was most fitting for the research question posed, since it allowed for further questioning and further explanations to

come to an in-depth understanding of the rationale older individuals had for understanding and explaining elder abuse.

While the method allowed for the mining of rich insights, the relatively small sample size may be considered a limitation, and therefore our findings may not be representative of all older residents in the Netherlands. Moreover, as the findings of the current study are based on interviews with Dutch individuals, they may not be generalizable to other countries. However, some of the relevant characteristics of the Dutch situation, such as the emphasis on self-responsibility and participation and the retraction of the welfare state, may be similar to processes in other countries. Further research is needed to establish the relevance of the current study in other contexts. Nevertheless, this study does point out that paying attention to the contextualization of definitions and explanations of abuse is necessary to fully understand older persons' perceptions of abuse.

Declaration of Conflicting Interests

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5

How older persons explain why they became victims of abuse

This chapter is based on the manuscript:
Mysyuk, Y., Westendorp, R., & Lindenberg, J. How older persons explain
why they became victims of abuse. Under review.

Abstract

Elder abuse greatly impacts the quality of life of older individuals. Worldwide, prevalence rates range from 3 to 30% depending on the definition used. Only few studies have explored how older victims themselves experience and explain abuse. Healthcare professionals are among the most important groups to handle and report abuse and it is therefore essential that they know the perceptions of older victims. A qualitative study on perceptions and experiences among victims of elder abuse was conducted using in-depth semi-structured interviews. Abused individuals, six males and eleven females aged 63 to 90 years, lived independently, in residential care facilities and nursing homes. The main causes of abuse identified by older victims themselves were mutual dependency between victim and perpetrator, power- and control-imbalances, loneliness and a marginalized position of older persons. Effects of abuse included negative feelings, physical and psychological complaints, a change of personal norms and values, a different outlook on money, and low self-efficacy. These differential effects seem to depend on the types of abuse experienced and the relationship with the perpetrator. Coping strategies as mentioned by victims were seeking informal or professional help and using self-help strategies. Older victims perceive abuse differently depending on the expected acceptability of the type(s) of abuse experienced and the expected stigma associated with the perpetrator involved. The effects and chosen coping strategies are influenced by these considerations and therewith also influence their help-seeking behaviour. Healthcare professionals are encouraged to use these findings in practice to detect, prevent and intervene in elder abuse.

Key words: elder abuse, causes, effects, coping strategies, qualitative research

Introduction

The perspectives of victims of elder abuse are not prominently present in existing literature. The majority of research on elder abuse focuses on theories of elder abuse, definitions, prevalence, types, risk factors, and prevention and intervention strategies (Anetzberger, 2004; Bennett, Kingston, & Penhale, 1997; Biggs, Phillipson, & Kingston, 1995; Comijs, 1999; Cooper, Selwood, & Livingston, 2008; Dong, 2012; Kurrle & Naughtin, 2008; Mysyuk, Westendorp, & Lindenberg, 2013; O'Keefe et al., 2007; Penhale, 2008; Peshevska, Sethi, & Serafimovska 2014; Pot, van Dyck, Jonker, & Deeg, 1996). Remarkably, within this growing body of literature only a few dozen studies explore and discuss elder abuse in the "eye of the beholder" (Comijs, 1999; Chen, Dolinsky, Doyle, & Dunn, 1981; Hurme, 2002; Comijs, Pot, Smit, Bouter, & Jonker, 1998; Pillemer & Prescott, 1989; Pritchard, 2000; Wolf & Pillemer, 1989; Yan & Tang, 2001, 2004; Yu, Zhang, Draper, Kassab, & Miles, 1997). Even less studies have researched the conceptualization of victims, and current knowledge relies much on individual case-studies Hightower, Smith & Hightower, 2006; Pillemer & Prescott, 1989; Pritchard, 2000, 2001; Sandmoe & Hauge, 2014; Thomas, Scodellaro, Dupree-Leveque, 2005; Wolf & Pillemer, 1989).

The insights of victims themselves are especially important to address, as explanations of victims should line up with our understanding of the occurrence of abuse to develop appropriate preventive measures, to establish methods for detection and to initiate fitting interventions. For older individuals, healthcare professionals are among the most important groups to identify and to report elder abuse, but they are lagging behind in the identification and reporting of abuse. Only a small proportion of cases are reported (Ahmad & Lachs, 2002; Rodriguez, 2006; Cooper, Selwood & Livingston, 2009).

To enhance the understanding of healthcare professionals and their modes of detection and intervention, in this article we shed light on how older victims experience, perceive and explain the process of abuse. We discuss the ideas of victims on the causes, consequences and effects of abuse, ways of coping with abuse and explore how victims think about what occurred to them.

Methods

A qualitative study on perceptions and experiences of elder abuse was conducted in the Netherlands among abused older persons. The method of data collection was in-depth semi-structured interviews with six older men and eleven older women in the age range of 63 - 90 years. Thirteen participants lived independently and four lived in residential care facilities or nursing homes. The male respondents were formerly employed in the field of finance, accounting or management. Four out of the eleven female participants had earlier worked as tailors or housekeepers; others had no professional experience and did not attend higher education. Participants in this research were fully informed of the purpose of the interviews and their contribution was completely voluntary. Respondents received a notebook as token of appreciation.

Six victims of elder abuse were recruited through advertisements in freely distributed local newspapers. Eleven were contacted via elder advisors and welfare managers who work in healthcare institutions or support centers of domestic violence. The main inclusion criterion was experience with any type of abuse. Some weeks before the interview, these contact persons asked older victims to participate in the study. When interested, the primarily responsible researcher contacted them personally. After a full explanation of the purpose of the research by phone, appointments were made for a place and time to meet as chosen by the interviewee. Before the interview, informed consent was obtained (confidentiality and anonymity were guaranteed) and permission for recording was given by all interviewees. All the participants were considered to be cognitively intact and had capacity to consent to involvement in the study. We did not ask for permission from the medical ethical committee because it did not concern patients, but we did adhere to the ethical standards as subscribed by the designated professional associations of anthropologists, in particular American Anthropological Association (AAA) and European Association of Social Anthropologists (EASA). In this article we have used pseudonyms for all informants.

The in-depth interviews were held with guidance of an interview guide as developed by the researcher. The interview guide was based on existing research literature on elder abuse. Five pilot interviews were held with older persons prior to present study and the interview guide was adjusted where necessary. The main topics of the interview were: demographic and social background; health status and daily life; care; experiences with elder abuse (including description of abusive situation, feelings, coping, changes in life); social network and help and support; and social life. In line with semi-structured interview techniques, open questions were formulated and adjusted while interviewing to enhance applicability, understanding and clarity for individual respondents. The interviews lasted two to four hours and took place between September 2012 and December 2013.

Interviews were transcribed verbatim for analysis. Verbatim transcripts were then thoroughly analyzed using NVivo, a computer software program for qualitative data analysis. The approach used was primarily inductive, and the coding technique was based on the grounded theory approach (Glaser & Strauss, 1967) in which concepts are derived from the transcribed data. Initially key themes were separated in segments, then coded on the basis of conceptual analysis, from which main categories were developed that served as the basis for exploring, analyzing and discussing experiences and perceptions of the participants. This method of analysis gives the opportunity to explore different ways in which respondents explain their experiences and feelings; it also allows unexpected topics, thoughts and ideas to arise that would be neglected with a predetermined questionnaire.

Results

Table 1 provides details on the abusive situations experienced by our interviewees. In our study, physical abuse encompassed intentional infliction of pain ranging from hitting or kicking to pushing. Psychological abuse included threatening, manipulating,

insulting, blaming, offending, intimidation and humiliation. Financial abuse involved spending the older person's money without their knowledge or permission, scams, and extortion. Neglect included denying the older person adequate care, nutrition, clothing or a clean environment.

Here we describe the main findings, these include causes, effects and consequences and coping strategies. In the Appendix D we present two case studies that allow for an in-depth understanding.

Causes of abuse

"I am dependent on care, I need help with some activities at home, also with finance, groceries...that does not put you in a strong and advantageous position, you are much more vulnerable and can easily become a victim...(Frank, 81 years)"

"I feel redundant because our society perceives me as such. I feel like there is a label "too old" in this society (Ingrid, 80 years)"

One of the first elements in self-explanations of older victims was the cause of abuse. First, they reported that loneliness and social isolation played a role in elderly becoming a victim of abuse. For instance, they often relied heavily on the perpetrator and did not have much contact with other relatives or friends, resulting in a limited social support network. They felt that this had contributed to the abuse, because there was a lack of alternative contacts to turn to when the abusive situation occurred.

In addition, our interviewees felt dependent on others for care and activities of daily living, and this support made them accordingly vulnerable and easy targets for abuse. At the same time they felt that the perpetrator was also dependent on them, for instance for living or financial support and victims felt responsible to support the perpetrator, even while they were mistreated.

Related to this was another cause of abuse identified, the inequality in power and control in relations between victim and perpetrator. Our interviewees felt that feeling powerless and losing control over the situation triggered violence from the abuser's side, for example, when victims relied much on the perpetrator the power balance shifted towards the perpetrator. At the same time, victims felt that abuse could occur rather as a response to a lack of power of that same perpetrator and an inability to deal with the situation concerned, for instance, when victims did not grant the wishes of the perpetrator or were unable to meet their requests. Victims thought that by abusing an older person the perpetrator tried to restore power and control, ultimately regaining superiority within the relationship.

Finally, our interviewees felt that the marginal position of older persons in our society impacts upon abusive situations. In this regard, the interviewees mentioned notions such as disrespect and devaluation of older persons. Perceptions of older victims of being useless and "too old" (as sensitively expressed by Ingrid in her statement above) were part of their explanations for the occurrence of abuse in their life. They reasoned that this change in the position of older people and the

associated negative image created a realm of acceptance and permissiveness for using violence against older persons.

Table 1
Description of abusive situations of victims

Type(s) of abuse	Age	Gender	Relationship perpetrator/victim	Duration of abuse	Seeking help	Coping strategy
Physical abuse	82	Male	Caregiver	3 months	After a couple of weeks	Professional help
Psychological abuse	65	Female	Partner	6 months	After 2-3 months	Informal help
Psychological abuse	72	Female	Partner	Abusive situation was ongoing		Self-help
Psychological abuse	74	Female	Granddaughter	2-3 months	After one month	Professional help, self-help
Financial abuse	76	Female	Son	4-5 months	After 1-2 months	Professional help
Financial abuse	80	Female	Acquaintance	Abusive situation was ongoing	After 2-3 months	Informal help, professional help, self-help
Neglect	90	Male	Partner	Abusive situation was ongoing		Self-help
Neglect	79	Female	Grandson	10 months	After 4-5 months	Informal help
Psychological and financial abuse	81	Male	Previously unfamiliar person	2 years	After a couple of months	Professional help, self-help
Psychological and financial abuse	84	Male	Daughter	Abusive situation was ongoing	After a couple of months	Self-help, professional help
Psychological and financial abuse	80	Female	Neighbor	8-9 months	After 2-3 months	Professional help
Psychological and financial abuse	77	Female	Granddaughter	One year	After 3-4 months	Professional help, informal help
Psychological and financial abuse	63	Male	Acquaintance	Abusive situation was ongoing	After 1-2 months	Professional help, self-help
Psychological and financial abuse	75	Female	Acquaintance	Abusive situation was ongoing		Professional help, self-help
Psychological and financial abuse	79	Male	Neighbor	Abusive situation was ongoing	After 2 months	Professional help, informal help, self-help
Psychological, financial and physical abuse	78	Female	Son	One year	After 6-7 months	Professional help, informal help and self-help
Neglect and psychological abuse	90	Female	Son	More than one year	After 4-5 months	Professional help, informal help

Effects of elder abuse

"This experience is shameful and humiliating. I felt stressed and at the same time desperate... (Iris, 79 years)"

"Times are changing, values and norms in society are different. It was normal to help your parents they said, but now my children are not doing this for me. They see me as not worth it, "as rubbish". I was treated like trash that has no feelings or thoughts (Adriana, 75 years)"

According to the interviewees the experience of abuse has various consequences for an older person, which were related to the type(s) of abuse, but also to the expected nature of the relationship with the perpetrator. Foremost, and rather independent of type and perpetrator, were mentioned psychological effects after becoming a victim of abuse. These included shame, helplessness, humiliation, fear and anxiety resulting in feelings of stress and depression. Older persons felt desperate, frustrated and hopeless. These effects came forth out of feelings of incompetence to change the situation.

Related to these feelings was that victims blamed themselves resulting in low feelings of self-worth. For victims, it was difficult to comprehend that trusted individuals, especially in the case of relatives, had become the perpetrators of abuse. This breach of trust not only placed shame on the perpetrator, but also on the abused for "letting it happen", as one of the interviewees stated who had experienced psychological abuse involving a family member as perpetrator. Older persons believed that they had contributed some way or another to the abuse.

Within the scope of physical effects, in the present study we have understood this as both the physical effects of abuse itself, and health problems encountered during or after abuse. Older victims brought up health issues that they deemed related to the stress or anxiety they had experienced during or in the aftermath of the abuse. The physical complaints they mentioned included continuous stomach ache, incontinence, sleeping problems and loss of appetite.

Victims suffering from financial abuse described that they had changed their perspectives on money. They became more watchful and meticulous with money and valuable items than ever before. They believed this attitude could protect them from similar abuse in the future. Saving money gave them some feeling of security and certainty.

Some of the interviewees, in particular those who were abused by non-relatives, noted that the abuse had changed their norms and values, for instance, they distrusted kindness, good intentions and fairness of others. They felt betrayed and deceived. Losing trust in people led to stress and frustration and for some of them also to depressive feelings. Changes in norms and values – as a result of the abuse – had a negative impact on their notion of certainty in approaching (daily) life, as these norms and values represented a fundamental basis in their lives.

The interviewees often reported, implicitly and explicitly, a low self-perception with as a consequence a decrease in self-efficacy, especially in cases in which they had trusted non-relatives. Victims of abuse used self-descriptors such as “rubbish”, “stupid” or “idiot”. These notions created a sustained, negative image about themselves. As a result of a feeling of incompetence and the denunciation of themselves, older persons also experienced difficulties in decision-making. This was especially prominent in cases of psychological abuse as this type of abuse caused interviewees to become uncertain of their own capabilities. Some of the older victims had difficulty in assessing what they wanted, sometimes they described being reluctant to suggest or follow-up on ideas. Such behaviors evoked further irritation among the perpetrator and often led to more abuse.

Coping strategies

“I’ve made a survival plan for myself. I have to do everything possible to be able to deal with the abuse and to keep living...I’m trying to keep myself busy: reading and reading, walking a lot, cycling...It helps (Anne, 65 years)”

“I needed to deal with the situation. I was trying to seek help; I called public health service, the support center for domestic violence. They were open to help... My relatives also offered their support and that meant a lot to me... (Gerda, 77 years)”

Older victims used different coping strategies. Some relied on themselves (self-help), others were seeking help and support from family members and friends (informal help) or from different institutions (professional help) amongst which were public health services, non-profit organizations, and support centers for domestic violence. Often the interviewees used different coping strategies at the same time (see Table 1). None of our informants sought help from health professionals from the cure and care sector such as a physician or (neighborhood) nurse. Most of the victims described asking for help when the abuse had reached an unbearable point and seeking help seemed to be the only way out. The interviewees who turned to professional help mostly experienced various types of abuse simultaneously, or were cases in which perpetrators were family members (children, partners) or close friends (see Table 1). When a close family member was involved in the abusive situation the period of abuse before asking for help was reported to be longer. Victims felt ashamed and described how they anticipated denunciation by the community for having close relatives involved and they also wished to protect those relatives. Suffering from financial abuse was the clear exception to this pattern; even the involvement of a close relative was not a strong barrier for seeking external help. The interviewees felt that financial abuse is a more widespread and therewith more publically discussed type of abuse. Interviewees expressed that financial abuse is considered “normal” and easier to talk about. It is thus less shameful to share your experiences with others and seek help, outsiders would understand.

Other interviewees used a different strategy, which we designate “self-help”. They tried to continue their lives and overcome the negative effects by keeping themselves busy with hobbies, work, and relaxation techniques. Unlike the older victims who sought help from professionals or family and friends, these interviewees thought that they could deal with the abuse and its effects by themselves. Some adhered to this strategy because they were afraid to lose contact with the perpetrator, or, were afraid to suffer even more abuse when they would seek help from outsiders. These victims typically experienced psychological abuse or neglect. The perpetrators in these cases were family members (see Table 1).

Discussion

The findings reported here illustrate the process of abuse as it is experienced and perceived by older victims. We inferred the main causes of abuse, explained why it tends to continue according to the victims, and reported on the impact it had on their well-being and self-perceptions, and finally we discussed the strategies victims used in order to deal with the abusive situation.

Other studies that have reported on perceptions and experiences of older victims of abuse are in line with our findings. A qualitative study among abused older women also found, similar to what our victims reported, that an imbalance in power and control was an important factor in the occurrence of abuse (Hightower et al., 2006). The mutual dependency between victim and perpetrator has also been identified earlier (Mysyuk, Westendorp, & Lindenberg, 2015a, 2015b). We additionally identified that the negative image of “being old” influenced the victims’ perception of themselves. This also led victims to conclude that abuse is somehow permitted by perceptions in current society and contributing to abusive circumstances.

There is also another side that emerges from the stories of the older victims. In retrospect, they felt that they did not stand up for themselves and allowed perpetrators to continue the abuse. They described themselves as being compliant with the abusive situation, which sometimes provoked even more violence. Other older victims felt that the abusive situation was beyond their control and influence. These reactions of older persons resemble the phenomenon of learned helplessness in which victims of abuse feel helpless to change abuse, refrain from doing anything and accept any treatment (Miller & Seligman, 1975; Quinn & Tomita, 1997).

The differential effects of abuse we found in our study have been reported earlier (Chen et al., 1981; Hightower et al., 2006; Pillemer & Prescott, 1989; Yan & Tang, 2001). Quite similar to our study, it was found that older persons who experienced abuse reported psychological effects such as grief, anger, disappointment, psychological distress, anxiety, depression, and feelings of social inappropriateness, social isolation, deterioration in physical health, loss of independence, and financial loss (Comijs et al., 1998; Yan & Tang, 2001; Mowlam, Tennant, Dixon, & McCreadie, 2007). In contrast to other studies, we found two

effects of abuse that were not commonly identified earlier: a change in values and norms and a lower self-efficacy. This might be the result of the qualitative design of the study that we have used and allowed participants to freely express their feelings and to detail on the consequences they experienced.

The findings of our study show that our respondents used different strategies to cope with abuse and overcome its consequences. The use of distinctive coping strategies appears to be explained by the different types of abuse and by the different relationships to the perpetrators. Although less clearly relating these two factors in abusive situations, previous studies have shown that older persons used informal and professional help to cope with abuse (Comijs et al., 1998; Mears, 2003). Survival strategies identified among older women in Australia, such as blocking out the violence, pitting energy into another activity, resemble the self-help strategies found in current study (Mears, 2003).

Implications and Recommendations

Healthcare professionals can use the findings from this study to detect and address elder abuse. Next to the commonly identified signs of abuse, they could pay closer attention to mutual dependency to detect high-risk situations for abuse. Healthcare professionals can play a vital role in the prevention and detection of abuse as older individuals frequently visit healthcare institutions. Moreover, special attention should be given to the social situation of a patient, especially relationships with informal caregivers and relatives and possible feelings of powerlessness, social isolation and low self-esteem. Together, picking up these kinds of signals could help in the (early) identification of abuse.

Besides the well-identified signs of abuse (Paris, Meier, & Goldstein, 1995), it would be advisable for healthcare professionals to consider an abusive situation, especially in cases of unexplained physical symptoms among the elderly, depressive symptoms and decreased feelings of self-esteem and self-efficacy. The latter might express in difficulties in making decisions and lack of motivation to engage in activities.

The differences in help-seeking strategies we observe seem to be associated with distinct feelings of shame and anticipated humiliation that are related to the different types of abuse and the relation between victim and perpetrator. Self-blame is an important element in this rationale. Healthcare professionals could aid older victims by discussing abuse in related, more neutral, terms (e.g. harm, unhappy, not well) and by discussing elder abuse more openly to reduce the stigma associated with most types of abuse. If suspicions of abuse cannot (yet) be discussed, a sign of attention can already help the victim, and alternative measures (e.g. expanding the social or care network) than direct intervention might alleviate the situation.

One of the possibilities to deal with lower self-esteem and self-efficacy among older victims is the organization of support groups for victims that will be coached and led by an experienced professional or peer. Older persons will be able

to share their experiences, the coping strategies they used and receive feedback and advice from other participants who had similar experiences. The participation in these groups could enhance members' sense of empowerment and belonging, which may itself have positive effects on self-esteem and mental health (Levy, 2000). These groups can include face-to-face conversations, empowerment training, and psychological support. Also trainings directed at assertiveness and self-support strategies can help older victims deal with abuse and the reduced self-efficacy we identified in this study.

Limitations

The sample size in this study may be considered relatively small. Some of the findings can therefore not be generalized to the whole population of abused older individuals; however our primary aim was to identify variables that play a role in the experience of abuse. We did so by an in-depth exploration of the understanding of the experiences of older victims of abuse. Although the empirical features of the variables might be different in different cases, we did identify variables that influence the process of abuse according to victims' experiences.

We only used one method of data collection to identify variables, mainly because in-depth interviewing allowed the older victims to express themselves unhampered. Although triangulation of methods is always preferable, the enduring sensitivity of the topic and the accompanying shame prevented the use of alternative methods, such as focus groups, to further delve into the self-explanations of older victims.

One of the possible limitations was self-selection bias; we did not use any exclusion criteria. Due to the sensitivity and complexity of the researched topic, it was difficult to reach respondents and that is why all the victims who agreed to participate in the study were included. Considering that the aim was to find variables of importance, the selection of informants does not impact the variables themselves.

The participants of this study were not followed-up longitudinally, which excluded the possibility to check how they feel nowadays and how their life changed over time. Therefore it is difficult to talk about the prolonged effects of abuse. Future studies can look into this.

Conclusion

Older victims perceive abuse differently depending on the expected acceptability of the type(s) of abuse experienced and the expected stigma associated with the perpetrator involved. The effects and chosen coping strategies are influenced by these considerations and therewith also influence help-seeking behavior. Healthcare professionals are encouraged to use these findings in practice and help to detect, prevent and intervene in elder abuse. Paying close attention to mutual dependency of victim and perpetrator, unexplained physical symptoms, feelings of depression and low self-efficacy next to the commonly identified signs of abuse

and discussing these signs in unobtrusive terms might enhance the identification of abuse by healthcare professionals.

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Conflict of Interest

None declared.

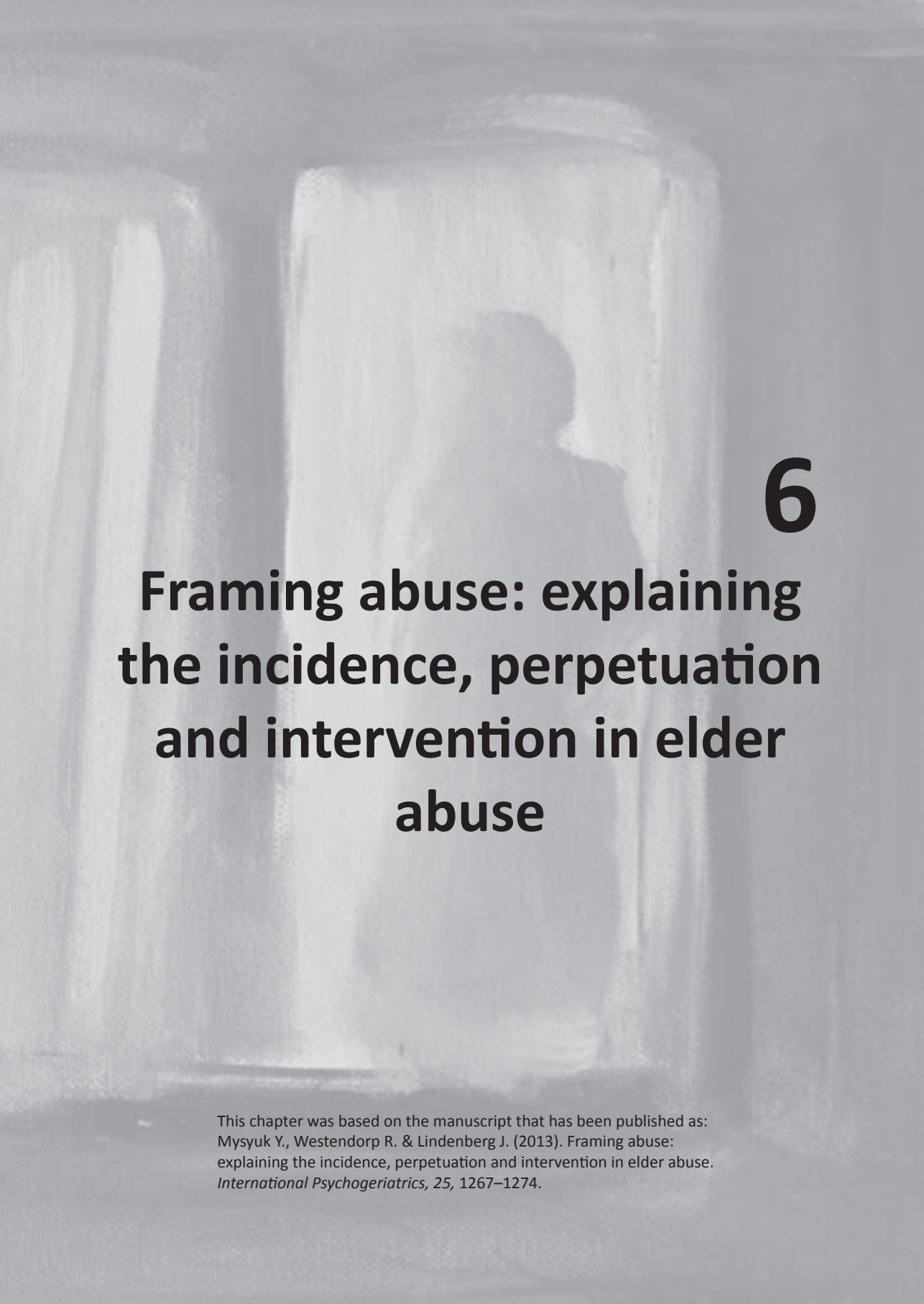
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6

Framing abuse: explaining the incidence, perpetuation and intervention in elder abuse

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Abstract

The role of individual characteristics in incidences of elder abuse has long been highest on research and policy agendas. Now it is timely to discuss factors that go beyond victim and perpetrator. Environmental factors also play an important role in elder abuse. In this article we address the framing of elder abuse as a social and a health problem. Attention is paid to the factors that influence societal context and the health care system, its organization, structure and principles. Focus groups and in-depth semi-structured interviews were held with different professionals and older people themselves. Qualitative analysis of focus groups and interviews transcripts was performed to analyze how different professional groups and older persons themselves view elder abuse, to determine opinions and attitudes towards elder abuse and the necessary actions that should be taken to prevent or intervene in the problem. Two main explanatory frameworks emerged in the discourse of older persons and care professionals: social arrangements and health care system. The themes within the social arrangements included social taboo, social control and responsibility, and institutional cultures. The fragmentation of care and changes in the financing of health care were two aspects distinguished within the framework of health care system. Two explanatory frameworks showed elder abuse as both a social and health problem. The environmental factors through social arrangements and health care system have an influence on framing of abuse. The different ways of framing abuse impacts the understanding of abuse, ways of intervention and prevention measures.

Key words: elder abuse, qualitative research, framing, environmental factors, health care, neoliberalism

Introduction

Previously scientific research on elder abuse focused primarily on individual characteristics of victims and perpetrators. Considering the in-depth research that has already been done on perpetrator-victim characteristics (see for instance Hörl, 2010; Lachs & Pillemer, 2004) it is timely to pay more attention to the relationship and interaction between victim and perpetrator, to environmental factors, which can in fact play a bigger role than previously assumed and studied in the context of elder abuse.

Factors in the environment can be viewed as mirroring the social institutions that are already established. For instance new institutional economic approach on informal social norms and how these structure institutional frameworks that can be incorporated or embedded in organizations and governing bodies. In other words, social institutions reflect the social arrangements in which they are based and incorporate the standards and expectations that are present within that society. Considering this background, it is indispensable to broaden the focus of elder abuse research and understanding from individual characteristics and situational circumstances of the victim or perpetrator to a focus that includes the environment in which older people live, interact and communicate with other people and in which they receive care, help and support.

In this article we explore the framing of elder abuse as a social problem and a health problem. It will also address how the changing culture of health care changes the role of older person in it. The scale of elderly who experience abuse draws more attention to the position of the elderly in society in general and the acceptable and expected help-seeking behavior from older persons in current health care systems. Through discussions about elder abuse of older persons and professionals involved in elder abuse in the Netherlands we investigate factors related to social arrangements and the health care system, its organization, structure and principles. The influence of environmental factors on older people is therefore crucial if we wish to understand and explain the circumstances of elder abuse.

Methods

A descriptive analysis of Dutch society and health care system was performed to provide more information about the changes in the Dutch society and the health care system, and better understanding of the discourse on elder abuse. Different studies about the Dutch health care system, its development, its shifts and integration of neo-liberal principles were analyzed.

A qualitative study was conducted to analyzed discourse on elder abuse in interest groups dealing with elder abuse. The methods of data collection were focus groups and in-depth semi-structured interviews. The study was conducted among older persons, men and women age 65 and over, professional groups and experts. The elderly were contacted through elderly advisors and were asked to participate in the research. The experts were approached through different organizations and

contact persons via snowball sampling technique and a round mail for participation in a network for people who work and are involved in the field of elderly care. Confidentiality and anonymity were guaranteed through signing an informed consent form or having an explicit oral agreement.

Focus groups

The data for this article is primarily based on eight focus groups. The topics that were discussed were defining elder abuse and the necessary actions that should be performed to prevent or intervene in the problem. We included different professional groups; experts, policy makers, managers and older people themselves. In total 42 participants were included. The focus groups lasted 1 to 2.5 hours, depending on the number of participants. The list with the potential participants for the focus groups was made on the basis of known organizations in the Dutch field of elder abuse. Then, persons from different organizations who are involved in the field of elderly care were included to the list using a snowball sampling technique (asking for further referral and potential participants). Following this, all the potential participants were contacted (via e-mails, phone calls) and invited to take part in a particular focus group (based on their expertise, experience, skills). The focus groups were not representative of the population in general as the group selection was not random and the sample was quite small but instead was intended to gather persons from diverse interest groups and diverse backgrounds as this study targeted to collect diversity of views and opinions.

All participants were informed of the purpose of the focus groups. Before the start of the focus groups permission was asked for recording. The focus groups took place between February and March 2012. All groups were transcribed verbatim. Analysis was done primarily inductive with NVivo qualitative software according to the grounded theory approach as outlined by Glaser and Strauss (1976).

Interviews

In-depth qualitative interviews with older people about their opinions, attitudes towards elder abuse and expert interviews with diverse professionals who are working in the field of elder abuse were conducted. The latter showed how the cases of abuse were identified, assisted and followed-up.

For the semi-structured interviews two interview guides were used. The first one was interview guide for people who experienced elder abuse. The main topics of the interview guide for older people who experienced abuse were: demographic and social background, health status and daily life, care, experience with elder abuse, social network/help and support and social life. The interviews lasted between 2 to 3 hours. Interviews for this group of older persons are still ongoing but the interviews discussed in this article took place between April and August 2012.

The second interview guide was a topic list for experts (professionals who work with older people, or who have experience in the field of elder abuse). The topics of the interview guide for experts included: background and meaning of

elder abuse, profiles of victim and perpetrator, collaboration/network, perspectives of wider society and necessary actions for dealing with the problem. The expert interviews lasted 1 to 1.5 hour.

Analysis

Interviews were transcribed verbatim for analysis. Interview transcripts were stored securely on a USB-stick with the researcher and did not include personal identifiers. Verbatim transcripts of the interviews were then comprehensively and systematically analyzed using the computer software NVivo, a tool for analysis of qualitative data. The approach used for analyzing data was primarily inductive, where analytical concepts and perspectives are derived from the data through coding technique based on a grounded theory approach (Glaser & Strauss, 1976). Such an approach allows exploring the ways in which respondents explain their own experiences and also allows unexpected topics, issues and thoughts to emerge.

Results

Dutch society

Pillarization based on religious or social-political affiliation, strong social control and concurring traditions were prominent characteristics of Dutch society in the last centuries. The feeling of common responsibility, dependence on the government and social system, a relative lack of individual choices and personal autonomy were leading and important principles of politics and society. With time values that were important earlier changed or were modified and new ones are becoming more and more salient.

Contemporary Dutch society is based on the principles of a mixed neo-liberal ideology that incorporates notion of individualism and personal freedom, independence, choice, responsibility and competition. These features are also central in the neo-liberal approach to health care; it emphasizes principles of self-sufficiency, responsibility, and independence in health care and encourages people to be responsible for their own lives and accountable for their actions and well-being. Hence, in a neo-liberal approach responsibility for disease and health is placed on the individual. Additionally, the neo-liberal individual is autonomous, self-reliant and self-concerned, and “free” of obligations to provide for the needs of others. Contrary to these neoliberal notions, health care is bound to interdependency and vulnerability. Furthermore, the patient’s abilities of self-management and autonomy may be weakened, and the patient may feel both intimidated and powerless as he or she is unable to fulfil basic needs or functions (Ruthjersen, 2007).

The Dutch health care system

To understand the discourse on elder abuse presented below we provide some background information about the Dutch health care system. The Dutch health care system is a hybrid system of public, private and professional elements (Schrijvers,

1998; Boot & Knapen 2001; Putters, 2001). According to the Dutch Constitution, the government is responsible for the accessibility, the quality and the efficiency of health care. In spite of this, the government plays only a minor role in the implementation of these main principles of health care and therefore depends on the collaboration and cooperation of insurance companies, private institutions of health care and other professional organizations which are dependent on each other. Already since the eighties, when more market elements were introduced in the health care system, these developments have been widely debated. For instance, hospitals introduced different methods commonly used in businesses such as “social entrepreneurship”, independence of the customer and centralization of the position of the manager (Grit & Dolfma, 2002; Picone, Uribe, & Wilson, 1998).

Current discourse in health care focuses on changes in the position of the patient, quality of care delivered, and leadership in health care organizations. Principles such as solidarity and equal access have long been guiding the Dutch health care system (ter Meulen & van der Made, 2000). However, instead of the collective responsibility that is characteristic of solidarity, an increased emphasis is now placed on the requirement for individuals to take care of their own health care needs. This emphasis on individual responsibility and personal autonomy can empower individuals to take care of their own needs, to arrange the necessary care services according to individual preferences and to take accountability for their own choices. However, individual responsibility finds its limits with vulnerable groups (elderly, children, individuals with psychological or mental disorders), for whom it is very difficult to realize personal responsibility for health, including financial responsibility. That is why the principle of individual responsibility in health care is important, but it has to be in balance with the principle of solidarity with vulnerable groups (ter Meulen & Maarse, 2008).

Environmental factors in framing abuse and neglect

We studied the transcripts to analyze how different professional groups and older persons themselves frame abuse. This included the circumstances under which abuse and neglect occurred, the explanation that was provided for why abuse occurred and continued, and the possible interventions. We discuss two main explanatory frameworks that were provided to frame abuse and neglect by our participants: social arrangements and health care systems. Both, as is clear, were pointing towards socio-structural factors that influence abuse and neglect. In our analysis, considering the social and health care changes as outlined above, we pay particular attention to how the framing of professionals and older persons reproduces, reflects, integrates or contradicts political agendas that incorporate neoliberal principles.

Social arrangements

Despite that prevalence rates show no distinct increase or decrease in elder abuse incidence since it was brought under attention in the 1970s, participants in this research did voice concern that current changes in society, especially in regard to

the position of older persons and social cohesion have led to an increase in abuse and neglect. In explaining elder abuse as influenced by social arrangements diverse themes were touched upon: social taboo, social control and responsibility, and institutional cultures.

A social taboo

Both professionals and older persons discussed the limited knowledge and awareness of elder abuse and neglect among the general public. Explaining this lacuna was done by reference to the social taboo that surrounds discussing elder abuse and neglect. For older persons elder abuse was something one rather not discussed: “It is not something you would like to talk about”. This apprehension was seen as logical, because of the feelings of shame and incompetence that were seen as related to its occurrence. The silence that surrounded it was according to older participants one of the reasons why it was not recognized easily. Professionals, especially in the group of managers and policy makers, voiced a similar idea. One manager stated it as follows: “Among elderly it [elder abuse] is still a taboo; a hidden problem and elderly have difficulty talking about it”.

The question *why* this is still taboo, and for some increasingly taboo, was explained by two social factors: the position of elderly and social expectations of self-reliance. One more individual factor was mentioned as explanatory factor for this taboo: the position of an older person within the individual life course.

The taboo-sphere was first explained by the social position of older persons both in the past and nowadays. Generational differences in attitudes were mentioned by older persons themselves to explain why abuse was still taboo: “It is different generation, older people accept everything, they are glad about the things they receive, you don’t create conflicts”. Others phrased this attitude in a principle of “older persons do not wish to bother others”. Both statements refer to a marginalized position of older persons within society at large.

This attitude of not wishing to be burdensome to others was not only framed as a generational difference, but also seen as something that run counter to social expectations. The occurrence of abuse and neglect was seen as a form of escalating dependence. Older persons stated that by saying one is abused one immediately became a vulnerable and dependent person. This was contrasted to the widespread imagery of older persons that are supposed to be embracing and choosing for “active ageing”, a good old life and to be “successfully aged”. This good old life is particularly portrayed in advertisements for pension schemes in the Netherlands, which are not unique for the Netherlands. In these advertisements a rather young (mostly famous) retired person is portrayed in an attractive retirement setting: in a nice, fast car, on a remote island, or in a second house in a rural setting in France or Italy. The retiree is often arguing in favor of the pension scheme and phrases the ‘good old life’ as something attainable for everyone and a *choice*. In the Netherlands this kind of portrayal is identified as *Het Zwitserleven gevoel* (The Swiss life feeling) after one of the largest pension insurers that is particularly successful with these kind of commercials.

The taboo of elder abuse was further explained by contrasting it within the individual life course. Being abused meant for older participants that a situation of dependence and vulnerability was reached that was challenging a self-image over the life course of an independent adult. Thus, both from a social perspective and an individual perspective, expectations towards self-reliance and independence were undermined by the occurrence of abuse.

It is striking that in a life phase where dependence seems a natural and inescapable part, simply because physical decline becomes inevitable, the framing of this dependence is an explanatory factor in the exact taboo around abuse and neglect. It seems to refer to the social acceptability of dependence. A comparison with child abuse and neglect makes the tension inherent in this most apparent. Child abuse has been thoroughly on the agendas for some time now, and despite that there are some major and important differences in approach it is quite illuminating to compare the situation of older persons that are mistreated with those of children. Children, as they are minors, are by extension seen as dependent and vulnerable, but more importantly *expected* to be dependent. In contrast, and this might seem straightforward, older adults are expected to be independent, because they are of age and have already led an independent life. The reversal from independence to dependence is filled with tension because from an individual perspective dependence is a break with the self-image that has been built throughout the life course, and from a social perspective an adult should be self-reliant, especially in current political discourse about older persons.

In several measures to reduce health care costs of an increasing older population – and the Netherlands is probably not an exceptional case in this respect – measures such as saving for health care costs at older age, compulsory informal care and even selling one's house to pay for health care are all referring to an individual responsibility to “take care of one's own old age”. Especially recurrent in the discourse in the Netherlands about older persons and care is the concept of *eigen regie* (own control) in which health care is chosen, initiated and organized by the health care recipient. Herewith the expectation towards older persons is changed from a passive receiver to an active coordinator. Even though this is, certainly for some older persons, a welcome change, it does make it hard to admit that one is no longer independent, competent and responsible and admitting the opposite comes with “shame” and “humiliation” as older persons stated. In this explanation the influence of a political discourse inspired by neoliberalism becomes clear: as older persons confronted with abuse they fail to fulfil and satisfy neoliberal principles of an individual who is autonomous, self-reliant and self-responsible.

Social control and responsibility

Besides a perceived social change to focus more on individual self-reliance and responsibility, and co-current changes in the social position of older persons, a related but somewhat differently framed societal change was mentioned by our participants in explaining elder abuse: a decrease of social solidarity and

responsibility. In the focus group of interest organizations of older persons one participant phrased it as follows:

... It is how the entire elderly care works nowadays. Elderly are more and more left alone, in the individual situation. So there is little social control and I ask myself: how far should that go? Elderly themselves sometimes need and wish for more social control... .

The decrease of social control and responsibility was considered important in preventing and in discovering elder abuse. Risk factors such as loneliness, disturbed family relations and derailed care were considered to thrive well in a situation where social control and responsibility decreased. "There is no social control, no feedback... the social context is very important, because then you have social control, you keep an eye out for each other. That actually counts for every vulnerable person, children, older persons... (GP in focus group)".

Social control then functioned as a safety net in case situations escalated, in particular for lonely older persons and (over)burdened informal caregivers. Similarly, it was argued that social control and responsibility could step-in in situations when increasing physical dependence escalated in already fragile family relations. Elder abuse within families was considered to occur within a family history in which relationships were already shaped and influenced by (disturbed) power relations. As one older participant phrased it "when family relationships are solidified in a certain pattern of behavior". Revenge from adult children for abuse occurring in their childhood was an especially vivid example of when accordingly "social control and responsibility" could have intervened. The described social change refers to a perceived individualism and the principle of being free of obligations to provide for others that is also put forward in neoliberal discourse, as outlined above.

Institutional cultures

A theme that recurred in several groups and interviews was a specific institutional culture. In some institutional settings such as residential care facilities and nursing homes this was viewed as a 'culture' that allowed certain behavior that can be seen as abusive. A lack of transparency, for instance to discuss burdened care professionals or colleagues that transgressed boundaries was sometimes mentioned. Some even argued that the acceptability of certain behavior was extended across what was termed as "acceptable boundaries" as professionals brought their own norms and values into these institutions and certain abusive behavior "[is] connected to your own norms and values, what you think is acceptable and what is not (Focus group GPs)". What abuse is, and what not, where the boundary is, is difficult to assess. Professionals who discussed this issue in their focus groups did not reach a consensus about this. Some felt it was when an older person "experienced harm" or felt "boundaries were crossed" and whether that might be feeling offended or experiencing harsh treatment was irrelevant. Others felt that the label abuse required more, but what exactly demarcated the boundary of abuse and where it lied was left open. This "grey zone" of abuse is something that cannot be resolved

easily; perhaps a doubt about the acceptability of certain behavior by any of the involved parties should already be enough for discussion.

Some even argued that the current health care system was actually a form of abuse, stating that “abuse is inherent in the culture of institutions (Focus group elderly)” and “is a bit in the culture [...] and think that this kind of treatment is fine (Focus group institutional care)”. The idea that current health care is conducive for an environment of abuse, or even is a form of abuse by itself, was remarked by some of the participants. As one of the interviewees phrased it:

What is not abuse? A lot of things are not seen as abuse, which are actually abuse. They are only put in such a cultural context that they are seen and perceived differently. The whole health care system has to be changed. You have a lot of abuse in health care. Abuse in the health care already begins in the emergency department when doctors are not willing to deal with elderly [...]. The needs of older people are not a priority, money is the priority. (Focus group elderly)

This respondent stated it rather strongly, but some of the other older interviewees also felt that older persons were neglected within the system and were perceived as difficult and burdensome and that this by itself was a form of abuse. Others felt that perhaps care professionals were not really to blame, but that the current system in which work pressure is high and individual attention is under pressure was enabling a form of neglect and an environment in which abuse occurred as a result of stress and a lack attention for the social dimension of care.

Health care system

The liability of the health care system itself in relation to institutional cultures that was mentioned by some of our respondents leads us to the way the role of the health care system itself was framed by our participants. As outlined above, in the explanatory framework referring to social arrangements elder abuse was seen as a social problem that is to be dealt with in broader society. In the explanatory framework discussed in the following paragraphs however elder abuse was framed as a health problem that involved the health care system.

The major reforms such as outlined earlier in this article have led to some large changes in the provision, financing, planning and monitoring of care for older persons and especially vulnerable persons. Although it is unclear up to what level older persons participate in the healthcare system, it can be expected that at least for some of the older persons involved healthcare systems are an important point for seeking help and assistance. In the Netherlands, on average older persons visit the GP more often than eight times a year and vulnerable elderly visit the GP more often than this average (van Campen, 2011). Thus, for as far as older persons who are abused participate in the health care system, participants felt that changes in the system were creating an environment in which abuse can occur and falls “through the cracks”. Two broad aspects, which are mutually interdependent, of the changes in the system were brought to the fore: fragmentation of care and changes in the financing of health care.

Fragmentation

Health care systems can be viewed in diverse ways. Whether seen as reaching from primary to tertiary care or from informal to formal care, numerous providers and institutions are involved in caring for the same persons. According to prevalence rates vulnerable elderly with for instance decreased mobility, loneliness or cognitive decline are at highest risk for elder abuse. They are also the ones that visit several health care institutions at the same time leading to a rather diffuse picture of who is overall responsible or has to take the coordinating role in providing help for older persons experiencing abuse. Professionals involved in caring for older persons spoke about a lack of cooperation or coordination among diverse health care organizations and levels that sometimes perpetuated a situation of abuse. As one participant in the focus group of outpatient care discussed:

Once we had an older woman, she was placed inside a residential care facility after the situation at home had become unbearable. When I arrived at the residential care facility I discovered that the caretaker who was responsible for the abuse was actually being involved in the care plan of the victim. There had not been an exact exchange of information so the situation could continue inside the home.

Whether this case is representative remains unclear as specific quantitative data is lacking. However, the mechanisms exposed, a fragmentation of care which results in a loss of information was confirmed by other participants as well. Thus one GP discussed a similar situation and said “the whole transfer of the client from a problematic home situation to a residential care home is not happening in a proper way... Problems in the system are appearing again”. The system referred to in this case was mainly pointing towards the organization of care in which diverse institutions have to cooperate in one case. The multiplex and multidisciplinary problems that come with a case of elder abuse, that can range from physical problems, family problems, personality and psychological problems and so on leads to an involvement of several organizations. The solution is no less fragmented as it requires additional involvement of care, but sometimes also a social worker, outpatient care and in some cases psychological care. The experience of the system as something external to the individual care provider is related to the feeling that influencing this system often goes beyond the individual care professional or organizations:

You need diverse partners to get things done, because once outside of the health care system I will no longer have an eye on the client. On the older woman and how she is doing. So well, we encounter heavy, rather complex cases. We actually encounter poignantly enough that increasingly more often, and that is sad...”. (Focus group outpatient care)

Some of the participants tried to combat these problems in setting up network meetings in which diverse medical, paramedical and social service representatives participate. In framing elder abuse a concern for health care, and by extension also as a health problem, it also justified intervention and supervision under this label.

The implications of framing it under this label go beyond this article. It is important, however, to mention that by treating it as a health concern, a prime, universal concern, certain actions become justifiable, acceptable and legitimate under the label of the integrity of health (in contrast to framing it as a social problem). Others sought the solution for a lack of coordination on the local level on a higher level, one expert interviewee stated that “the government has to determine the structure of elderly care; it should be responsible for monitoring the care system and give clear protocols. This can make changes”.

Financing

Perhaps a more specific factor for the Netherlands that is interrelated with the fragmentation of care is the financing of care. Since 2010 care organizations are preparing and slowly anticipating a change in which financing of care under some specific laws is shifted from the national governmental level to the municipal level. Important in the debate about elder abuse is the shift in responsibility for the allocation of care that is given under the social support act to the municipality. This act provides among other things provision of facilities, help or support for persons that are disabled in some way. The law includes support for older persons and covers for instance home care, but also a wheel chair or transport. The general idea is that this will enable a better assessment of the needs and demands on community scale. Participants however perceived this change to lead to a further fragmentation of care for elder abuse, exactly because financing means and distribution remained unclear:

Now it is dependent on the municipalities, on the municipality in which you live and what is currently the priority within this municipality. How poor is this municipality? How social is this municipality? And which choices does this municipality make? (Focus group outpatient care)

The uncertainty about whether certain interventions would be financed and diverse priorities of individual municipalities was also a concern for participating elderly. As one of the participants in that focus group for elderly stated rather boldly: “For municipalities it is now a choice between street lightening or elder abuse intervention”. Even if it is somewhat doubtful that this was the exact case, as care and infrastructure facilities do come from a different budget, however, it was perceived and felt this way by the older participant. This statement, however, seemed to refer much more to a questioning of the capabilities and competence of municipalities to decide on the allocation of money in the within the framework of the social support act. Some case managers discussed the difficulty they had in working within the given budget. In practice, a certain amount of hours is allocated for each case of abuse, but sometimes there are more cases of abuse or there are certain particularly difficult cases that require more investment. Money, however, had run out in the meantime. Some care professionals therefore resorted to shopping around, to put it rather simply, and asked for the involvement of long term care facilities to be able to apply for budget as part of the Act for Long Term Care, which again led to a further fragmentation as the case had to be handed over.

Decentralization in both care organization and financing, also partly inspired by neoliberal tenets, might seem a way of increasing a fit between needs and provision, but for a multiplex and multidisciplinary problem there is no specific financing structure. By framing it as a health problem the involvement of a wide variety of organization and care acts was legitimized. This also enabled, conversely, a further fragmentation of practices, which participants felt were sometimes responsible for prolonging situations of abuse.

Conclusion

In this article we have discussed the way health care professionals and older persons frame elder abuse. The environmental factors appeared important in framing of abuse. We have shown that two explanatory frameworks were most prominent in the discourse studied; on the one hand social arrangements and on the other hand factors in the health care system. In the first, elder abuse was foremost framed as a social problem. In the last, elder abuse was primarily framed as a health problem. Especially the social problem referred to neoliberal principles of an autonomous, self-reliant and self-responsible individual. Prominent in the framework of health care was more the conceptualization of a system that went beyond the individual health care provider. Current changes in health care system that were mentioned as impacting practices and intervention in the area of elder abuse were decentralization in organization and financing.

For health care professionals, and providers, it is important to be aware how a phenomenon such as elder abuse is framed as it can have important implications (as became apparent in the discourse of older persons) for help seeking behavior and the way the problem is expressed. Therefore it is equally important to be aware of how different professional groups frame elder abuse as it affects the way they navigate through the health care system in seeking help for their affected older person. Being aware of differences in conceptualization can help to create a better understanding between health care professionals and older persons.

Conflict of interest

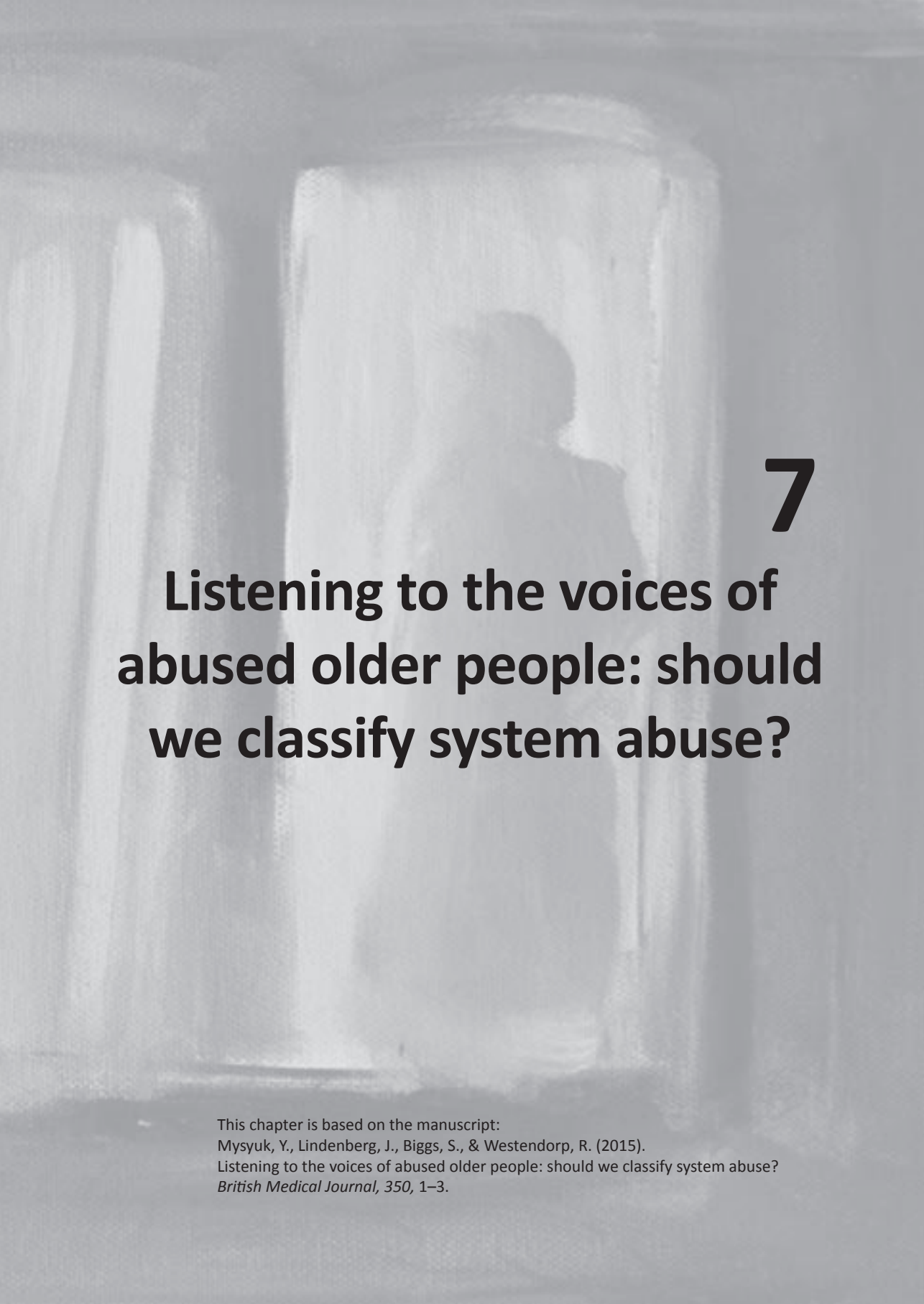
None.

Description of authors' roles

All three authors contributed equally to the thoughts expressed in this article. Yuliya Mysyuk and Jolanda Lindenberg wrote the draft of the article, whereas Rudi Westendorp assisted and contributed to the final manuscript.

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7

Listening to the voices of abused older people: should we classify system abuse?

This chapter is based on the manuscript:

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Listening to the voices of abused older people: should we classify system abuse?
British Medical Journal, 350, 1–3.

Over the past few decades it has become clear that abuse of older people is a far reaching public health problem that affects the quality of life of people worldwide (Lachs & Pillemer, 2004; Anetzberger, 2004; Melchiorre et al., 2013; Cooper, Selwood, & Livingston, 2008). It disproportionately affects people with mental health problems, such as depression and dementia (Lachs & Pillemer, 2004; Acierno et al., 2010).

Currently, the most widely used definition comes from the World Health Organization: “A single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person” (WHO, 2002). The definition focuses on a trusting relationship, includes acts of omission and commission, and is mostly interpreted as referring to interpersonal relationships (Tinker, Biggs, & Manthorpe, 2010). However, scandals in the UK, such as at Mid Staffordshire (Mid Staffordshire NHS Foundation Trust, 2010) and Leas Cross (O’Donovan, 2009) indicate that the problem goes beyond interpersonal relationships.

For older individuals, care professionals are among the most important groups to identify and report elder abuse (Ahmad & Lachs, 2002; Rodriguez, 2006). Despite this, only a small percentage of the cases are reported by physicians (Ahmad & Lachs, 2002; Rosenblatt, 1996) and elder abuse remains under-reported (Berman & Lachs, 2011; O’Keeffe et al., 2007; Cooper, Selwood, & Livingston, 2009). It is therefore important that those involved in healthcare are in touch with the experiences and perceptions of elder abuse among victims. Yet, despite some exceptions (Killick, Taylor, Begley, Carter Anand, & O’Brien, 2015) the voices of older people are relatively absent in debates about the typology of elder abuse, which is generally categorized as physical, emotional, financial, sexual, and neglect (Lachs & Pillemer, 2004).

To illustrate older people’s views on abuse we draw on our qualitative studies on perspectives on elder abuse involving more than 100 people in the Netherlands—comprising experts, professionals, and, in particular, older people (≥65 years) (Mysyuk, Westendorp, & Lindenberg, 2013; Mysyuk, 2015).

An abusive system?

When we asked older people, “What do you think of when you hear the word abuse?” one of the issues recurrently highlighted was inadequate and insufficient care in institutions. One 69 year old woman who had received hospital treatment told us:

There is no respect for older persons in all these institutions [nursing homes, home care organizations, and hospitals]. Older persons are abused in these institutions, abused by the healthcare system. It happens all the time; we can experience it every day. If you are old, then you are only a stick that lies in bed.

They can only think: why is he still here and not dying? That is what we feel.

Rather than blame individuals, older people identified institutional structures as responsible for their experience of abuse and neglect. Research in other countries,

particularly in the UK and US, and recurring scandals in care of older people (Mid Staffordshire NHS Foundation Trust, 2010; O'Donovan, 2009; Commission for Health Improvement, 2003), confirm these findings and have led to proposals to reorient institutional abuse to pertain to structural arrangements instead of individual behavior or excesses (Burns, Hyde, & Killett, 2013; Hyde et al., 2014).

Older people also said they felt disadvantaged or neglected as a result of changes in the financing and structuring of the Dutch healthcare system. One 82 year old man said:

In general nursing homes, residential care facilities, and other institutions function particularly badly. And in my opinion the problem is in cuts and in restructuring that takes place. These have an influence on the quality of care provided to older persons, which is insufficient.

Studies among older people in countries as diverse as Ireland, Sweden, the US, and Australia show a similar pattern (Erlingston, Saveman, & Berg, 2005; Naughton, Drennan, Lyons, & Lafferty, 2013; Anand, Begley, O'Brien, Taylor, & Killick, 2013; Hempton et al., 2011; Phelan, 2008; Levine, 2003; Hudson et al., 2000). The analogous restructuring of many healthcare systems worldwide through introduction of mixed economies of care (Boyle, 2011; Schäfer et al., 2010; Hunter, 2013; Dixon & Poteliakhoff, 2012; Rothgang, 2010) and increasing specialization seems to explain these parallels. Important aspects that were highlighted in these studies, also mirrored in the narratives of our participants, were excessive bureaucracy and a lack of clear responsibility in healthcare institutions. Even though these problems seem to be general, older persons believe that the way healthcare works, in terms of non-transparency, administration, and lack of overarching organization is particularly harming them (Hyde et al., 2014; Anand et al., 2013). This may be because many older people may have multiple conditions, making them more likely to encounter the negative effects of the resulting fragmentation (Barnett et al., 2012) and leaving them feeling vulnerable, powerless, and unable to approach someone because they cannot identify the person with prime responsibility.

Older people also felt that healthcare professionals were hostile towards them. For example, one 75 year old woman whose husband had been treated in a hospital and nursing home, said: "Often the staff of the hospitals or outpatient facilities are unfriendly. I experienced some hostility; it is quite strong in such environments."

They sought the explanation for the hostility not just in ageism but also inefficient planning by the care organization, leading to a lack of supervision, knowledge, and training. They reasoned this contributed to high levels of stress and work pressure that resulted in negative attitudes towards older people—as if they were too demanding. Older people did not so much blame professionals for this, but as also detailed in studies from the US and Ireland (Phelan, 2008; Levine, 2003; Phelan, 2009), discussed how the care system was responsible for the behavior shown by these professionals and how this particularly affected care for older people, who simply needed more time and patience.

Older people felt that institutions did not have a place for them and are unable, or unwilling, to take into account difficulties older people can encounter. These experiences seem related to negative attitudes towards older people in wider society but also show a tacit acceptance of the low priority given to later life, as shown, for instance, by the 20% decrease in healthcare spending on people aged ≥ 65 in England over the past 10 years (Triggle, 2015).

This highlights, as others have also argued (Levine, 2003; Göergen, 2002; Hörl, 2002; Scodellaro, 2006) that the healthcare system and society at large is responsible for creating permissive circumstances in which abuse can occur. These permissive factors contribute to an implicit culture of abuse and neglect in which older people's care outcomes become compromised and self determination is ignored. For example, studies on pressures to speed up discharge have shown that they may inadvertently lead to higher mortality risks and have exposed the lack of involvement of older people in decisions to move to residential care (Connolly, Broad, Boyd, Kerse, & Gott, 2014; Hall, Schroder, & Weaver, 2002; Oswald & Rowles, 2007; Reed, Cook, Sullivan, & Burrridge, 2003).

Systemic nature of abuse

How can we acknowledge these views? We need to ensure that the voices of older people are heard and their experiences find resonance. One way to do this is to include what we call "system abuse" in the types of abuse. By system abuse we mean the organization and resulting practices in our institutions that are (implicitly) abusive and cause harm or distress to an older person. This further extends WHO's definition to include a relationship between an individual and a system that finds its expression in the practices in our institutions.

Although the descriptions of abuse by older people might seem to resemble ageism, system abuse goes beyond Butler's (McDonald, Charlesworth, & Graham, 2015) definition "as a process of systematic stereotyping of and discrimination against people because they are old." System abuse includes measures that are not necessarily ageist but disadvantage older people and eventually lead to actions that can be considered abusive or negligent—for example, digitalization of healthcare and fragmentation of care leading to the exclusion or disempowerment of older people. By introducing system abuse into our definitions of elder abuse we can increase awareness of the, at times, implicit disadvantaged position, embedded hostility, and lack of respect older people experience as a result of structuring and financing.

One consequence of adopting the term system abuse is that the instigator of abuse is located in the system and not necessarily tied to the individual professional. This makes the responsibility for abusive acts less clear. Accountability for system abuse lies in the organization and culture of care, and we should develop resources to integrate this liability. A multilevel approach (Benbow, 2008; Griffith et al., 2007) is needed in which the implications of people's behavior are seen as set in organizational practices. We should monitor organizational incentives and ensure

that they are changed if they are found to be associated with system abuse. This means that accountability is extended from the individual to singular institutions, to overarching sectors, and to local and national governments. We also need to develop definitions of injustice and wrongdoing based on older people's accounts, as has been done for sexual harassment and racism (McDonald et al., 2015).

Care of older people is facing rapid change, including increased numbers of patients, cultural shifts in expectations for later life, and retrenchment of welfare regimes. Healthcare systems, including the NHS (Hunter, 2013), are also dealing with big changes to their structure. By drawing explicit attention to the effects of (re)organization on older people we can stop system abuse. We should make use of the opportunity offered by the transformational change that is needed in the NHS (Hunter, 2013) and other healthcare systems by making older people participants in decision making and restructuring, instead of the subjects (Ronch, 2004; McDonald & Harvey Wingfield, 2008). Analysis of the hidden disadvantages that any organizational changes may pose to our older patients will require further research into the experiences of older people. This way, the healthcare system, and society at large, will take a step closer to the lifeworlds of older people, opening up a debate about the organization of healthcare and how we practice medicine.

Summary points

Older people often attribute neglect and abuse to organizational failures rather than individuals.

Such feelings do not fit current types of abuse.

We propose adding system abuse—harm or distress to an older person that is caused by the organization and resulting practices in our institutions—to the classifications of abuse.

Older people's views should be sought when restructuring healthcare systems.

Conflict of interests

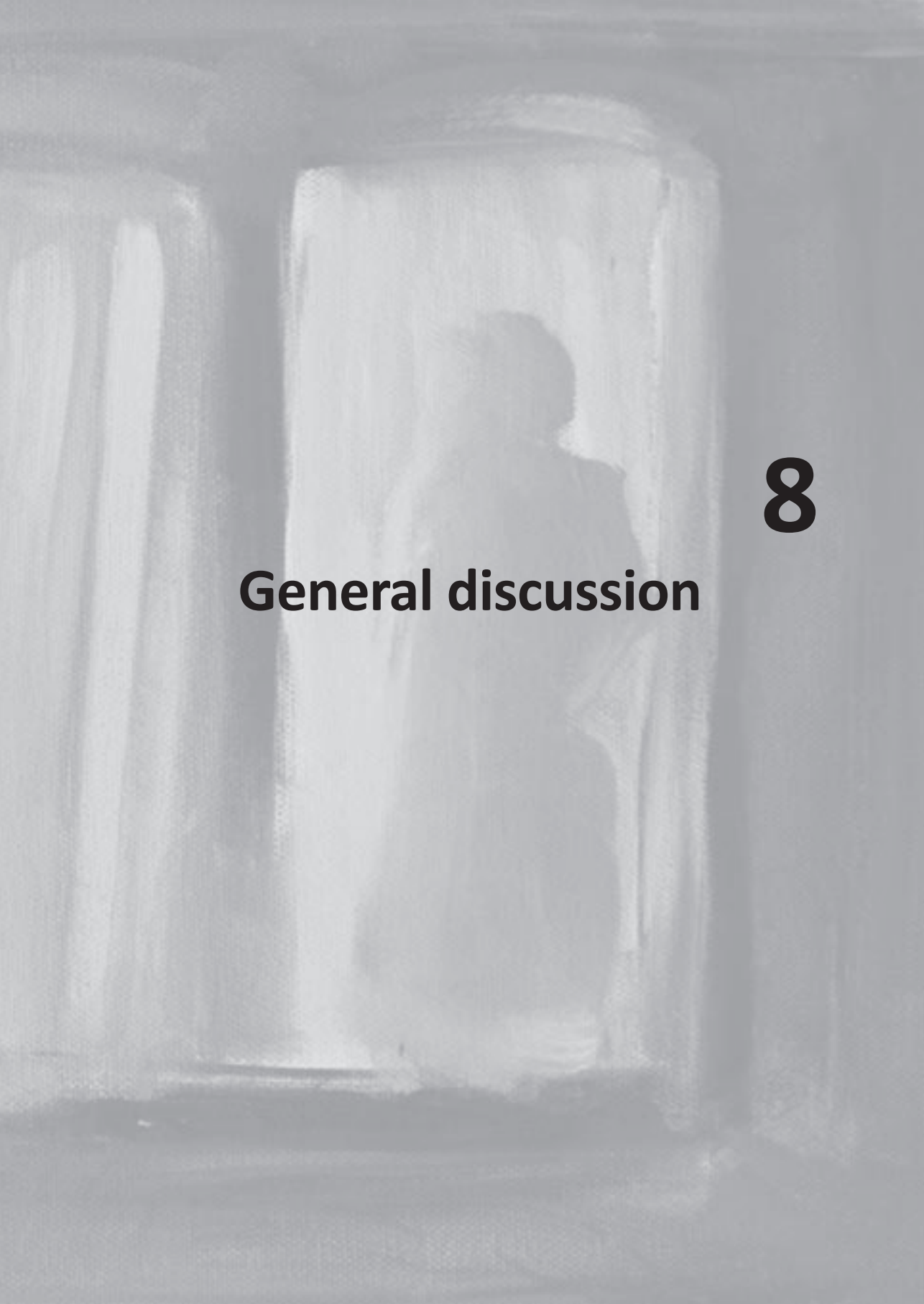
We have read and understood BMJ policy on declaration of interests and have no interests to declare.

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8

General discussion

Elder abuse is a field in need of framing and conceptualization. Definitions of elder abuse and explanations for its occurrence are important building blocks that need to be explored in order to conceptualize and understand elder abuse. A variety of definitions of elder abuse that currently exists creates definitional disparity therefore we do not know which definition to adhere to. Perceptions and views of different groups involved in elder abuse, and their possible implications, are not known. In this thesis, we investigated these building blocks by analyzing the existing definitions of elder abuse and discussing diverse perspectives on the etiology of elder abuse of experts and other professional groups, older persons and victims of abuse.

Definitions of elder abuse

Debates on the definitions of elder abuse have been ongoing, during and even now as this study is coming to a close. There is no agreement on one, comprehensive and uniform definition of elder abuse (Anetzberger, 2005; Manthorpe, Penhale, Pinkney, Perkins, & Kingston, 2004; Bonnie & Wallace, 2003). The absence of a common definition of abuse, and therewith a variety of definitions of elder abuse for different purposes is often described in the literature as “definitional disparity” (Barnett, Miller-Perrin, & Perrin, 1997). This creates difficulties in developing a solid knowledge base in the field of elder abuse. The questions that are often raised in relation to this are: do we need one common definition of elder abuse and what elements should it incorporate? Is there a difference between various definitions of elder abuse?

Different definitions of elder abuse

Some definitions of elder abuse focus on the possible consequences of abuse. At the heart of other definitions are actions and behaviors that help to define the abusive situation. The other definitions, in contrast, focus on risk factors that influence the occurrence of abuse (Erlingsson, 2007) or, rather are used rather in a specific setting or with regard to the specificity of the situation (National Research Council, 2003). All these definitions emphasize the importance of particular elements such as effects of abuse, risk factors or certain behaviors that are considered as abusive, and are quite narrow and subsequently limit the context of abuse and circumstances under which it can occur.

Some studies propose to include in the definition of elder abuse concepts such as intentionality, harm, responsibility, blame, and vulnerability (Erlingsson, 2007; Hudson, 1991; Phillips, 1996). However, this list of the elements of elder abuse is not as exhaustive as other important considerations, for instance, settings in which abuse occurs, relationship with the perpetrator and actions that can be considered as abusive. Other key elements found in several definitions of elder abuse are a trusting relationship, violation and “harmful effects” (Hudson, 1991; Bonnie & Wallace, 2003; Department of Health, 2000; WHO, 2002). All these elements should also be taken into account for these kinds of definitions to be fully inclusive. The list of elements of the definition of elder abuse is non-exhaustive, it

does not give clear answers and raises even more questions like: can abuse only happen in relationships where there is an expectation of trust? Must elder abuse be only intentional action? Do only vulnerable older persons suffer from abuse?

The definition for research

To resolve some of the definitional disparity in the research field of elder abuse that often lead to diverging results and has hampered comparative understanding of the phenomenon), we proposed to adhere to the WHO definition (WHO, 2002) – at least in research and policy-making. This will aid in the development of effective policy, legislation, prevention and intervention strategies. It will also allow comparative studies, for instance of prevalence rates and their underlying factors. The WHO definition is a lexical, broad and comprehensive definition that encompasses different behaviors constituting abuse and the settings in which it occurs. It is well known and widely used and our suggestion is to consistently adhere to this definition. This definition focuses on the interactions and trusting relationship between victim and perpetrator and widens the context of the abusive situation (WHO, 2002). The choice of the WHO definition will not solve all the problems or answer all the questions described above but it is a step forward to defining the phenomenon of elder abuse for research purposes.

The definition for professional practice

However, a definition such as that of the WHO is too broad to be used in a professional practice setting, as it contains too many elements which need further specification to help professionals identify and intervene in situations of abuse. The definition used by professionals should be concrete and allow them to work with and clearly identify elder abuse and set boundaries to the phenomenon. It must guide professionals and help them to understand the characteristics of a particular situation. Therefore, it should also reflect the reality of dealing with abuse and fit with the cultural and social context of the professional practice.

Disadvantages of having two definitions

We cannot ignore the fact that having two definitions of elder abuse can have disadvantages. For instance, it can create a bigger gap between research and practice, as they will originate from different definitions. It may make it difficult to use the findings, implications and recommendations from research in professional practice since they will be based on a different definitional framework than the one used by practitioners. Instead of bringing better understanding and clarity this can even complicate the dialogue between research and practice. Can this discrepancy be resolved by adhering to one definition of elder abuse that will be common for both research and practice? Taking into account the fact that elder abuse is a complex phenomenon that is usually defined differently depending on the setting, it is complicated and unrealistic to have one definition of elder abuse that can be

used simultaneously for different settings such as research or policy making, and professional practice. Thus it makes more sense to separate these settings and try to adhere to two definitions of abuse discussed above, albeit consistently.

Views of our participants

Through further exploring the views of our participants, experts, professional groups, older persons and older victims of abuse, different elements of the definitions of elder abuse identified in the literature were established as also relevant to them. However, distinctive elements in the definitions of older persons have a strong focus on physical violence and intentionality, both of which are not prominent in current definitions of abuse. This shows that non-abused older persons understand abuse differently than it is described and defined in existing literature and we also found this in our research among experts and professionals in the field. This emphasis on physical violence and the centrality of intentionality hints that older persons wait for evidence of abuse that is palpable and provable. This seems to be important for older persons to ensure reports of elder abuse will not be doubted or ignored. The strong emphasis on visible evidence of abuse that prevailed in the definitions of non-abused older individuals can be explained by how they described and experienced their marginalized position in society. To be taken seriously, taking into account that they feel somewhat sidelined, they feel the need for clear and visible proof of abuse to be heard, believed and noticed.

Types of abuse are often in the focus of elder abuse definitions described in the literature and distinguished by our analysis of the definitions discussed above. Our elder participants, both non-abused older persons and older victims of abuse, also distinguished different types of abuse. However, for older individuals with no prior experiences of abuse, other types of abuse than physical abuse were mentioned less often. This is in contrast to professionals, experts and also of older victims, who defined a variety of types of abuse, such as psychological abuse, financial abuse and neglect as well as a combination of different types of abuse.

Thus to answer the questions raised in the beginning we can conclude that the complexity and diversity of elder abuse does not make it possible to have one definition of elder abuse that can be used in all settings. Therefore, we advise to adhere to two definitions of abuse mentioned above. Moreover, we need to incorporate the perceptions, views and definitions of various groups involved in elder abuse: professionals, researchers, policy makers, older persons and victims to be able to obtain an understanding of elder abuse that will enable the development of an elder abuse definition.

Explanations of elder abuse

Until recently, in elder abuse studies the main focus was on the intra-individual factors that played a role in the occurrence of abuse, together with the dynamics of interpersonal relationships. It is only recently that more substantial attention has been paid to sociocultural factors (Anetzberger, 2004; Biggs et al., 1995; Burnight &

Mosqueda, 2011; Phillips, 1986; Pillemer, 1986). Our participants also discussed interpersonal factors in the occurrence of abuse, but according to them the role of societal factors was even more significant.

Interpersonal factors in the occurrence of abuse

Both victims of abuse and non-abused older persons discussed interpersonal factors that can play a role in abusive situations. These included dependency of older persons on the perpetrator and vice versa and power and control imbalances. The notion of reversed and mutual dependency was prominent in different perceptions of elder abuse by professional groups, experts and older persons. This notion implies that not only can older victims be dependent on their abusers, but perpetrators can also be dependent on their victims. This important finding gives an additional meaning to the concept of dependency than usually described in the literature on elder abuse and family violence at large as mutual dependency. This shows that in the process of the occurrence of abuse it is necessary to analyze and recognize not only factors that are related to the victim, but also to the perpetrator as they can play a crucial role in abuse.

Societal factors of abuse

The participants in this study paid more attention to societal factors than other factors. This included the disadvantaged position of older persons in society resulting in disrespect toward older persons and their devaluation. These ideas were extensively discussed by victims and non-abused older individuals. The individuals most crucially involved in elder abuse, older persons themselves, therewith imply that society is explicitly or implicitly responsible for the occurrence of abuse. This finding coincides with the findings of a Spanish study of Garcia (2003) that suggest that elder abuse is tolerated by society and remains invisible. Other studies have stressed that the organization of institutions, and also the socio-political system underlying it, could be responsible for or, indeed permitting abuse (Biggs & Haapala, 2013; Göergen, 2002; WHO, 2002). This important finding shows the need for more thorough and systematic consideration of the role of society in the occurrence of elder abuse.

This finding is further evidenced by issues such as changes in society and dependency and vulnerability of older persons that were identified in the perspectives on elder abuse of all the different groups involved in this study. Indeed, our participants considered current societal changes, especially in regard to the position of older persons, decreases in social control and emphasis on individual responsibility as principles that led to and – speculatively – increased the occurrence of abuse. Thus, in the exploration and discussion of perspectives of various groups involved in elder abuse, the societal explanation that was given to abuse played an essential role.

This interpretation of abuse as a societal phenomenon was also replicated in the explanations of experts and other professionals involved in the field of elder

abuse who frame and explain abuse as a societal problem bringing forward principles of individualism, independence and responsibility prevalent in current society. Vulnerable older persons cannot be of great value or importance in such a neoliberal society. This shows that society itself somehow puts older vulnerable persons in a dependent position which may allow abuse to occur. These perspectives in some way resemble the ones of non-abused older individuals who emphasized the important role of ill-attainable norms around productivity, individualism, personal responsibility, efficiency in current society and therewith a devaluation to unnecessary older persons. Older persons see abuse as something prevalent in society, as something that is allowed or permitted by society and that can also be justified by such a society. Even though experts and other professionals also focus on societal factors of abuse, such as social control and responsibility, and current societal changes, they rarely mentioned a disadvantaged position of older persons in society. These older persons' explanations of abuse represent their experiences that are obviously different from the ones of the experts and professionals. It also implies that although in the past years research has focused on personal and interpersonal dynamics, and have therewith constructed elder abuse foremost as an individual and inter-individual problem, we should consider reframing elder abuse as a societal problem, thereby also shifting the focus of research and practice. And it shows that we must not disregard societal factors in the understanding of abuse and accept abuse as a social issue and take into account the role of society, its norms, values, prevailing principles and images and position of older persons in such society.

System abuse

In the different chapters of this thesis, it becomes evident that the participants of our study including experts, professionals and, in particular, older persons, alluded to occurrences of abuse that we could not categorize among the commonly distinguished types of abuse. Our participants believed that the system itself permits abuse by creating the conditions in which abuse can occur. We proposed a new type of abuse that we call system abuse (chapter 7). This abuse results from the organization and practices in institutions of our society, and expresses itself in broader societal abuse. Neoliberal principles prevailing in current society are also part of today's healthcare system which focuses on independence, personal autonomy and responsibility. An integration of these principles in the health care and social welfare system brings forward earlier discussed issues of vulnerability of older persons, their powerlessness against these systems and disadvantaged position of older person in current systems and society. It seems inevitable to put system abuse at the same level as other types of elder abuse to allow an awareness of the abuse felt by older individuals.

Contribution of current study

The current study contributed to the conceptualization of elder abuse by exploring, comparing and linking together definitions and explanations of abuse of various groups involved in elder abuse. This illustrated that these groups have notable

differences as well as similarities in their perceptions of abuse and this affects upon what they define as abuse, what they consider appropriate action for abuse and on how they view the context of elder abuse. By including persons who are directly involved in elder abuse as well as potential witnesses and reporters as research participants, this study enabled the understanding and framing of elder abuse from various unique perspectives. It created a bridge between definitions in the literature and real life perceptions that showed what really matters to the people involved in elder abuse.

We also reviewed the variety of existing definitions of elder abuse that have been proposed over the years and the included elements, and boiled these down to two definitions. In this way, this study hopes to contribute to more uniformity and comparability in the field of elder abuse that may strengthen the impact of research and practice across contexts.

The exploration of different perspectives on elder abuse enabled understanding abuse in the ways professionals, experts, older persons and victims see and experience it. Salient in the framing of elder abuse by experts and professionals was the focus on environmental factors that they regarded as responsible for the occurrence and continuation of elder abuse. Non-abused older persons understood abuse as foremost physical violence that is performed intentionally. In addition, older victims identify a situation as abusive depending on the expected acceptability of the types of abuse experienced, the expected stigma and the relationship of the perpetrator with the older person. Furthermore, all the participants saw mutual dependency of the perpetrator and the victim as an important factor in the etiology of elder abuse.

This study drew attention to societal factors that were identified by older individuals and older victims as crucial variables in their explanations for the occurrence of abuse. We emphasized the importance and the need for considering these perspectives on elder abuse by proposing system abuse as a separate, and additional, type of abuse. Moreover, through our in-depth exploration of perspectives, we enhanced understanding of the way older persons perceived their position in our society that turned out to be seen as marginalized and disadvantaged.

We believe the current study contributed to the conceptualization of elder abuse by showing, analyzing, and comparing different perspectives on elder abuse and thereby created a deeper and more comprehensive understanding of abuse that enables a closer convergence between the views of those directly involved in elder abuse and those investigating and studying it. This will allow the field to make a step forward theoretically, as it furthers the development and understanding of frameworks that aim to understand the occurrence and continuation of abuse on the basis of perspectives that were previously not taken into account. It also contributes to a practical step forward, as it gives the opportunity to consider and implement these perspectives in practices of prevention and intervention.

The current study helped to situate elder abuse in the wider field of family violence. Delving into diverse perspectives on elder abuse made it evident - and confirmed

previous studies (Anetzberger, 2004; Bennett, Kingston, & Penhale, 1997; Pillemer & Finkelhor, 1988; Podnieks, 2008; Wallace & Roberson, 2011; Hyde-Nolan & Juliao, 2012; Tolan, Gorman-Smith, & Henry, 2006) - that certain concepts used to explain the etiology of elder abuse are similar to ones in the field of family violence. However, our study made clear that core concepts such as vulnerability and dependence have specific and additional meanings in elder abuse. Indeed, the concepts of dependency and vulnerability are situated in particular in divergent social expectations of maturity and independence and dependence at the same time, mutual dependency, and ambiguity surrounding these concepts show how these concepts have a different meaning in explaining elder abuse in contrast to how they are commonly used in explanations of family violence at other stages of life. This implies that there is a need for a recognition and acknowledgement of elder abuse as a separate form of abuse in the field of family violence. At the same time it proves its' important place in the wider field of family violence by showing how concepts commonly used to explain family violence at other stages of life [such as dependency, vulnerability, social isolation, power and control imbalances, stress, history of violence] show at least some family resemblance to how our participants use these concepts to explain elder abuse.

Limitations of current study

The findings of current study are based on interviews with only some representatives of the older population in the Netherlands (that may be considered a relatively small sample), therefore they may not be generalizable to the whole population of Dutch older residents, all victims of abuse, and to other countries. Further research is needed to establish the relevance of the current study in other contexts.

However, as the study conducted was a qualitative study, generalizability and validity are different for the evaluation of qualitative research. Both are determined not on the basis of their representativeness for the larger population to which the group studied belongs to, as with quantitative research, but rather on the basis or whether the theory developed can be exported beyond the specific context studied. The question then is whether the findings in current study and the explanatory variables provided can be exported to older individuals in similar situations. Given that other scholars have found similar findings in different contexts, as discussed in the discussions of the chapters, we can assume that indeed this is the case.

One of the possible limitations of current study is that we did not fully use the process of triangulation, in particular triangulation of methods and researchers. Triangulation strengthens a study by studying the same phenomenon by different methods (Patton, 2001). Triangulation of data collection and data analysis was used, but not in all aspects of data collection and analysis. As described above, older persons and experts were both interviewed and participated in the focus groups. The professionals were both observed and participated in focus groups. Besides, systematic searches of the literature were used in defining elder abuse (chapter one) and explanatory frameworks (chapter six). During data collection two researchers conducted the focus groups to establish triangulation of observers.

As for triangulation of data analysis, focus groups (eight) were transcribed and two researchers, YM and JL, coded the transcripts. The first transcripts with the coding of the interviews with non-abused older persons were cross-checked by two researchers. The rest of the interviews were transcribed and coded by one researcher with recurrent discussions with a second researcher (JL). Thus, during the whole process of transcription and coding another researcher was consulted and gave feedback.

Moreover, to enhance external validity, and adhering to principles of relevance, we intentionally included participants from different settings: individuals living independently, in residential care facilities and in nursing homes. This way we ensured the participation of older individuals from diverse social backgrounds, with different health statuses and in diverse living arrangements. As a result, we were able to capture the diversity of opinions and views of various groups of older persons, even though we may not necessarily have covered all perspectives and perceptions.

A further limitation of current study is that one researcher solely conducted interviews. Multiple researchers could have added alternative perspectives, backgrounds and yield a more complete picture of the phenomenon of elder abuse. On the other hand, having one sole interviewer did ensure that interview-bias – the differential effect each interviewer may have – was reduced given that the same interviewer interviewed all interviewees.

Another limitation that needs to be mentioned is that we did not conduct follow-up interviews with all interviewees. A few follow-up interviews were conducted with non-abused older persons, but the majority of them were not open and ready for another interview and did not want to discuss issues related to elder abuse again. They felt enough had been said, perhaps also because they considered it a taboo subject (see chapter six). With victims of elder abuse the follow-up interviews were not possible to conduct as for them it was extremely difficult to tell their story to the researcher, they were still experiencing the effects of abuse and even those who were successfully coping with abuse and its effects. Older victims did not wish to relive their experiences, and as outlined above a trust relationship was essential. Although the primary responsible researcher YM built up contacts with a small number of older victims after the interview, and talked to them several times, they did not wish to recurrently discuss their experiences with abuse.

Future studies and recommendations

This study developed a basis for future studies on elder abuse. Professionals and policy makers can use the findings of the current study for the development and implementation of a reporting system for elder abuse, prevention and intervention strategies, policy making and program development.

Our findings clearly show that different groups involved in the field of elder abuse perceive elder abuse as a general societal problem. Other studies have also found that various groups perceive elder abuse as a problem stemming from

structural societal factors, in particular issues of disrespect, ageist attitudes or changes in social roles (WHO, 2002; Taylor et al., 2013). They argued that changing social values and attitudes have led to a general lack of respect to older individuals. In addition to what we have found, the study of WHO (2002) found that with the changes in social roles, older persons became care recipients rather than caregivers, and this created situations in which older persons ended up abused or neglected. In a Swedish study by Erlingsson et al. (2005), older persons mentioned societal factors that possibly lead to elder abuse on a family level, including changes in family structures that manifested in increasing amount of divorces, geographic distances between generations and social isolation of older persons, and on a societal level, changes in health care and policies and age discrimination. These findings show that in other countries attention was paid to societal factors of abuse and demonstrates that the Dutch case is not exceptional. They acknowledge the influence societal factors may have on abuse.

It is therefore logical that an intervention directed at preventing elder abuse will have to target general changes in society, both on a macro level in society, on a meso level in how different generations interact and view each other, and on a micro level within families. This will require changes in attitudes and behavior, changes in perceptions on old age and older persons and changes in the position of older persons in our societies. Obviously, this is not an easy task. It requires the acceptance and integration of ageing in society, it requires valuing the strengths of older persons and it requires an honest discussion about the ageing process. Considering this, we propose promoting a positive image of older persons using role models, social media campaigns and increasing involvement of older persons in community life and society. Furthermore providing people with information about ageing will enable a better understanding and acceptance of the ageing process and challenges related to it.

Future studies

The perspectives of perpetrators are not often included in studies of elder abuse. However, as our findings show, the relationship between victim and perpetrator is crucial in situations of abuse. For instance, the involvement of close family members in abuse had an influence on the choice of coping strategy of older persons. If we include research on perceptions and perspectives of perpetrators of elder abuse in future studies we will be better able to understand and explain the interaction between victim and perpetrator, as well as understanding victims' help-seeking behaviors and coping strategies and perpetrators' behavior, motives and reasons.

There are a limited number of studies that focus on potential reporters, in particular older persons, of elder abuse. We know very little about factors that can influence reporting of elder abuse and motives of potential reporters. We have started this debate showing that non-abused older persons perceive abuse differently, and may therefore also detect and report abusive situations only in later, evident stages of abuse. Further increasing the knowledge about whether and

how this reporting behavior is influenced and understanding of these factors will enable a fuller mapping of reporting behavior of potential reporters, as well as their reasoning for reporting particular abusive situations or refraining from doing so.

Moreover, help-seeking and reporting behavior of older victims of abuse is also understudied. We still do not fully understand why older victims refrain from reporting abuse. Although our study gave some indications (in that older victims help-seeking behavior depends on the type of abuse and the relationship with the perpetrator), more in-depth qualitative studies that include the perspective of perpetrators could shed light on this interaction. We do not know much about the possible combinations and relations between various types of abuse experienced, different perpetrators involved, and coping strategies used to deal with these situations. Studies are needed that can explain how one type of abuse, or a particular perpetrator can have an impact on the choice of reporting and coping strategy of older victims.

Societal explanations of the occurrence of abuse by older participants can be a part of a rationale behind their reporting behavior and reasoning. As they see abuse as a social problem and society as responsible for abuse, their perceptions of the abusive situation and reporting of abuse will be affected by norms and values prevailing in society, societal changes and what is considered as acceptable or unacceptable behavior.

Recommendations

The findings of our study show that elder abuse causes a lot of negative feelings and emotions to older victims with which they cope in different ways. Shame plays a prominent role that influences both reporting and coping. Older individuals also suffer from self-blame, even after reporting, and find it difficult to pick up their lives again. Based on these findings, we recommend the initiation and organization of support groups, for example self-help groups for victims of elder abuse that can be coached or led by an experienced professional or peers with similar experiences. These groups can also include face-to-face conversations, empowerment training, and psychological support. Support and help for victims of abuse is also one of the foci of the action plan “The Elderly in Safe Hands” launched by the Dutch government (Ministry of Health, Welfare and Sports, 2011).

We recommend the involvement and inclusion of older persons in professional practices concerned with elder abuse. This will increase older persons’ participation and vital role in the decision making process surrounding elder abuse, encourage and educate them, and, at the same time may increase their reporting behavior. This could be accomplished by organizing special trainings and workshops on elder abuse for older persons and inviting them to meetings and gatherings related to the topic of elder abuse, including them in teams that deal with cases of abuse, and, initiating community volunteer groups of older persons. For instance, in the Netherlands, Rotterdam introduced a unique approach to elder abuse that involves local multidisciplinary elder abuse teams (WEDO, 2012). Such a team consists of

different specialists and professionals and is now more often used across the country and also commonly used in other countries such as the USA and Canada. It can be useful to include for example a representative of a community volunteer group to this team. This can first be initiated as a pilot and, following success, implemented on a larger basis.

As our study shows older persons' understanding of abuse is crucial for defining a situation as abusive and also impacts reporting of an abusive situation. One of the recommendations arising from this study is to develop educational materials, programs and trainings that includes the views and experiences of non-abused older persons and victims of abuse for professionals who work in the field of elderly care and have direct contacts with older persons.

Elder abuse is framed as a societal phenomenon by our participants. Older victims and especially non-abused older individuals see abuse as a societal issue for which we as a society are all responsible. However this responsibility has not yet been realized and understood by the general public. Thus, we need to update the current norms and values that permit widespread social tolerance of elder abuse to active social responsibility, one that will be visible and hold us all accountable. It is time to take responsibility, start acting and stop ignoring the voices of older persons.

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A grayscale photograph of a person sitting in a chair, viewed from the side. The person is wearing a light-colored top and dark pants. The chair has a high back and armrests. The background is a plain, light-colored wall. The word "Appendices" is overlaid in the center of the image in a bold, black, sans-serif font.

Appendices

Appendix A

Focus groups' protocol/guide

Welcome!

The topic that we would like to discuss today is elder abuse. We are interested in your opinion about elder abuse. The results of this focus group will be only used for research purposes.

Today I am your discussion leader. To begin with, I would like to introduce myself...

As discussion leader/facilitator I will try to make sure that we will listen to each other, respect each other and give each other space. Your opinions, so variable as possible, are important for us to come to better understanding about what we can do about elder abuse and what elder abuse is about. I am here to facilitate the discussion and to pay attention that we are remaining within the timeframe/within the time. Starting point/premise is that there are no wrong answers, only different opinions that I am as a discussion leader will be pleased to hear.

Information package: folders (brochures about then institution, pen, notebook and gift voucher of "... euro).

Rules

I would like to introduce a few rules:

- For the research purposes we are going to record focus groups. The recording is aimed only for transcription and analysis and will be used only for the research purposes. In the transcript we will feign the names. We would kindly ask you to give the word to one person at the same time for better quality of the recording.
- “First name rule”: for an ease we would like to use your call you by first names. Does anyone object?
- Listen to each other, give each other space, respect each other
- Talking to each other

The most of you know each other but not everyone. That is why I would like to start with an introduction round.

Opening

Can you please introduce yourself? Your name? Your background? What is your profession? What do you like to do during your free time? *If people know each other then* This group is familiar with each other, that is why anonymity is not anymore possible but it is important to remember that everything that will be said here is confidential. *Emphasis: confidentiality.*

This group is not very familiar with each other, it is important to remember that everything that will be said here is confidential. Now we are sitting next to each other and we are not anymore anonym but lets try to keep in this setting everything that will be said here.

Topics for discussion

Main topics:

1. What do you consider as elder abuse?
 - Definitions, meaning of the term
 - Forms of elder abuse
2. What is necessary to do in order to solve the problem?
 - Actions (interventions, campaigns)
 - Awareness (policy makers, general public)
 - Different (social) aspects (quality of life, social life). Are there other aspects?/And social aspects?

Possibilities of ending focus group

- Is there something that we have missed? Is there something that was not mentioned?
- Resume of discussion OR: remind important points (2-3 min)
- Asking about additions/comments/remarks/questions
- Follow up (article or report)
- Thanking the participants
- Expense statement
- Have a nice trip back

For researchers: 10 min of debriefing

Probes and clarifying questions

I don't understand it completely. Can you explain it please?

Can you please explain it?/illustrate it? Explain further?

How does it work?

Could you please tell us more about it?

Can you give an example?

Who has something to say?

Base don which experiences you are saying that?

What exactly do you mean?

Can you please describe what you mean?

To lead the discussion

Would anybody like to react on this?

Does anybody have something to add to that?

Would anybody like to add something to that?

Does anybody see this differently? Does anybody think differently about it/that?

Are there different views? How the others are thinking about it?

I see some people nodding, can you please tell me about it? Somebody has something different?

Silence: 5 sec, taking time to think about the answer
 Repeating the question

As no answer: why this question is so difficult? Not possible to answer?

Redirecting

Back to the question: thank you for sharing that, but i would like to go to another aspect
 Thank you, it is a n interesting comment. This aspect we have discussed, I would like to...
 This is an interesting discussion but we have to go further....

Dealing with challenging participants

“Macho behavior”: We are here not to come to agreement but for listening different opinions.

Talking together: sorry, i can not hear you. I would like to ask you to talk only by one at a time (for recording).

Somebody who is dominant: You have without any doubt a lot of experience, now i would like to hear something from the others? Do the others have also experiences? Has anybody remarks? Do the others think differently? Anybody would like to add something?

Appendix B

Interview guide (experts)

I am a researcher at the Leyden Academy. I am investigating elder abuse in the Netherlands. I am a sociologist. I studied Public Health in Maastricht. I am currently conducting my research at the Leyden Academy on Vitality and Ageing. This interview is a part of my qualitative study on perspectives of elder abuse. The aim is to get a better understanding of the issue of elder abuse by elucidating the background of abuse and explaining the factors that influence elder abuse. I am trying to obtain an overview of experiences of elder abuse.

The information will be used for research purposes only. All you say will remain confidential. Anonymity will also be guaranteed. I will not use your name/place of work/occupation or any of your other identifying characteristics. Would you mind if I use a recording device? Alternatively: Would you mind if I record this interview?

I ask you this, because I want to represent your words as truthfully as possible. I will type out the recording and use this for my analysis. The recording will not be used for any other purposes nor will it be listened to by the others.

Background information

Could you (please) introduce yourself?

Sex (observe)

Education: What training have you received? Workplace: Where do you work? / Could you describe your position here/what you do here?

Experience

In what way do you involve yourself with elder abuse? What is your experience with elder abuse?

The background and meaning of elder abuse

What is the prevailing view on elder abuse within your practice/field of work?

Do you make use of a definition of elder abuse? *If so, what definition?*

What kind of behavior do you consider as abuse?

What forms of elder abuse have you come into contact with? What factors, in your opinion, play a role in elder abuse?

Could you please describe signals of elder abuse? What do you consider to be signals of elder abuse?

How often did elder abuse occur here in the past year?

How does this compare to previous years? What do you think influenced this?

Profile of the victim

What characteristics do you find typical for a victim? What similarities do you see between victims?

Profile of the perpetrator

What characteristics do you find typical for a perpetrator? What similarities do you see between perpetrators?

Collaboration/network

What do you do when you encounter a case of elder abuse? What is the plan of actions/procedure in the case of elder abuse? Could you please describe this?

When you encounter a case of elder abuse, which aspects of the situation do you try to influence first? Where do you start? (Aspects: Which circumstances of the situation/of the older person do you try to influence first?) What is important?

From whom do you receive help, advice and support? With what organizations do you work together? What organizations are involved?

Societal views

How do people react to your line of work/profession when you introduce yourself?

In general, how do people react when elder abuse is mentioned?

Necessary actions (interventions, prevention)

What do you think needs to be done to reduce the problem?

What kind of preventive actions/interventions are still necessary?

Ending

Contact information

Gift

Appendix C

Interview guide (non-abused older persons)

This interview is part of my study about the lives of older persons and family relationships. The topics, in which I am interested, are: 1. How older people are treated, and 2. How they experience their own ageing process. The information will be used for research purposes only. All you say will remain confidential. Would you mind if I use a recording device? Alternatively: Would you mind if I record this interview? I ask you this, because I want to represent your words as truthfully as possible. I will type out the recording and use this for my analysis. The recording will not be used for any other purposes nor will it be listened to by the others.

Background information

Could you (please) introduce yourself?

Sex (observe)

Age: How old are you? or What is your age?

Are you married? Do you have children?

Education: What level of education have you received? / What do/ did your do for a living?

With whom do you live?

Health status and daily activities

How would you describe your health?

Do you have any health-related problems? Do you use medication? What do you use this medication for?

Could you please describe a typical weekday – what you do from the moment you wake up to the moment you go to bed?

Risk/protective factors

Social contacts/network

How do you spend time with your family? Do you talk to your family/ about their lives/ your life?

How do you feel talking to your family/friends about things is going? (Or somebody in your neighborhood) Are there moments when you feel that this is going less well?

Alternative: How do you feel about/what is your experience of how well you are able to keep in touch with family/friends? Is there anyone with whom you are less well able to keep in touch?

Whom do you see every week? (For instance: family, friends, neighbors, care professionals...)

Probes: With whom do you get together most? In whose company do you feel most comfortable?

How do you feel in the company of other people?

Social support and help

Do you receive help from anybody in your environment? What kind of help? From whom?

How would you describe the help that you are receiving? (*about average, good, below average... and why?*) Who else provides you with support?

With whom do you like doing various activities (going for a walk, grocery shopping, drinking coffee)?

Stress and coping strategies (risk/ protective factors)

Could you please describe the last time you felt stressed/tensed/put under pressure? How did you deal with this situation?

In general, how do you cope with stressful situations?

Do you often feel stressed/tensed? And: Why?

Could you give an example of (a different) stressful situation?

How do you feel when you are able/unable to find a solution to a problem?

The questions I will ask next will specifically concern negative experiences, in particular elder abuse.

Perspectives of abused person

The meaning of elder abuse

What do you think of when you think about elder abuse?

Followed by other possible questions:

What does the term “elder abuse” mean to you?

How do you feel about elder abuse?

What kind of behavior do you consider elder abuse? According to you, what is elder abuse?

Have you ever seen/experienced it? (Perhaps involving someone around you)

Older people’s attitudes towards, perceptions of and ideas about elder abuse

In general, how do people react to you? When you walk down the street? (Why is this, do you think?)

Do you ever feel that you are being treated differently by other people? (Differently than when you were younger/differently than others)

Do you ever feel that you are receiving less care/attention because of your age?

Experiences of elder abuse

How would you like to be treated by others most? / How would you like to be treated by the others?

Could you please describe when this was not the case?

Extra questions:

Is there anyone around you in whose company you feel uncomfortable/unpleasant?

Has anyone around you hurt you recently?

Do you recall anyone ever trying to force you to do things that you did not want to do?

What do you think of the level of privacy in your home (to have one's own space, be able to go about one's business)?

Social life / recreation time

What do you like to do in your spare time? What are your hobbies?

Do you occasionally go to social events/clubs? Are you a member of one?

What do you find was the happiest period in your life and why? (From young age onwards...)

Is there anything else that you would like to add?

Would it be possible to have a second meeting/interview if I have any remaining questions?

Ending

Gift

Contact information

Appendix D

Case studies

In this appendix we present two case studies that illustrate some of the patterns of how older victims explain the occurrence of the abuse to come to grips with some of the dilemmas victims struggled with. These case studies can be useful for practitioners and clinicians as they show how older victims explain and experience abuse and therefore can help these professionals to come closer to needs of potential victims of abuse while examining them or making an assessment.

The first case study is an example of financial and psychological abuse and involves an older man who lived independently at the time. He got involved with a woman in his environment and later she became the perpetrator. The second case study illustrates a complex combination of financial, psychological and physical abuse. The female older victim lived alone in her own apartment, but received care from her son who later on became the perpetrator. The names and some of details have been changed to protect interviewees' confidentiality.

Case 1: Henk

Henk is an 83-year-old widower living alone in an apartment building. His wife died four years ago and they did not have children. He described the chronology of events as well as a detailed description of his perception of the abuse during our interview.

Henk opened the interview by describing how the abusive situation started five years ago and how it continued. He described how he has a garden in a community area and he regularly goes there. One day a woman originally from Haiti named Leila came to his garden and started talking to him and told him her story. The story of Leila is complicated and includes a lot of personal issues: she had a brain operation earlier, mental problems and issues with alcohol and drugs, moreover her children were living in a foster family.

She told him that she had to visit her children but did not have money for the train ride; Henk felt he should help her out, as he felt sorry for her, so he gave her some money. The day after she came to the garden again, and Henk felt they had a nice and pleasant conversation. She continued to come to Henk's garden and they kept in touch. He said that he felt happy to have someone with whom he could talk and share his life story. After a while Leila started becoming more demanding, aggressive and abusive in the end. She used a lot of Henk's money and did not care so much how this would impact Henk. She could easily become rude and offensive.

After a while, Henk reflected during our interview, he felt that Leila controlled him, she had power over him and he always felt anxious and stressed: "I was always under enormous pressure. I was doing what she wanted me to do. I was kind of dependent on her but I loved her." The relationship between Henk and Leila involved issues of power and control and mutual dependency. For Henk, at least, it was kind of a love affair. He always believed that they could be together. Retrospectively, Henk thought Leila probably used him and his feelings for her own purposes. She demanded

money and he gave it to her: to pay the bills, to buy cigarettes, and to repair the house. "I can name at least 50 different examples..." said Henk describing the demands she made. Their relationship and this situation continued for about 5 years and it did not stop at only financial exploitation. After a while, Leila also threatened, screamed, and offended Henk and she became physically aggressive. Henk wanted to refuse her requests, but in the end he did not. Whenever he tried, Leila would become really angry and rude to him: using verbal offences. Or she would just tell him to do everything what she wanted, or otherwise they would not be together anymore, and thus blackmailed him. Henk noted that "there were periods I felt completely threatened, surrounded by aggression and anger, I could not say 'no'". He was slowly getting used to this situation and he also loved her.

At times the situation became unbearable for Henk and he reported her actions to the police, this happened a few times. Leila was even in prison a couple of times for suspicion of prostitution and the use of drugs and during their relationship she was also in several rehabilitation centres. Henk visited her during her stay at these institutions. He believed that she, and therewith the whole situation could change for better. Despite all previous experiences, Henk was still ready to forgive her, marry her and have a happy life with her. At the same time Henk also realized and understood that it could not continue like this. The situation ended when Leila was placed in a mental health institution with restrictions. She was not allowed to go outside or receive any visitors. Henk said he felt that the accusations he made about the abuse also had an influence on her placement in this facility. At the moment of the interview Henk still had occasional contact with her by phone.

The experience of abuse changed and influenced Henk's life. He still feels insecure and uncertain in life and he struggles with that: "You never feel certain, you do not know anything for sure, that is the most terrible...you are living in doubts, you cannot believe what happened". Henk's description particularly puts in view the low self-efficacy and self-esteem that is experienced during and results from the abusive situation. Moreover, besides feeling insecure about himself he also feels he has difficulties trusting others. Even though he still kept faith in a better life, Henk said: "I am not desperate, I am not desperate, I am not hopeless but it (abuse) did have a huge influence on me". This experience also changed some of his values, especially his attitude towards money. "I became very tight with money". Sometimes however he is somehow grateful for this experience: "even though I had all this misery, I am thankful that this had happened to me. I became wiser, I understand people and their behavior better".

Henk's self-explanation of the causes of abuse is fitting with patterns identified in this study, he described how he made mistakes and blamed himself: "I think that I did it completely wrong". Despite this self-blame, he showed how ambiguous these feelings were as at the same time he realized that it was abuse, and she was a perpetrator and he was a victim. "I can not understand how somebody can do such things, I have never done them myself, it is just violence. I was a victim and still am a victim of bad treatment of that woman, a victim of abuse". In the end, Henk had not only lost thousands of euros - almost all his savings – he also sees life differently now. He is now well-aware that some people might use others just because it is convenient

and good for them, without caring much about their feelings; he is aware of elder abuse and understands that it can happen to every older person; he analyses daily situations much more carefully, trying to see them more rationally.

Henk tried to deal with the abuse and its consequences in several ways. Before seeking help at different organizations, such as the support center for domestic violence, Henk reported abusive actions to the police. However, he felt that the police could not help much; they were unable to return his money. The other institutions could also not do much for him; they could only provide emotional support and he expected they would also have helped with providing some information and maybe return a part of money he lost. Henk also attended a victims' support group that was recommended by an advisor for older persons. Now, he wants to live: he fills his life with things that are interesting and meaningful to him like reading, gardening and travelling. Despite this abusive experience, Henk is open to new, positive experiences and hopes to find someone with whom he can spend the rest of his life. "I would like to meet a woman with whom I can do nice things together and enjoy life".

This case study shows the main patterns of occurrences of abuse identified and described above. Issues such as mutual dependency, power and control inequalities caused and explained further continuation of the abusive situation. Feelings of insecurity and low-self efficacy, and feeling a victim, while at the same time blaming oneself, and a new attitude and perspective towards money and life in general were the effects of the experienced abuse. Two coping strategies were used: the interviewee sought external help at various organizations and he tried to deal with the abuse by doing things he enjoys.

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Case 2: Ellen

Ellen is an older lady of 79 years old living alone in her apartment in a big city in the Netherlands. She has a son and a daughter. Her son lives in the same city and her daughter lives further away. At the time of the abuse, she did not have a very close relationship with her daughter. Her son Erik helped her with finances, housekeeping, groceries and other daily affairs.

Ellen described that about a year ago she noticed that different amounts of money were withdrawn from her bank account. There were first bigger amounts (thousands of euros), which were followed by smaller ones (hundreds of euros). This money, she could see from the account statement, was used, for travelling, new furniture and home appliances. Since her son was doing her finances, Ellen asked him about the missing amounts but he told her that he had used the money only for her needs. When she showed him the printouts from the bank, Erik became furious, he screamed and offended Ellen while yelling that everything he did was only done for her.

Ellen was unable to talk to him, he would not answer or simply scream and offend her. Ellen asked him to return the money, but he refused. She felt her son had changed: from a caring child he became an angry and disrespectful person. "I always had a good relationship with my son, I trusted him...and now he is completely different, he doesn't want to talk to me, he only screams and offends me". Ellen felt

she could not influence, control or change the situation. “I do not know what to do. I feel powerless”. Ellen’s son blackmailed her by saying that he would not take care of her anymore and would no longer visit her if she would go and ask for help. From the words of Ellen, he knew and realized that she was dependent on him for care. In the end, Erik’s aggressiveness increased. Ellen described that during the last fights with her son, he slapped her in her face a couple of times, grabbed her and pushed her on the bed. “I myself felt terrible. It is difficult to describe my feelings. How can your child do such things to their mother? I was always a good mother to my children”. That’s unbelievable. Can you do this to your mother? I saw the cases of abuse only on TV, I couldn’t even imagine that it would happen to me”. Ellen was scared as she felt Erik’s behavior was unpredictable.

This situation caused her a lot of emotional distress and resulted in health problems. She described having pain in her stomach and bladder. “I do not feel good...I feel really bad, physically and emotionally. I have a lot of problems with my body. I feel tired all the time, I cannot do anything”. She did not want to tell her relatives or neighbors about this situation. Ellen felt, and still feels, ashamed: “You wouldn’t share such experiences with other people...especially about your own child. It is shameful”.

A few months ago Ellen finally decided to ask for help. She called the public health service in her town. An elderly advisor from the public health service came to visit. The advisor evaluated the situation and wrote a letter to Ellen’s son and now a legal case is opened. Ellen receives support and help from the public health service. A support center for domestic violence and home care service are also involved. Together with the elderly advisor they developed a plan with concrete actions that should be performed in order to deal with the experienced abuse. These actions included that together with Ellen they evaluated the situation and they created a safety net for Ellen. This safety net consisted of the elderly advisor, general practitioner, family members and friends. In addition, the elderly advisor talked to Ellen’s son. The elderly advisor supported Ellen during the whole process. In the meantime, Ellen tried to cope with the situation. She kept, and still tries to maintain, herself busy with different activities, hobbies such as listening to music, watching TV and solving crossword puzzles. She told her daughter the whole story and she is willing to support her. Currently Ellen does not have any contact with her son. She feels she has to adapt to a new reality (and changes in her life) and learn how to live with them. Ellen wishes the whole situation to be over soon and believes she could then live normally again. “I want it to be finished...this is such a painful and horrible experience, I hope that I will have a normal life again”.

In this case study the main causes and effects of abuse, and coping strategies described in the article can be identified. Ellen was dependent on her son’s help, and her son seemed to rely on the finances of his mother. Power and control imbalance between her and her son and dependence on care are important factors that played a role in the occurrence and continuation of abuse. The abusive situation caused emotional distress, especially feelings of fear and shame, and physical problems to Ellen. In order to deal with the abuse, she received help and support from the

public health service and her daughter and also she described how she used self-help strategies to continue her life and forget about the abuse, for Ellen this meant listening to music or watching TV and finding relieve in these daily activities. Despite this negative experience, Ellen believes that she will overcome this situation and life will continue.

Appendix E

Interview guide (abused older persons)

This interview is part of my qualitative study on perspectives of elder abuse.

The information will be used for research purposes only. All what you say will remain confidential.

Would you mind if I record this interview? Alternatively: Would you mind if I use a recording device?

I ask you this, because I want to represent your words as truthfully as possible. I will type out the recording and use this for my analysis. The recording will not be used for any other purposes nor will it be listened to by others. If you do not want to answer a particular question, you can always decide to withhold the answer, without the obligation of providing a reason. This is no problem at all. If you have any questions throughout, you should always feel free to ask them.

First I would like to know a little bit more about you, before I begin the actual interview.

Demographic and social background

Could you (please) introduce yourself?

Sex (observe)

Age: How old are you?

Are you married? Do you have children?

Education: What did you study? / What did your do for a living?

With whom do you live together? (if applicable)

In order to better understand how you live your life, I would now like to ask you some questions about your daily activities.

Health status and daily activities

How would you describe your health? Alternatives: Do you have any health-related problems? For what reason do you use medication and/or make use of healthcare?

Could you please describe a typical weekday? For instance: yesterday...

Possible questions (probes):

At what time do you get up in the morning? And after that? What do you do?

Do you cook yourself? What do you do after breakfast? Do you need any help?

How do you get there? What mode of transport do you use to get there?

Do you occasionally get visitors? Do you occasionally visit others? How do you feel about that?

Who decides on household matters?

Who takes care of bills/money/financial matters?

How do you feel when you are at home/ in your own home?

Care

How would you describe care that you receive? What kind of care do you receive?

Quantity: how many times a week and about how many hours a week/how many hours

a week on average? How often do you go to the hospital/doctor/medical specialist/ other healthcare/social services?

My research, as you perhaps already know, is also about the way people treat you and the way you would like this to be. The questions that I am going to ask now are about this subject:

Transition: Has anyone ever treated you badly?

Experience of elder abuse

In the case of already established/ already known abuse: Could you please describe what happened? Could you please describe your experience of abuse?

Who was involved in this situation?

Could you please describe how this happened?

Probes: How often did it happen? And for how long, roughly speaking? Where and when do you think it started?

Could you please describe how you reacted? What did you do about it?

How did you feel?

How did you deal with that? How do you feel now?

What changed in your life after this experience? What influence did this experience have on your life? How do you feel about it in hindsight? Why, do you think, did it go as far as it did? What advice would you give to someone who is being maltreated/abused now?

Social network/help and support

Whom do you see on a regular basis? (Family, friends, neighbors, care professionals...)

How well do you keep in touch with family/friends/neighbors/acquaintances?

Do you receive help from anybody in your neighborhood? What kind of help? From whom?

How would you describe the help that you are receiving? (*about average, good, below average...*) How do you feel about this?

Who else provides you with support?

How do you feel in the company of other people?

How do you feel talking to your family/friends about things is going? (Or somebody in your neighborhood)

Are there moments when you feel that this is going less well?

Social life

What do you like to do in your spare time? What are your hobbies?

What do you find was the happiest period in your life and why? (From young age onwards...)

Is there anything else that you would like to add?

Ask about possibility of second meeting/interview if I have remaining questions/ Would it be possible to have a second meeting/interview if I have any remaining questions?

Ending

Gift

Contact information

Appendix F

Methodology and methods

Elder abuse

Underlying this study and the development of the research design was a review of the literature on elder abuse. This revealed that a comprehensive understanding of the phenomenon of elder abuse was at the time still lacking. Concerning elder abuse itself, as a concept, it highlighted how different definitions of elder abuse have created definitional disparity. Partly, this complexity and ambiguity seems inherent to the phenomenon itself. However, also this is because different scholars, professionals and organizations adhere to different terminologies and have defined which variables – and what these mean – differently (Abbey, 2009; Ansello & O'Neill, 2010; Erlingsson, 2007; Anetzberger, 2005; Manthorpe, Penhale, Pinkney, Perkins, & Kingston, 2004; Bonnie & Wallace, 2003). These different definitions influence the detection of cases of abuse, incidence and prevalence rates, reporting of abuse and therewith prevention and intervention strategies, and the development of policy and legislation. This conceptual ambiguity about the phenomenon itself was confirmed, when next to the careful study of the literature on elder abuse, initial conversations were held with professionals and experts (four informal conversations) in the field of elder abuse. These evidenced that there was no strong consensus – yet – on what elder abuse entails, in chapter two we have therefore compared these definitions.

For purposes of this study, the core concept of this study “elder abuse” still needed an initial definition to delineate our subject of study. After all, our search for understanding abusive situations required an initial demarcation of the phenomenon. On the other hand we wished to explore the perspectives on elder abuse, and thus also allow for an empirical redefinition of elder abuse. Initially, a combination of the core elements of the elder abuse definition of the WHO (2002) and the Dutch definition of Comijs et al. (1998) – given that this study was conducted in the Netherlands – was adhered to. Elder abuse refers to violence perpetrated by anyone in the environment of an older person that is trusted by this person (see also chapter seven). We explicitly refrained from further defining ‘older person’ by a chronological age (see next paragraph) and the types of abuse to ensure that the empirical perspectives would find their place in our study. By using the concept “relationship of trust” we emphasize that incidental criminal behavior was not considered abuse. A relationship of trust necessarily implies that harm is done by people the older person knows or with whom they have a relationship, such as a spouse, partner or family member, a friend or neighbor, or people that the older person relies on for services, support or help (WHO, 2002). This definition is broad and all-embracing and prevents unjustified exclusion. The understanding of elder abuse was considered an “open” concept that can be modified, on the basis of the empirical data collected to incorporate how it was perceived, defined, explained and experienced by different participants of the study.

The victim and perpetrator

Elder abuse refers to a victim that is older, but the concept “older person” is socio-culturally and contextually determined, after all what is old? A number of countries

use the chronological age of 65 on the basis of the entitlement age for state pension benefits, others use chronological ages based on average life expectancies. However, it is questionable whether defining “older person” based on chronological age is appropriate as these cut-offs are arbitrarily determined. The common use of chronological age as a threshold marker of old assumes equivalence with biological age; at the same time it is widely accepted and acknowledged that these two are not necessarily synonymous (Thane, 1978; WHO, 2002; WHO, 2011). A chronological age-limit will exclude and unjustifiably include persons who have experienced ageing differently than others, as the ageing process is heterogeneous and can express earlier or later in age-related problems. Age-related damage – whether cognitive, physical or social – would be the most naturally cut-off. For this study, such a natural boundary was adhered to for those individuals being abused. Individuals who were abused because of age-related problems were included. This means that we considered older persons as individuals who had diseases or experienced problems that were results of the ageing process and for whom these problems, according to them, played a role in their experiences with abuse. This required a post-hoc evaluation of the lead researcher (YM) and a co-researcher (JL) whether or not the situation of abuse could be attributed to and was influenced by age-related problems. In two cases, this led to the later exclusion of these individuals from the data used in current study.

For non-abused older persons such an empirical approach was not feasible, as we could not assess a causal effect of age-related problems to abuse, and we thus stumbled upon another issue of demarcation: when are age-related problems sufficient to result in an inclusion of being old? Taking into account these considerations, in the beginning of the study of non-abused older individuals we adhered to a societal demarcation of “older person” and we used the age of 65 as an inclusion to the study, being the retirement age in the Netherlands at that time.

In the initial phase of our study, we attempted to include the individuals that harmed or distressed the older victims. In the end, we succeeded talking only with two such individuals and had to refrain, because of limitations of time and sample size, from including this study group. People in the environment of the older person who caused harm or distress to the older person were considered and named perpetrators throughout this study (Dutch: *pleger*), in line with current insights in elder abuse (Killick, Taylor, Begley, Carter Anand & O’Brien, 2015; Daly, Merchant & Jogerst, 2011; Naughton, Drennan, Lyons, & Lafferty, 2013; Erlingsson, Saveman & Berg, 2005), we refrain from using the word offender, because this has the connotation of purposeful behavior.

The framework of concepts

In the development of the main concepts of this study we used the definition of the WHO as a starting point: “Elder abuse is a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person” (WHO, 2002). All concepts, however, were open, and treated in an iterative way, that is depending on how the individuals involved in this study conceptualized the concepts (or not) we re-conceptualized these concepts.

Dependency and vulnerability

We considered the concepts dependency and vulnerability in line with the vulnerability theory that views dependency as a cause of vulnerability, which then causes abuse. These two concepts complement each other and the combination of both can lead to violence in later life (Anetzberger, 2004).

By dependency we mean relying on other people for assistance or care. This can be in the physical, economic, social, or psychological domain. Older persons can become dependent on their children, partners or other family members. Vulnerability is closely related to dependency. It has a specific meaning in the context of elderly. Vulnerability occurs because of increased physical frailty associated with aging (Slaets, 2006). Vulnerability may refer to an older person's exposure to abusive situations, the risk of suffering harm, as well as older person's capacity or diminished capacity to defend against abusive acts or to the older person's capacity to cope with the abusive situation and its consequences (Goergen & Beaulieu, 2013). The concept of vulnerability focusses on intrinsic characteristics of the victim (Fulmer et al., 2005). Thus the characteristics of the perpetrator or the environment are not taken into account. The role of vulnerability in elder abuse is debated (Grundy, 2006). However, together with dependency, it is considered an important contributor, and some would say prerequisite, for elder abuse and important to consider while conceptualizing elder abuse.

Trust relationship

The concept of trust relationship was one of the starting points for the exploration of the issue of elder abuse. Trust implies the expectation and some degree of confidence that the other person will behave as agreed upon (Goergen & Beaulieu, 2013). Relationships with the expectation of trust are considered as such on the basis of victims' perspectives and include victims' relationships with family members, friends, professionals (social workers, case managers, nurses).

Trust is linked to dependency and vulnerability as older persons who are in a trust relationship with their perpetrators experience increased dependency on the perpetrator and can also be more vulnerable to the actions of the others, in this case to the actions of the perpetrator (who can also be a carer). Therefore, victims' dependency and vulnerability increase their need for trust, and trust can become even more important for them as they may also feel less independent and autonomous (Goergen & Beaulieu, 2013).

Harm

By harm we understood physical, psychological, financial, sexual damage. Harm was conceptualized based on the perceptions of the interviewees. Severity and intensity thus may vary of the conceptualized harm. We also excluded incidental criminal behavior as abuse based on the idea that a trust relationship requires longer term relationships. This harm was defined following the commonly distinguished types of elder abuse, e.g., physical, psychological, financial, sexual and neglect. The term "abuse" excludes cases of self-neglect in contrast to some states in the US (Bartley, O'Neill, Knight & O'Brien, 2011; Pavlou & Lachs, 2008). Self-neglect is a controversial type of abuse. It implies that older

persons fail to meet their own physical, psychological, and/or social needs. It invokes further questions: If an individual is competent but chooses to neglect his/her own needs, is this then abuse? Moreover, self-neglect does not include a situation of abuse occurring within a trust relationship and the harm is caused by the older person (victim) him/herself. Therefore, it is not included in our initial list of the types of elder abuse.

Older person

Defining “older persons” in this study is a conceptually challenging task. Debates about the age at which a person becomes old show that it is problematic to adhere to a chronological age. Ageing is a process and a cut-off creates a rather artificial boundary that leads to exclusion and inclusion of participants that might conceptually fall at either side of the boundary. Some studies use an age limit because it marks the entry into retirement status, but retirement ages vary between different countries and societies (see for instance Comijs, 1999; Erlingsson, Saveman & Berg, 2005; Naughton, Drennan, Lyons, & Lafferty, 2013; Daly, Merchant & Jogerst, 2011) and so does the meaning of retirement over the life course (depending on a person’s socio-economic status) (Goergen & Beaulieu, 2013). Taking into account these considerations, we decided to adhere to the age of 65 years (the entitlement age for pension benefits in the Netherlands) for non-abused persons and for abused older individuals we decided not to use an age limit in order not to exclude anyone by a rather arbitrary age limit (also see the considerations described above).

Thus, we considered abuse as an act that occurs within a trust relationship and causes harm or distress to an older person. We paid close attention to situations of dependence and vulnerability as that is known to increase the risk for abuse to happen.

Research design

This thesis was based on a qualitative study on elder abuse. Qualitative research enables exploring, understanding and explaining of a phenomenon. It allows getting to the inner experience of participants, to explore and discover the meanings, rather than testing variables (Corbin & Straus, 2008). Moreover, it allows for exceptions, and differential opinions, for the minority, to be heard which would have been missed with a positivistic approach. It also enables the exploration of complexities, of important details. The iterative approach used allows for the exploration of rationales and its emergent nature fits with the target of current research that was to explore and understand the phenomenon of elder abuse.

Choice of methods

Semi-structured in-depth interviews were chosen as the most fitting choice in terms of methods, because they allow exploring a topic, in this case elder abuse, to discover views, perceptions, experiences, beliefs, and that is what we aimed for. Moreover, it contributed to another important goal; namely to be able to discuss and follow perceptions, explanations and attitudes on the individual level. Moreover, the individual nature of semi-structured interviews and the way informants are free to express themselves takes into account the sensitivity of discussing elder abuse.

Focus groups use group dynamics to generate ideas and opinions. Since we wanted to explore the phenomenon from diverse perspectives, this method was chosen in addition to the semi-structured interviews. Furthermore, focus groups enable interaction between participants, which stimulates richer responses and new ideas and thoughts. It challenges the thinking of participants and thus illuminates conflicting and alternative opinions.

We considered interviews and focus groups more appropriated, because despite that observation is generally the best method for studying natural behavior, we wanted to explore opinions and perspectives. However, to situate our study better and develop appropriate terminology and questions we did observations that helped to obtain knowledge and understanding of the ideas about growing older and practices around elder abuse and to build connections with professionals in the field (this process will be described and discussed below, pp. 177-179).

Epistemological considerations

What did we consider data? Data is empirical representation of concepts and measurements. In our study, data mostly included spoken words that were transcribed verbatim. Our data was therefore text-based. As described above, the considerations and ideas about the concepts were taken into account before the process of data collection. During the research process new and adapted concepts were added as we continued our data collection and analysis, we reflected on the concepts and new ideas developed and this gave new directions and ways to analyze. Thus the iterative process of bridging ideas and data was continuous and interactive (see also Neuman, 2003).

As the core aim of current study was to study diverse perspectives, we wanted to keep the concept of elder abuse open to be able to change or modify it along with its exploration. The interaction between data, concept and theory remained iterative throughout the study as this approach allows openness to unexpected themes and enables changes in the direction or focus of the study along the way. Given the text-based data we collected, we used a hermeneutic approach, to give meaning and to make it understandable, a method of “continual interpretation and reinterpretation” (Bernard, 2006, p. 22). As such, we primarily used an inductive approach of grounded theory that implies that theory is built from data or grounded in the data (Glaser & Strauss, 1967; Neuman, 2006).

Development of interview guides

We developed the main concepts that we used in our interview guides and focus groups’ protocol, and correspondingly the topics and questions of the interview guides from existing literature on elder abuse. Besides this, our terms and questions were formulated based on observations and informal conversations in a residential care facility, and pilot interviews with older persons (see Appendices A, B, C, E).

We used research literature on ageing and elder abuse - in particular concerning perceptions of older persons, both abused and non-abused, definitions of elder abuse, risk factors for abuse and theoretical frameworks on elder abuse. Furthermore, we conducted two literature studies on the definitions on and explanatory frameworks of

elder abuse that also served as a basis for the development of the main concepts and terms that we have used while interviewing our respondents.

Since perspectives in the literature usually say more about what is being said and observed, but less about what is happening in practice, the lead researcher YM complemented this literature overview with informal conversations and participation in a residential care facility. These conversations and observations helped to better understand the ageing process, perceptions and attitudes of older persons towards aging, family relations, social networks and support. We used this information to gain deeper insight into aging, challenges and troubles older persons may encounter, and their awareness of elder abuse that later played a role in the development of the terminology and concepts used for the interview guides.

Partly, the initial results of the focus groups helped to choose the terms we used further in the interview guides for the interviews held with experts and non-abused older persons. After analyzing the relevant literature, obtaining information from observations and informal conversations we developed interview guides, which we tested in pilot interviews with ten participants (non-abused older persons, professionals from the field of elder abuse, and in addition, middle-aged individuals) in order to obtain more information on the subject and to check whether the topic lists and questions were clear and straightforward. After analysis and discussions of this pilot phase between the lead researcher (YM) and co-investigator (JL), subsequently, some of the questions were modified and adjusted (see Appendices B, C, E for further information).

Sampling and recruitment of participants

The sampling of participants for current study was not random, as would be the case in quantitative research. Instead, it is important that the sample yields the type of knowledge necessary to understand the structure and processes in which the individuals or situations are located. In this case, we strived for a sample that allowed us to understand the processes and perspectives of the individuals involved in the field of elder abuse. To do so, the principle guiding the selection of interviewees and participants was relevance instead of randomness.

Interviews

Non-abused older persons were recruited through convenience sampling and snowball sampling (Polit & Hungler, 1999) through referrals from other respondents and via contact persons, being primarily coordinators of volunteers and welfare managers in residential facilities and nursing homes (see also chapter four).

Six older victims were recruited through advertisements in freely distributed local newspapers. The advertisement was placed in local, freely available newspapers. In the advertisement the aim of the study was shortly described. Older persons were asked if they wished to share and discuss their experiences and stories and were suggested to contact the researcher. Confidentiality was guaranteed and it was emphasized that after contact there was no obligation to participate. An additional eleven abused older individuals were recruited through elder advisors and welfare managers who work in healthcare institutions or support centers of domestic violence.

The main inclusion criterion was experience with any type of abuse (see chapters one and five). Some weeks before an interview, these contact persons asked older victims to participate in the study. When interested, the primarily responsible researcher contacted them personally. After a full explanation of the purpose of the research by phone, the interviewees were given a few days to think about the request after which the lead researcher would contact them again. If the interviewee still agreed, appointments were made for a place and time to meet as chosen by the interviewee (see also chapter five).

Experts in elder abuse were identified through different organizations in research, elder abuse care and elder abuse fields. Furthermore they were approached through contact persons via a snowball sampling technique (see chapter three).

All the participants were considered to be cognitively intact and to have the capacity to consent to involvement in the study. In a few cases, the primarily responsible researcher was in doubt about the capacity of the interviewee after the initial conversation. If in doubt, the researcher would refrain from including this individual to the data sample. Participation in the study was voluntary. The respondents were told that they would receive a small gift (notebook) after participation in the interviews. Prior to the actual interview, the purpose of the study was again explained to each participant.

To maximize inclusion of a heterogeneous sample, we included participants (e.g. older individuals) with a broad age range and in diverse living situations and geographic placements. The heterogeneity of the sample also enabled a differential expression of participants' ideas regarding elder abuse.

Focus groups

The list with the potential participants for the focus groups was made on the basis of known organizations in the Dutch field of elder abuse using a web-search and cross-referencing. After this, persons from the different organizations were contacted and asked for further referral to additional organizations and participants, thus using a snowball sampling technique. Following this, all the potential participants were contacted and invited to take part in a particular focus group (based on their expertise, experience, skills). This also meant that at times initial invites for focus groups were assigned to another focus group after contacting the potential participant. Experts were approached in a similar way through contact persons and via a snowball sampling technique. The experts were considered as such based on their experience with elder abuse, and/or specific knowledge and expertise related to the field of elder abuse.

All the participants were considered to be cognitively intact and had the capacity to consent to involvement in the study. Confidentiality and anonymity were guaranteed through an explicit oral agreement. With the permission of the participants, the interviews were recorded. At the same time notes were taken by the interviewer. The presence of the audio-recorder did not seem to influence the process of the interviews, as often the interviewer observed that the respondents forgot about it and did not pay attention to it when the interview moved along. Only three interviews were not recorded as the respondents felt safer and more comfortable when the interviewer was only taking notes.

Finding participants

Getting acquainted with the topic of elder abuse, establishing contacts with various organizations and professionals in the field and the process of data collection and finding respondents included several phases, which at times occurred simultaneously.

The first phase included participant observations and (in)formal conversations with older persons. As soon as empirical data collection on elder abuse was initiated the primary responsible researcher YM also started volunteering at a residential care facility in a large city of the Netherlands, part of the conurbation of Western Holland. This participant observation continued for two and a half year. YM participated in the activities, helped and assisted older persons and carried out informal conversations. YM observed, made notes for herself and analyzed them. Permission to take notes was obtained from older persons. This experience later helped to find respondents for interviews (non-abused older persons) and was also a good basis for the development of interview guides and modifying some of the concepts that were studied in the study.

Simultaneously YM tried to establish contacts with different organizations and professionals in the field of elder abuse in order to receive access to future participants (foremost victims of abuse). These organizations were support centers for domestic violence, welfare organizations for older persons and public health institutions. It was important to get to know the principles of their work, how they function and to understand how they worked with clients. This included how these professionals communicated, how they collaborated with other professionals and how they interacted with elderly care advisors, welfare and case managers, and other professionals involved. YM participated in the meetings of the elder abuse multidisciplinary team and gatherings of regional welfare organizations in Leiden, Haarlem, Utrecht, The Hague and Rotterdam. Moreover, several times, especially in the initial phase, YM conducted day visits at the same organizations to observe their way of practice. In addition, together with case managers elder abuse YM visited older persons who experienced problems in the family, who were in abusive situations or who were visited because of suspicions of abuse. Involvement in these activities helped YM not only to find respondents, but also to better understand the field of elder abuse, the management of cases of abuse and prevention or intervention strategies used in the practice of elder abuse.

An interesting observation, not really delved into in the manuscripts, is that some elderly care advisors could be seen behaving as “gatekeepers” between older persons and the lead researcher YM. They were not willing to ask older persons whether they wanted to participate in the study as they felt they need to protect them and considered that giving interview would be too difficult and painful for these older victims. They did, however, allow YM to participate in the chain of activities and interactions that they had with these individuals. We later analyzed this protective behavior as coming forth out of an understanding of these individuals as vulnerable. However, older persons themselves could, during the very same visit, be open and willing to share their experiences and stories. We decided to refrain from including those individuals despite this willingness, since it would disturb professional practice of the professionals involved. Thus, such behavior of elderly care advisors was an

important barrier, perhaps justified but also influenced by their perception. In contrast to this behavior, some of the elderly advisors and case managers assisted YM to come in contact with older victims of abuse. They played a crucial role in the process of finding and approaching the potential interviewees. These individuals seemed to have a different perspective on vulnerability and especially self-reliance (see chapters three, six, seven) than the 'gatekeeping' professionals.

In addition to above mentioned and described activities, I collaborated with experts and professionals from other countries (for instance France, Australia) in order to create a network of international experts who gave valuable advice, support and feedback. They also shared their experience with approaching older victims in their countries.

The researcher's role and position

As it is well-known the role of the researcher in a qualitative study is quite different from that in quantitative study. The researcher is considered an instrument of data collection, which means that data is mediated through a human instrument rather than through questionnaires or other means (Lenzin & Linkln, 2003). YM tried to write down thoughts, reactions, new ideas and insights during the process of conducting interviews and observations. It helped to reflect and better understand own perceptions and attitudes.

The role of qualitative researcher can be emic and/or etic (Punch, 1998). YM's role was both emic and etic. YM started as an outside observer but then slowly participated in the activities of older persons (during the initial phase of participant observation). They perceived YM as someone with whom they could chat, share their ideas, as a friend, not as a "stranger from outside or observer". After that roles changed to more of a participant, but rarely fully so. While conducting interviews YM was again more an observant.

YM listened carefully to what respondents told, asked probing questions, thinking over, and then asked more questions in order to get to deeper levels during the conversations. The place where the interview took place, day and time of the interview, mood of the interviewee influenced the process of interviewing and the answers of the interviewee. These factors are not always under control of the researcher, therefore it is important to try to take them into account and realize what effects they can have in the analyses. It is therefore that throughout this thesis we have tried to show how there are core variables, with differing expressions.

During the data collection, it was crucial to develop trust relationships with the interviewees. First, the topics discussed were sensitive; moreover, some of the interviewees were victims of abuse and we asked them to share their experiences with abuse. It was very important for them to feel safe and to trust the person with whom they shared their experiences. Therefore YM starting points were to show respect, empathy, engagement, and understanding of their situation and their experiences. In addition, for the victims of abuse the researcher (YM) also represented a neutral outsider, someone who would listen without judgements. Moreover, YM tried to be aware of verbal and non-verbal expression (reactions, posture, emotions). Unfortunately, it was not possible to rely on continuous contact, which is also important in developing trusting relationships, as with some of the respondents YM could only meet once, as the topic of elder abuse

was sensitive and it was difficult and at times burdening for older persons to discuss and share their experiences. Admittedly, at times, at least initially, respondents did give socially acceptable answers. For instance, on questions about their relationships with children and grandchildren, they normally answered that the relationships were “good”, however, later on after telling more, they would describe them differently and as not so good and mentioned some problems in these relationships.

As YM interviewed different target groups (e.g. non-abused older persons, victims of abuse and experts), their ideas and understanding of the role as a researcher differed. Indeed, some of the respondents (in particular, older persons) did not view YM as a traditional researcher. Sometimes they thought that YM’s role was similar to a journalist who asks different questions and wants to gather information, which was partly true as YM did ask questions and aimed to gather relevant information. It was not so common for them to be interviewed, especially not on such a topic as elder abuse. For some of the respondents it was the first time that they were asked to give interviews. That is why in the beginning of the interview they sometimes felt nervous or were slightly worried. However, these feelings went away after a few minutes – also because we paid close attention to the chronology of topics after our initial experiences and revisions in the pilot interviews. For experts this was different. They were fully aware of my role as a researcher. For a lot of them it was common to give interviews and they felt quite comfortable from the very start. Moreover, they were happy to share their knowledge and make their contribution to this study.

As for the focus groups, YM together with JL acted alternating as discussion leader and discussion assistant. The discussion leader tried to make sure that participants listened to each other, respected each other and gave each other space to describe their views to facilitate the discussion. This role can be described as an observer who does not try to get involved in the discussion, but to facilitate and support it.

Data analysis

Organization of data and coding procedure

As described above, the grounded theory approach was used to analyze interviews and focus groups’ data (Glaser & Strauss, 1967). The interviews and focus groups were transcribed. Fieldwork notes that were taken during the focus groups and interviews were also transcribed. The transcripts of the interviews and focus groups and other data (notes, literature on elder abuse (articles, protocols, relevant documents) were carefully read and studied. After the first interviews and focus groups were conducted, the transcripts were made and they were read, analyzed and coded by two researchers (the researcher who gathered the data YM and her supervisor JL) as this first data coding served as a foundation for further data collection and analysis. Based on these initial transcripts, a code-list was developed.

First, the data was ordered. The transcripts of the interviews and focus groups were organized based on the professional background and inclusion criteria of respondents with whom interviews and focus groups were conducted. For the focus groups they were ordered by each focus group (experts, policy makers, managers, interest organizations of older persons, physicians, professionals from intramural and extramural care and older people themselves). The transcripts of the interviews were

organized by the group of interviewees (non-abused older persons, experts, victims of abuse). The coding of the data was performed for each group, using the same principles as described above.

The other transcripts were also subsequently coded. We used inductive and primarily “open” coding that allows the generating of theory that is grounded in the data and enables emergence of understanding from the close study and constant comparison of the data. In vivo coding was also used (the actual words and/or phrases of the respondents themselves) whenever open coding could not capture the interpretive meaning of the concept. In discussion with the co-investigator JL, after coding of the interview transcripts of all the groups (non-abused older persons, experts, victims of abuse) the lists of codes were developed (repetitive codes were removed). After studying the relations between these concepts and in discussion with JL, these codes were further used for developing of bigger themes (grouping codes of the concepts) and then from these concepts main categories were derived. These main categories form the basis of the findings and conclusions that were discussed and drawn in the chapters (scientific articles) of current thesis.

For organization, coding and subsequent analyzing of data we used NVivo, a software program for analyzing qualitative data. It allows classifying, sorting, arranging information and examining relationships in your data.

Analytical tools

For analyzing the data we (YM and JL) used different analytical tools. JL was time to time involved in the transcription, coding and further analyzing of data to cross-check the process of analysis of the data. One of the most important tools was asking continuous questions. Constantly asking questions to the data (e.g. what, who, where, how, why this one, or with what consequences) helped to become acquainted with the data and understand what it tries to tell, to find other ways of thinking and to probe the data in order to capture a diversity of experiences and perspectives and relevant variables of elder abuse.

Another analytical tool that was used was making constant comparisons between the data. For instance, comparing definitions and explanations of elder abuse of within and between different groups of respondents (older persons, victims, experts), their similarities and differences. This tool suggested further interview questions and moreover, forced to examine researcher’s (YM) assumptions, perspectives on the topic of elder abuse and the ones of the participants.

An additional analytical tool used was semantic exploration, thinking about the various meanings of a word. YM and JL brainstormed about the meanings of keywords and phrases, including sometimes even the most farfetched possibilities, then discarded those meanings that were irrelevant and improbable when analyzing the data. For instance, phrases of older participants such as “take control of your own”, “boundaries were crossed”, “care is insufficient”, “double dependency” were explored and analyzed. Therewith while finding and analyzing possible meanings and relating them to the rest of the interview, and other interviews, we could make sense of the data and these particular terms that at first were not entirely clear. As such, we conceptualized the key variables and themes in this research.

Saturation

Theoretical saturation of data means the continuation of sampling and data collection until no new data emerges (Douglas, 2003). Hence, interviewing will take place until the data arising from the interviews becomes repetitive. This kind of theoretical saturation was reached while interviewing non-abused older persons and experts. With older victims of abuse the theoretical saturation was not entirely reached as our sample was quite small. The identified variables (see chapter five) did reach saturation level, but we were uncertain whether the expressions of those variables did show sufficient saturation (as acknowledged in chapter five). Experiences of abuse are quite unique and differ among victims. However, for example, no new data emerged while asking victims of abuse about coping strategies and how they dealt with abuse and its effects.

In the analysis we worked towards conceptual or descriptive saturation meaning that the researcher finds no new codes, categories or themes emerging from the analysis of data (Rebar, Gersch, Macnee & McCabe, 2011). The conceptual saturation was reached with the analysis of the data from experts' interviews and interviews with non-abused older persons as sufficient data was acquired to develop relevant categories. It is more difficult to determine whether saturation was reached with the analysis of data from the interviews with victims of abuse as the sample was relatively small (as was already discussed above while describing theoretical saturation). However, no new categories emerged from the analysis of data concerning coping strategies that victims used to deal with elder abuse. We estimate that, perhaps, additional ways of expression of these themes might emerge when data collection would have continued (as acknowledged in chapter five).

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Appendix G

Nederlandse samenvatting

Introductie

De afgelopen jaren is er meer aandacht besteed aan geweld tegen ouderen dan in de tien voorafgaande jaren. Deze groeiende belangstelling heeft zich geuit in een toename van discussies in de media, in wetenschappelijke publicaties. Dit alles heeft geleid tot een groeiend aantal beleidsdocumenten en programma's. Illustratief is het actieplan "Ouderen in veilige handen", dat werd gelanceerd door de Nederlandse regering in 2011. Dit plan is erop gericht mishandeling, uitbuiting en verwaarlozing van ouderen tegen te gaan en streeft naar een betere preventie van geweld tegen ouderen, betere slachtofferhulp en stelt strengere acties voor naar plegers (Ministerie van volksgezondheid, welzijn en sport, 2011). In de tussentijd kunnen wereldwijd veranderingen in de houding en percepties ten aanzien van oudermishandeling worden waargenomen: terwijl in de jaren zeventig en tachtig er nauwelijks erkenning was van ouderenmishandeling, is het in de laatste twee decennia gedefinieerd en erkend als een belangrijk maatschappelijk fenomeen.

De publieke aandacht voor geweld tegen ouderen valt samen met het toegenomen relatieve aantal ouderen in de samenleving. Er worden zorgen geuit over hoe we gaan zorgen voor deze ouderen en of wij dat wel zullen kunnen doen op een juiste manier. Er worden vragen gesteld over of onze geïndividualiseerde samenlevingen hebben geleid tot verminderd respect en waardering voor onze oudere generatie. Ondanks toenemende belangstelling voor ouderenmishandeling zijn er nog diverse aspecten en problemen niet onderzocht of onontgonnen, zoals de diversiteit aan definities van ouderenmishandeling, risicofactoren, en percepties en ervaringen van verschillende groepen die betrokken zijn bij geweld tegen ouderen. De belangrijkste vragen die dit proefschrift zal beantwoorden zijn: hoe wordt geweld tegen ouderen gedefinieerd, ook door ouderen zelf? Hoe leggen ouderen mishandeling uit? Hoe ervaren oudere personen het proces van mishandeling? Hoe leggen verschillende groepen die betrokken zijn bij geweld tegen ouderen de etiologie van geweld in de latere levensfase uit?

Methoden

Gezien het feit dat de vragen hoofdzakelijk gaan over het proces, het begrip en de uitleg van mishandeling is dit proefschrift gebaseerd op een kwalitatieve studie naar geweld tegen ouderen in Nederland. We hebben de definitie van de WHO gekozen als referentie om de definities te vergelijken, alsmede als kader voor het exploreren van de elementen in de definities van de diverse doelgroepen (WHO, 2002). De primaire methoden van gegevensverzameling waren semigestructureerde diepte-interviews en focusgroepen. Daarnaast hebben we ook een systematische review over definities van ouderenmishandeling uitgevoerd en een literatuurstudie naar de theoretische achtergrond van mishandeling.

De kwalitatieve studie werd uitgevoerd onder oudere mensen, professionals en deskundigen die betrokken zijn bij geweld tegen ouderen. De studie bestond uit 35

diepte-interviews met oudere, niet-mishandelde personen en 17 interviews met oudere personen die ervaring hebben met mishandeling. Voor niet-mishandelde ouderen is de leeftijdsgrens van 65 jaar aangehouden, omdat dit aan het begin van de studie de leeftijd was waarop ouderen in Nederland het wettelijk pensioen ontvangen. We hanteerden voor mishandelde ouderen geen leeftijdsgrens. Indien hun ervaringen pasten binnen de WHO-definitie namen we hen op tijdens de dataverzameling, dit betekent dat zij een van de algemeen onderscheiden vormen van mishandeling hadden ervaren met als additionele voorwaarden dat dit het gevolg was van leeftijdsgerelateerde problemen, zoals bijvoorbeeld ontstane afhankelijkheid gerelateerd aan de zogenoemde geriatrie reuzen, om te voorkomen dat participanten werden buitengesloten door een nogal arbitrair ingestelde leeftijdsgrens. Bovendien werden 35 expert interviews afgenomen met professionals die momenteel op het gebied van geweld tegen ouderen werken. De ondervraagden werden gecontacteerd na verwijzing door residentiële opvanginstellingen en de steunpunten van huiselijk geweld. Ook werden oudere personen, professionals en deskundigen gecontacteerd met behulp van een sneeuwbal techniek. Tot slot werden mishandelde ouderen opgeroepen via advertenties in vrij verkrijgbare lokale kranten in de grotere regio van de Randstad, Nederland. Alle deelnemers werden beschouwd als cognitief intact in het bezit van de capaciteit in te stemmen met deelname aan de studie. De interviews werden gehouden tussen april 2012 en december 2013.

We hebben daarnaast acht focusgroepen gehouden met professionals uit de intra- en extramurale zorg, managers van de gezondheidszorg organisaties, artsen, beleidsmakers, deskundigen, belangenorganisaties van ouderen en oudere mensen zelf. In totaal 42 personen namen deel aan deze focusgroepen. Deelnemers werden geworven door een sneeuwbal steekproef. De focusgroepen werden gehouden in de periode tussen februari en maart 2012. De focusgroepen en interviews zijn letterlijk getranscribeerd. De transcripties werden uitvoerig en systematisch geanalyseerd met behulp van NVivo, een softwareprogramma voor kwalitatieve analyse. De aanpak die is gebruikt voor het analyseren van de gegevens was vooral inductief; analytische concepten zijn afgeleid van de gegevens via een codering techniek gebaseerd op de *grounded theory* (Glaser & Strauss, 1967).

Overzicht van dit proefschrift

Hoofdstuk 1 van dit proefschrift geeft een algemene inleiding en bespreekt de achtergrond van het onderzoek en de bredere relevantie, de veranderingen op het gebied van ouderenmishandeling, de huidige kennis over de definities, de prevalentie van mishandeling, de risicofactoren en perspectieven op ouderenmishandeling. Bovendien worden de belangrijkste methoden die gebruikt zijn in deze studie besproken.

In **hoofdstuk 2** bespreken we de ontwikkeling van verschillende definities van ouderenmishandeling en hun belangrijkste eigenschappen en situeren we ze in socio-historische context. We analyseren de toepassing van de verschillende definities die werden gebruikt door de tijd om hun geschiktheid voor verschillende werkgebieden te evalueren. De belangrijkste vraag die we beantwoorden is of we een gemeenschappelijke definitie van ouderenmishandeling nodig hebben of dat verschillende definities kunnen worden gebruikt in verschillende contexten. De analyse laat zien dat definities kunnen

worden gegroepeerd in lexicale, stipulatieve en verklarende types en dat ze diverse doeleinden dienen, namelijk als verwijzingen naar het sociale probleem in kwestie, en voor het scherp stellen van een effectieve interventie en preventiestrategieën. Op basis van onze analyse stellen we twee verschillende definities van ouderenmishandeling voor: een voor onderzoek en een voor de beroepspraktijk. De definitie voor onderzoek moet breed en volledig zijn om willekeurige uitsluiting te voorkomen en om ons tot het begrijpen van mishandeling te brengen; voor deze doeleinden kan de definitie van de WHO geschikt zijn. De definitie voor professionele settings moet specifiek, smal en concreet zijn. Professionals moeten deze definitie als hulpmiddel en gids kunnen gebruiken bij de identificatie, signalering en interventie van mishandelende situaties.

De verschillende (professionele) groepen die zijn betrokken bij ouderenmishandeling bekijken en ervaren geweld in de latere levensfase op verschillende manieren. **Hoofdstuk 3** gaat in op hoe geweld bij ouderen wordt begrepen en uitgelegd door verschillende, bij dit onderzoek betrokken, groepen. Deze vraag wordt onderzocht aan de hand van de analyse van de bevindingen van de focusgroepen met verschillende stakeholders, betrokken bij het werkgebied van ouderenmishandeling, en de expert interviews. We komen tot een conceptueel model voor het verklaren van het ontstaan van het geweld in het latere leven vanuit hun perspectief. De bevindingen tonen aan dat in de uitleg van onze deelnemers de variabelen afhankelijkheid, kwetsbaarheid, macht en controle, sociaal isolement, stress en (zorg)belasting en de geschiedenis van het (huiselijk) geweld centraal staan. Er was geen consensus over de rol van een familiegeschiedenis met huiselijk geweld in ouderenmishandeling. We hebben vastgesteld dat verschillende graden en omgekeerde kwesties van afhankelijkheid en kwetsbaarheid, en dan met name de notie van wederzijdse afhankelijkheid en diverse houdingen en verwachtingen ten aanzien van afhankelijkheid en onafhankelijkheid, onderscheidend zijn bij de uitleg van geweld in de latere levensfase onder deze professionals, in vergelijking met huiselijk geweld in andere stadia van het leven.

Ondanks dat er steeds meer aandacht is voor de diverse groepen die betrokken zijn bij ouderenmishandeling, zijn er slechts een beperkt aantal studies gedaan waarbij is onderzocht welke opvattingen ouderen zelf hebben. In **hoofdstuk 4** onderzoeken we de definities van ouderen en hun verklaringen voor ouderenmishandeling door middel van interviews met niet-mishandelde ouderen. We vonden dat ouderen ouderenmishandeling vooral als opzettelijk, fysiek geweld definiëren. Minder direct werden ook andere onrechtmatige acties, zoals psychische mishandeling, financiële mishandeling en verwaarlozing, onderscheiden. Ouderen verklaren ouderenmishandeling als een gevolg van de toenemende afhankelijkheid en kwetsbaarheid, veranderende normen en waarden in de samenleving, en de gelijktijdige veranderingen in de positie van ouderen, hetgeen leidt tot gebrek aan respect richting ouderen en een gebrek aan sociale controle en verantwoordelijkheid. De onderscheidende kenmerken in de definitie van ouderenmishandeling van ouderen zijn de focus op fysiek geweld en de nadruk op intentionaliteit, die afwijken van de bestaande definities van ouderenmishandeling. Dit inzicht en deze uitleg van ouderenmishandeling kunnen het meldgedrag van ouderen beïnvloeden, omdat zij zich alleen richten op ernstige gevallen van opzettelijk fysiek geweld, die dus eenduidig en duidelijk zijn. Bovendien lijkt ouderenmishandeling door

ouderen vooral te worden uitgelegd als een sociaal probleem en niet zozeer als een volksgezondheids- of medisch probleem.

De meerderheid van de studies over ouderenmishandeling focussen op de definities, de theoretische achtergrond, de risicofactoren, de diverse vormen van ouderenmishandeling en de prevalentie, en in een meer beperkte mate op preventie- en interventiestrategieën. Slechts een beperkt aantal studies onderzoeken hoe de oudere slachtoffers zelf mishandeling uitleggen (Killick Taylor, Begley, Carter Anand en O'Brien, 2015). Daarom bespreekt **hoofdstuk 5** ervaringen en percepties op het mishandelingsproces van oudere slachtoffers. We onderzochten dit door middel van diepte-interviews met zeventien participanten die elk een van de algemeen onderscheiden vormen van mishandeling hadden meegemaakt. Het mishandelingsproces zoals waargenomen door de oudere slachtoffers omvat de oorzaken van mishandeling, de effecten die de mishandeling op deze slachtoffers had en de manier waarop ze probeerden om te gaan met deze effecten. De belangrijkste oorzaken van mishandeling zoals geïdentificeerd door slachtoffers waren wederzijdse afhankelijkheid tussen slachtoffer en pleger, disbalans in macht en controle, eenzaamheid en sociaal-maatschappelijke een achtergestelde positie van ouderen. De effecten van mishandeling op oudere personen omvatten negatieve gevoelens en emoties; lichamelijke klachten; gewijzigde normen en waarden van ouderen; gewijzigde perspectieven met betrekking tot geld; en een verminderde zelfeffectiviteit. De door oudere slachtoffers meest genoemde coping-strategieën waren het gebruiken van informele en professionele steun en zelfhulp. De keuze voor een bepaalde coping-strategie kan worden verklaard door twee factoren: de ervaren vormen van mishandeling en het stigma wat een slachtoffer verwacht te krijgen. Coping-strategieën worden ook beïnvloed door de relatie met de pleger, bijvoorbeeld of de pleger een naast familielid is, of een vriend of een buur. Deze overwegingen beïnvloedden gevoelens van schaamte, en waren daardoor van invloed op het hulpzoek gedrag en de coping-strategieën van de slachtoffers.

De rol van individuele kenmerken in gevallen van ouderenmishandeling staat al lang hoog op de onderzoek- en beleidsagenda's. Ons onderzoek geeft aan dat factoren die verder gaan dan het slachtoffer en de pleger, zoals omgevingsfactoren meer aandacht verdienen. In **hoofdstuk 6** bespreken we de resultaten van focusgroepen en semigestructureerde diepte-interviews die werden gehouden met verschillende professionals en ouderen zelf. Twee belangrijke verklarende kaders ontstonden in deze sessies: een op basis van sociaal-maatschappelijke structuren en een kader die betrekking had op ouderenmishandeling als gezondheidszorg structuren. De belangrijkste thema's die in het verklarende kader op basis van sociaal-maatschappelijke structuren werden genoemd omvatten sociaal taboe, sociale controle en verantwoordelijkheid, en institutionele culturen. De versnippering van de zorg en de veranderingen in de financiering van de gezondheidszorg waren twee verklarende factoren die naar de rol van de gezondheidszorg verwezen. De twee verklarende kaders kunnen worden gekoppeld aan perspectieven op ouderenmishandeling als ofwel een sociaal-ofwel een gezondheidsprobleem.

Ondanks het ontstaan van consensus over de definitie en de vormen van ouderenmishandeling worden de stemmen van ouderen, zowel mishandelde als niet-mishandelde, relatief weinig gehoord in discussies over de typologie van

ouderenmishandeling. In **hoofdstuk 7** besteden wij daarom expliciet aandacht aan de perspectieven van mishandelde en niet-mishandelde ouderen. In de verhalen verteld door deze deelnemers bespreken ze in het bijzonder contextuele factoren in instellingen die leiden tot gevoelens van mishandeling. Deze gevoelens vallen niet binnen de huidige vormen van ouderenmishandeling en worden dus niet erkend. Daarom stellen wij voor om een nieuwe vorm van mishandeling te introduceren: systeem mishandeling. Met de term systeem mishandeling bedoelen we mishandeling en verwaarlozing die het gevolg zijn van de organisatie van en de praktijken in de instellingen binnen onze samenlevingen die opereren in een impliciete, mishandelde manier en schade of leed veroorzaken aan een ouder persoon. We stellen dat systeem mishandeling moet worden opgenomen in de lijst van vormen van mishandeling, om de schade te erkennen die dientengevolge wordt ervaren door oudere personen.

Tot slot, wordt in **hoofdstuk 8** ingegaan op de belangrijkste conclusies van dit proefschrift door het verkennen, analyseren en vergelijken van perspectieven op ouderenmishandeling van ouderen, slachtoffers van mishandeling, deskundigen en andere beroepsgroepen. Op basis van de bevindingen van dit proefschrift, raden we preventiestrategieën aan die zich richten op algemene veranderingen in de samenleving. Bovendien doen we aanbevelingen gericht op oudere slachtoffers van mishandeling, niet-mishandelde ouderen en professionals op het gebied van ouderenzorg. Verder stellen we voor om toekomstige studies te richten op de vooruitzichten van de plegers, potentiële melders van mishandeling en het hulpzoek- en rapporteergedrag van oudere slachtoffers.

Conclusies

We hebben een verscheidenheid aan bestaande definities van ouderenmishandeling geïdentificeerd in de literatuur, die een verschillende focus hebben en verschillende onderdelen hebben. Hierdoor ontstaan definitieverschillen en is het moeilijk een solide kennisbasis op het gebied van ouderenmishandeling te ontwikkelen. In dit verband is de vaak gestelde vraag of we een gemeenschappelijke definitie van ouderenmishandeling nodig hebben. Eén definitie zou immers waarschijnlijk niet alle gewenste doeleinden dienen, zoals een definitie verondersteld te moeten doen. Om dit op te lossen stellen wij voor om gebruik te maken van twee definities van ouderenmishandeling: een lexicale definitie die breed en veelomvattend is voor onderzoek en beleidsvorming en een stipulatieve definitie, specifiek en concreet, voor de professionele praktijk.

Verskillende kenmerken van de definities van ouderenmishandeling die werden geïdentificeerd in de literatuur zijn ook relevant volgens de deelnemers aan dit onderzoek. Echter, kenmerkend voor de definities van oudere, niet-mishandelde personen zijn de sterke focus op fysiek geweld en intentionaliteit die niet prominent voorkomen in algemene definities. Verschillende andere vormen van mishandeling die vaak worden onderscheiden werden ook gemeld en herkend door onze deelnemers, zij het met verschillen in nadruk zoals in het geval van niet-mishandelde ouderen, die andere vormen van mishandeling dan fysiek geweld minder direct noemden dan andere groepen die betrokken zijn in deze studie.

De interpersoonlijke factoren die zijn geïdentificeerd en beschreven ter verklaring van ouderenmishandeling door zowel slachtoffers als oudere, niet-mishandelde

deelnemers zijn afhankelijkheid van ouderen van de pleger en vice versa, en de macht en controle onevenwichtigheden tussen het slachtoffer en de pleger. Wederzijdse afhankelijkheid was prominent aanwezig in de verschillende opvattingen over geweld tegen ouderen. De participanten besteedden veel aandacht aan maatschappelijke factoren in het verklaren van het voorkomen van mishandeling. Hieronder vallen bijvoorbeeld een achtergestelde sociaal-maatschappelijke positie van ouderen in de samenleving, die resulteert in gebrek aan respect naar hen, en wordt ervaren als een verminderde waarde van ouderen voor de samenleving. De problemen die werden geïdentificeerd vanuit de gezichtspunten van de verschillende groepen betrokken bij deze studie ondersteunen deze bevinding, deze groepen noemen ook veranderingen in de samenleving en effecten op de afhankelijkheid en kwetsbaarheid van oudere personen in hun verklaringen voor ouderenmishandeling.

In de verschillende hoofdstukken van dit proefschrift wordt duidelijk dat de participanten van onze studie voorbeelden van mishandeling beschreven die we niet onder de algemeen onderscheiden vormen van mishandeling kunnen categoriseren. Ze vonden dat de gezondheidszorg en de samenleving als geheel verantwoordelijk is voor het ontstaan van permitterende omstandigheden waarin mishandeling kan optreden. Om recht te doen aan deze bevinding, hebben wij een nieuwe vorm van mishandeling voorgesteld, die we systeem mishandeling noemen. Met systeem mishandeling bedoelen we de organisatie en de resulterende praktijken in onze instellingen, die (impliciet) mishandeling en schade of leed veroorzaken aan een oudere persoon.

Bijdrage van deze studie

De huidige studie heeft bijgedragen aan de conceptualisering van ouderenmishandeling door het verkennen, het vergelijken en het koppelen van definities van en verklaringen voor mishandeling door diverse groepen die betrokken zijn bij ouderenmishandeling. Door personen die rechtstreeks betrokken zijn bij ouderenmishandeling te includeren als onderzoeksparticipanten, evenals mogelijke getuigen en melders, heeft deze studie het vergelijkende begrijpen en de framing van ouderenmishandeling verduidelijkt. Het creëerde een brug tussen de definities in de literatuur en de percepties in het echte leven die toonden wat echt belangrijk is voor mensen die betrokken zijn bij ouderenmishandeling en die mishandeling ervaren (hebben).

Wij analyseerden bestaande definities van ouderenmishandeling en na hun systematische vergelijking en categorisatie hebben wij voorgesteld het aantal terug te brengen naar twee definities. Op deze manier hoopt deze studie bij te dragen tot meer uniformiteit en vergelijkbaarheid op het gebied van ouderenmishandeling waardoor de impact van onderzoek en beroepspraktijken in verschillende settings kan worden versterkt.

Deze studie wijst op systemische factoren die werden geïdentificeerd door oudere personen en slachtoffers als cruciale variabelen in hun verklaringen voor het voorkomen van mishandeling. We benadrukten het belang en de noodzaak voor aandacht voor deze perspectieven op ouderenmishandeling door systeem mishandeling voor te stellen als een afzonderlijke, en aanvullende, vorm van mishandeling.

Wij geloven dat de huidige studie een beter en vollediger begrip van mishandeling creëert, waardoor een verdere convergentie tussen de standpunten van degenen

die rechtstreeks betrokken zijn bij het geweld tegen ouderen en degenen die dit onderzoeken en bestuderen kan optreden. Hierdoor kan het veld een theoretische stap voorwaarts maken, doordat het de ontwikkeling en het begrip van kaders bevordert, die erop gericht zijn het voorkomen en voortduren van mishandeling te begrijpen op basis van vooruitzichten die eerder niet of marginaal werden beschouwd. Het kan ook bijdragen tot een praktische stap voorwaarts, want het geeft de mogelijkheid deze gezichtspunten te implementeren de praktijk van preventie- en interventiestrategieën.

Toekomstige studies en aanbevelingen

Onze bevindingen tonen duidelijk dat de verschillende groepen die betrokken zijn bij geweld tegen ouderen mishandeling niet alleen beschouwen als een interpersoonlijk of individueel probleem, maar ook als een algemeen maatschappelijk probleem. Wij raden daarom een aanpak aan die is gericht op algemene veranderingen in de samenleving, zoals interventies en preventiestrategieën die ten doel hebben veranderingen in het gedrag naar en de bejegening van oudere personen te bewerkstelligen, alsmede in de beeldvorming van ouderdom en oude mensen. Daarom stellen wij voor om een positief beeld van ouderen te promoten met bijvoorbeeld rolmodellen en sociale mediacampagnes. We moeten een grotere participatie van ouderen zien te bewerkstelligen in de gemeenschap en de samenleving als geheel. Mensen voorzien van informatie over ouder worden zal bovendien een beter begrip kweken over het verouderingsproces, en de daarbij horende veranderingen en uitdagingen.

Toekomstige studies naar ouderenmishandeling dienen zich te richten op percepties en perspectieven van plegers van geweld tegen ouderen. Meer aandacht moet worden besteed aan potentiële melders van ouderenmishandeling, met name ouderen zelf. Bovendien is er ook weinig onderzoek gedaan naar het hulpzoekend gedrag en meldgedrag van oudere slachtoffers. Er is behoefte aan onderzoek naar de mogelijke combinaties en relaties tussen de verschillende vormen van mishandeling, de betrokken plegers en de copingstrategieën die worden gebruikt om te gaan met mishandeling. Studies die onderzoeken hoe één vorm van mishandeling en een specifieke relatie met een pleger impact kan hebben op de keuze van het melden en de copingstrategie van het slachtoffer zijn nodig.

Een van de belangrijke aanbevelingen van deze studie is gericht op de slachtoffers van mishandeling en komt voort uit hun ervaringen met mishandeling. We bevelen de oprichting en organisatie aan van steungroepen, bijvoorbeeld zelfhulpgroepen voor slachtoffers van geweld tegen ouderen die kunnen worden gecoacht of geleid door een ervaren professional of peers met soortgelijke ervaringen. Oudere mensen zullen hun ervaringen kunnen delen en feedback kunnen ontvangen van andere deelnemers.

We raden ook het inschakelen van oudere personen aan bij praktijk- en beleidsbepaling ten aanzien van geweld tegen ouderen, bijvoorbeeld door ze op te nemen in de teams die zich met de gevallen van mishandeling bezighouden en door vrijwilligersgroepen van oudere personen op te richten. Ook speciale trainingen, workshops, vergaderingen en bijeenkomsten over geweld tegen ouderen kunnen worden georganiseerd voor oudere mensen.

Op basis van de uiteenlopende perspectieven die we onder oudere personen vonden, raden wij het ontwikkelen van educatief materiaal aan, evenals trainingen en

programma's voor professionals die werken op het gebied van ouderenzorg en waarin de standpunten en ervaringen van niet-mishandelde oudere personen en slachtoffers van mishandeling zijn opgenomen.

Oudere slachtoffers en vooral niet-mishandelde oudere personen zien mishandeling als een maatschappelijke probleem waarvoor we als samenleving verantwoordelijk zijn. Deze verantwoordelijkheid wordt echter nog niet is gevoeld en begrepen door het grote publiek. We moeten onze normen en waarden van sociale tolerantie ten opzichte van het probleem van geweld tegen ouderen omzetten in actieve sociale verantwoordelijkheid, één die zichtbaar is. Het is tijd om iets te gaan doen, en te stoppen met het negeren van de stemmen van oudere personen.

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Appendix H

List of publications

- Mysyuk, Y.,** Lindenberg, J., Biggs, S., & Westendorp, R. (2015). Listening to the voices of abused elderly: should we classify system abuse? *British Medical Journal*, 350, 1–3.
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Appendix I

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Appendix J

Curriculum Vitae

Yuliya Mysyuk was born on the 14th of January, 1984 in Ivano-Frankivsk, Ukraine. After graduating cum laude from high school in 2002, she entered the National University of Kyiv-Mohyla Academy where she studied sociology, social work and psychology. Upon completion of her studies in Kyiv in 2008, Yuliya was offered a MTEC Scholarship from the Dutch Ministry of Foreign Affairs and Maastricht University to study at the Faculty of Health, Medicine and Life Sciences at Maastricht University, the Netherlands where she acquired her second degree, a Master in Public Health. Possessing a broad range of interests, Yuliya is an active volunteer and has spent much of her free-time involved in activities with Amnesty International, Organization for Migration, various nursing homes and residential care facilities, as well as other non-profit organizations and projects.

In 2010, she began her PhD research project on elder abuse at the Leyden Academy on Vitality and Ageing. During her PhD study, Yuliya successfully completed the Master programme on Vitality and Ageing at the Leyden Academy graduating in 2011. In the last four years, Yuliya collaborated with various national and international organizations, scholars, experts and professionals in the field of elderly care and elder abuse. She is a member of Dutch Society for Gerontology and International Network for the Prevention of Elder Abuse (INPEA).

