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Department of Health and Behavioural Sciences, Kalmar University

"Global response against elder abuse"

Report from Sweden

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Abstract

The aim of this pilot-study was to explore perceptions of elder abuse among primary healthcare professionals and elderly people in Sweden. Data was collected through focus group interviews with one group of primary healthcare professionals and one group of elderly senior citizens. Data was analysed by qualitative content analysis. The major theme *public responsibility* and the sub-themes of *issues of ageism, issues of elder abuse* and *suggested interventions and recommendations* emerged. Elder abuse was described as ”crossing the line” and unacceptable. Changes in family structure, less respect for elderly people, and cutbacks in healthcare were some of the causes cited. Elder abuse was discussed both in the home and institutional context. Consequences of elder abuse were inter alia increased fear and insecurity for elderly people. The most important tendency in this study was the discovery of a commonly held naiveté about elder abuse and uncovering the belief that interventions are expected at a society level. Suggested interventions included elderly people’s rights groups, clearer guidelines on how and where to report elder abuse, and increased resources for healthcare.

Table of contents

Demographic Characteristics

Sweden is an affluent industrialized nation in Scandinavia. It is also one of the most sparsely populated countries in Europe (~ 20 inh/ km²). The current population is approximately 8,9 million (Statistics Sweden, 2000a). Only 2,5% of the total land area are developed. Eighty-eight percent of the population lives within 50 km of the four large inland lakes or the 3,218 km long coastline (Statistics Sweden, 1998).

As is the general trend in Europe, life expectancy has gradually increased since the beginning of the 20th century. Life expectancy in Sweden is now 77,5 years for men and 82,1 years for women. This increase is clearly indicative of the general improvement of health. The fertility rate, though, is only 1,5 births per woman, which is the lowest since 1750. These two trends will lead to an increased percentage of elderly people in the population. Today over 18% of the population are older than 65 years (the retirement age). Five percent are older than 80 years and 83% in this age group are women (Folkhälsorapporten, 2001). The prognosis is that 21% of the population in 2020 will be elderly (Statistics Sweden, 2000a).

Seniors in Sweden today live both longer and richer lives. They have better health, better economy, and a more active lifestyle than 20 years ago. Aging, though, do entail a more limited social network and more illness (Statistics Sweden, 2000b). Ninety-two percent of the elderly in Sweden live in ordinary housing (8% of these seniors receive municipal in-home service). Eight percent of the elderly live permanently in special forms of municipal housing. Noteworthy is that in the age group 65-74 years, only 1% lived in special housing while in the age group +90 years the same proportion is about 45% (National Board of Health and Welfare, 2000).

Healthcare in Sweden is a responsibility for the public sector and is an important part of the Swedish welfare system. It is a universal welfare system that covers everyone regardless of income or occupation. Services are 90% publicly financed from a combination of taxes and social insurance. There are three political and administrative levels; central government (the Ministry of Health and Social Affairs and the National Board of Health and Welfare), county

councils (hospitals and primary care), and the local municipalities (social welfare services and elder care) (Swedish Institute, 1999a).

Primary care is provided both at local health centers staffed by nurses, general practitioners, midwives, and physiotherapists and at district nurse clinics. District nurses also visit patients in their homes. In-home service is provided by the municipalities, as is all special housing for the elderly. The right to remain living at home and obtain help is legally established and there is no official upper limit to the hours of input. This is something unique to Sweden (Swedish Institute, 1999b). Healthcare in the municipalities has not decreased, despite major cutbacks in funding during the 90ties. The trend that has emerged is that fewer people are receiving help but the average input per person has increased. Those receiving help are the most severely ill. Another trend is that of more extensive care and nursing in the patient's own home. This presupposes, though, the presence of family and next of kin. Families have to assume a growing share of responsibility (National Board of Health and Welfare, 2000).

Elder Abuse Research in Sweden

Tornstam's (1989) investigation of elder abuse in Sweden reported 8% of a random sample of Swedish adult citizens knew of an elder abuse case. This was the first study indicating the existence of elder abuse in Sweden. The very recently published report from the Swedish Crime Victim and Support Authority also indicates how widespread elder abuse is**.** One thousand ninety-one senior citizens between 65 and 80 years in a municipality in northern Sweden answered a questionnaire. Sixteen percent of the elderly women and 13% of the men responded that they had experienced some kind of abuse since turning 65 years (Eriksson, 2001).

Saveman (1994) have done research on elder abuse in Sweden since the early nineties. Healthcare professionals were interviewed and answered questionnaires. The typical victim was described as a female and over 80 years and the typical perpetrator was most often a close relative, with or without care giving responsibilities. The situation was often described as a long lasting family conflict. Mental disturbance, alcohol abuse, and financial concerns were considered to be contributing factors. Psychological abuse was the type of abuse most commonly reported (Saveman & Norberg, 1993). Relationships between the victim and the

perpetrator were characterized by lack of love, inhibiting dependency, and the execution of power over the weaker victim (Saveman & Norberg, 1993). Professionals reported feelings of powerlessness, with few intervention possibilities (Saveman, Norberg, & Hallberg, 1992). Three professional groups (district nurses, home care coordinators, and general practitioners) responded differently and proposed various interventions to hypothetical abuse situations (Saveman & Hallberg, 1997).

Elder abuse in residential settings in Sweden is a current focus for Swedish elder abuse research. Psychological and physical abuse related to care giving activities was the most commonly reported type of abuse in the residential setting. The abuser was typically described as aggressive, hot tempered, exhausted or burnt out. The typical victim was over 80 years and mentally or physically handicapped (Saveman, Åström, Bucht, & Norberg, 1999). General practitioners' (GP's) awareness of elder abuse have been investigated by Saveman and Sandvide (2001). Seventy-seven percent of the GP's responding to the questionnaire had a patient at risk for being abused. Twenty-five percent of the GP's had verified cases of elder abuse. Risk situations were described as involving elderly people suffering from dementia, caregivers who had angry feelings about the burden of care, and paid caregivers who could not meet the caregiving demands.

Aim

The aim of the pilot-study was to explore perceptions about elder abuse among healthcare professionals and elderly people in Sweden.

Method

The WHO/INPEA investigation had already started in the other participating countries when Sweden was invited to contribute to the global project. Therefore, only two pilot interviews are reported here and the rest of the study is in progress. The total Swedish study will be a part of a master thesis, and will subsequently be submitted for publication in early 2002.

Participants and settings

This pilot-study was conducted in one of the most heavily populated regions of southern Sweden (13% of the total population). Within this region approximately 18% of the inhabitants are over 65 years. A total of 14 people participated in the study. Seven participants

work as primary health care professionals and seven participants were senior citizens. The primary health care group consisted of six women and one man (n=7). Their ages ranged from 32 to 55 years (median 49 years). These participants work as registered nurses (n=2), district nurse (n=1), occupational therapist (n=1), and home care coordinator (n=3). Four women and three men participated in the group of seniors (n=7). Their ages ranged from 67 to 92 years (median 80 years). They had previously worked in such diverse areas as health care, business, industry, journalism, and administration in a police department. All participants signed an informed consent form before participating in the study. The Chairperson of the Research Ethics Committee of the Faculty of Health Sciences, University of Linköping, Sweden, has approved the Swedish study.

Data collection and analysis

The first two authors conducted two focus group interviews, one with health care professionals and one with seniors. The interviews, took place in a room where there would be no disturbances, and were characterized by natural conversation and interaction between the participants. The health care professionals were interviewed in a conference room at a health care centre and the elderly person in the home of one of the participants. A semi-structured interview guide was used, and the following areas were covered: introduction to elderly people's situation in society today, an overview of elder abuse (i.e., definitions, categories, causes), perceptions, solutions, interventions and challenges. The interviews lasted between 70 to 90 minutes, and were audio-recorded and transcribed verbatim. The nonverbal communication of importance to the context was marked, as well as group interaction such as individual opinions compared to general opinions of the group. Attention was also paid to how closely participants stuck to the discussion topic, the mood of the group and to whether there was anything that provoked conflicts. At the end of each interview, the moderator summed up the discussion so that the participants had a chance to verify the summary of the key points. After the focus group interview, the moderator and the assistant moderator talked and compared their experiences. This debriefing captures the first impressions and highlights and contrast findings from previous focus groups.

The interview text was analysed by means of qualitative content analysis (c.f. Berg, 1998; Woods & Cantanzaro, 1988). The overall aim of qualitative content analysis is to find coherent patterns of ideas, thoughts, utterances and beliefs (Polit & Hungler, 1999). Data

collection, preparation, analysis and interpretation are processes that overlap in qualitative work and it is impossible to read the text without interpreting it. There are also different levels of interpretation from concrete to abstract and many shades of interpretation are possible (Burnard, 1995). The three authors independently analysed the text through several steps that includes a descriptive structure of the message and an interpretative reading. First, the transcripts were read straight through to get a sense of what it was all about and to gain ideas to further analysis. Second, the text was split into meaning units appearing to deal with the same content and thereafter sorted into areas relevant to the purpose of the study. Third, the statements in area were critically analysed and questioned, read and compared to achieve reasonableness. Fourthly, the authors reflected on and discussed the findings taking the research question and their personal pre-understanding into account and decided the main themes.

Findings

The analysis resulted in one main theme ‘Public responsibility', with the sub-themes ‘Issues of Ageism’, ‘Issues of Elder Abuse’, and ‘Suggested Interventions and Recommendations’. The three sub-themes in relation to the major and running theme of ‘Public Responsibility’ like three notes in a chord in a song about the situation for elderly people in Sweden today, (Table 1).

Issues of Ageism

“You have your future behind you. You are nothing to make an effort for.”

Throughout the interview with the seniors the recurring theme was ”things were better in the old days”.

> *”Everything is different now. Why has it become so negative and so lax in society? We had to learn to behave and we had to work, but we weren’t hit. But one had respect for one’s elders.”*

The seniors pointed out repeatedly that changing family structure is a major negative trend in society today.

> *”Half of all marriages end in divorce...First, they get married and buy a new house and build a family, and then it’s a new house, new spouse, new children. It’s a terrible mess.”*

Table 1. Main and sub-themes of the perceptions of elder abuse

Public Responsibility		
Issues of Ageism	Issues of Elder Abuse	Suggested Interventions and recommendations
Better in the old days	Taboo	Knowledge and education needs
Ageism in the social context	Crossing the line/ Violation of rights	Society's duty to help the helpless
Elderly people have no place within families	Perpetrator	Supervision in institutions
Ageism in healthcare	Victim	Elderly people's rights organization
Lack of respect for elderly people	Risk situations	Staffing improvements
Elderly people as undervalued	Consequences	

They further said that they felt as if seniors no longer have a natural place within the family. People moving and that families are not geographically close was also questioned as a problem.

> *"Youth today no longer socialize with the older generation...Families used to stick together...and it was very common to take care of the older relatives, there always was a grandmother."*

All the participants in the senior group were of the opinion that elderly people are undervalued in today's society.

> *"You have your future behind you. You are nothing to make an effort for. Out! Out with you as quick as can be. I also think that is a kind of abuse."*
> *"No one takes you seriously anymore, despite the fact that you could still contribute so much."*

On the contrary, the primary health care professionals perceived elderly people as being wise and good listeners who always showed respect for personnel. *"Elders have so much to share. You feel you have been given so much."*

Among the senior participants there were some, who felt that elderly people have a low priority in the health care system. There were comments that indicated that elderly people experience a lack of respect from organized health care personnel.

> *"In the doctor-patient relationship the older patient isn't such an immediate interest for treatment compared to a young soccer player. He has all the possibilities but the older patient doesn't."*

> *"...an old man isn't worth the effort...He* (doctor) *said 'We don't think like that'. But there must be something to it when you prefer 25 year olds ... They* (doctors) *think this is a very uncomfortable discussion topic."*

Home care workers were described, on the other hand, as most often showing respect to the elderly. The participants in the primary health care professional group agreed that geriatric patients have a low priority in the health care system.

> *"You often hear at the hospital that no treatment is initiated, for example cancer treatment, on account of the patient being too old.".*

Medical personnel's patronizing attitude towards the elderly and lack of information both to the elderly patients and to the county home care workers were seen as problems. One health care professional reported, *"...Sometimes I don't even get a report on the patient's diagnosis from his doctor. And we are the one supposed to do the care plans"*

Issues of Elder Abuse

"There was such a silence. It just wasn't talked about."

In answer to the question, "Is elder abuse really a problem in Sweden?", the seniors conceded that it occurs in families. They also felt that elder abuse is drawing more public attention now than it has before. The primary health care professionals did not consider elder abuse to be a big problem but agreed that it happens. They felt that fewer cases of abuse occur but that more are being reported. They also discussed a new public awareness due to increased media coverage. *"We are followed by the press. They are on the alert, all the time."*

In the senior group abuse was considered a taboo subject, often shrouded in secrecy. *"There was such a silence. It just wasn't talked about."* It was repeatedly described as unacceptable and inexcusable. Several different types of abuse were discussed, including psychological and physical abuse, as well as neglect. Ageism and crimes against elderly people (e.g. robbery) were also considered to be forms of abuse. Abuse entailed "crossing the line" and "violation of rights". Interesting was that the participants in the group of seniors questioned at length the issue of visits from representatives of a certain religious denomination and their aggressive door-to-door canvassing campaigns. There was a consensus in the group that elderly people are a specially attractive target group for these campaigns.

"...This is also to be considered abuse, for they come into the house. We don't let them in, rather, they just come in. We don't want them and they don't listen to us, that we don't want them."

Among the senior participants the perpetrator was typically described as a male, with a violent personality, who abuses someone weaker. It was suggested that a child who is abused could grow up to be an abuser. The perpetrator was also described as being a stranger. Another common theme was the involvement of alcohol in the abuse situation. You could sense, though that the perpetrator generated a certain sense of sympathy among some of the elderly participants, who described him as unhappy, disharmonious and having feelings of guilt. Potential victims of abuse named by the elderly participants were women, wives, and people suffering from dementia. Elder abuse was described most often in the context of the home or institution. Situations for risk of elder abuse included living with a person suffering from dementia, in a situation where alcohol or drugs were involved, a history of wife battering, or where the elder person was isolated. Elder abuse in institutions was also discussed. The personnel were described as potential abusers. Causes of this, however, were immediately offered and included understaffing, personnel burnout, and caring for demanding patients.

The primary health care professionals, like the group of seniors, discussed elder abuse as being unacceptable. Besides psychological and physical abuse and neglect, they also named financial abuse.

"There many who exploit the mentally ill...when they shop with a credit card and need assistance when paying."

The primary health care professionals also discussed risk situations for elder abuse in the institutional environment (understaffing on the weekends, unsuitable health care workers, and having an overburdened schedule). They also discussed risks as arduous life situations, provocative situations, and when a person experiences feelings of powerlessness.

"Imagine the day that starts with hassles with the kids-who call you a witch-you have more hassles at work and you are in conflict with your work mates, and on top of it all your husband calls and say he is not coming home tonight either..."

The increasing level of general violence, especially in cities, was seen as a risk for the elderly. The primary health care professionals also considered the following to increase risk for abuse; a family member suffering from Alzheimer's disease, psychiatric illness, individuals requiring

caregiving, mental retardation, being unable to communicate basic needs, older women having difficulties standing up for their rights, when a person was not allowed to speak for himself, when caregiving is exaggerated, when there is harassment on account of physical appearance, cultural clashes, and when there is an unwillingness to confess that the family requires help.

When the question was raised as to what one notices about a person who might be abused, only vague answers were given in the group of seniors, such as, *"You just know*." The primary health care professionals thought that it would be difficult to identify a victim and said they would need a lot of clear signs. Consequences of abuse discussed by the participants in the group of seniors were those of increased fear, insecurity, and suspicion of strangers among elderly people today.

> *"You bolt your door with double locks and you always check carefully when someone rings the doorbell...You never just open the door."*

The participants of seniors said they felt that abuse destroys lives. Primary health care professionals discussed their fear of malpractice suites.

> *"Since it has become an issue...elder abuse... one is so overly careful because you are afraid of being reported to the authorities."*

Suggested Interventions and Recommendations

"...teach the children early, what is right, what is wrong, what is good, what is evil."

There was a general agreement in the senior group that one should always intervene even though it is not always an easy thing to do. Getting involved is one way to show compassion. The primary health care professionals associated "intervention" with "police intervention". Involving the police was experienced as an upsetting situation and was an intervention used only in emergency cases.

The participants in the group of seniors felt that organised healthcare offered no support to mistreated elderly persons. They felt they were poorly informed as to what kinds of support were available. There was a general lack of knowledge about whom they would call. Neither district nurses nor general practitioners were thought to be appropriate choices.

At the same time, the seniors also felt that elderly people know what is best for them and made some concrete suggestions about how they themselves could be active in prevention of elder abuse. For example there was a total agreement among the seniors about the need for an elderly people's rights organisation. They also discussed the need for increased communication and human compassion. Support/discussion groups were suggested as well as a telephone help line. Tight-knit neighbourhoods with a "neighbourhood-watch" system were praised.

The primary health care professionals described elder abuse as a current topic for discussion within eldercare. They also discussed the more explicit legislature that has been passed, the changing roll of the legal administrator, and the general improvement of healthcare. Personnel is given ongoing information and education focusing on the two Swedish mandatory reporting laws, "Lex Maria" and "Lex Sara" that can be utilized to report mistreatment within the organized health care system. These laws target maltreatment in general within institutional settings and Lex Sara is specifically aimed at protecting elderly people and disabled adults within institutions but does not cover those living in their own homes.

The primary health care professionals felt that better work environments are needed for both personnel and the elderly patients. Suggestions included a less hierarchical organisation, more active leadership, continuing education of staff, the availability of clinical supervision in nursing care, and an increased awareness of one's approach in the nurse-patient relationship. This group brought up the problem of how hard it is to find temporary staff with adequate training. They also felt that the work situation for county home care employees, characterized by heavy workloads, small possibilities to influence their situation, and lack of support, needs to be addressed in the future.

> *"...when you've tried four times to help someone to the toilet, who is super heavy and in the end have to give up, and they have an accident in their wheelchair...that can lead to completely wrong actions, when one is totally exhausted."*

The primary health care professionals suggested the use of therapeutic conversations and involving social workers. They also felt that it was of importance to give practical help in the activities of daily living. The primary health care professionals felt that possibilities for caregiver respite exist, but psychological support for caregiving relatives does not.

Involvement of local associations and organizations was suggested as a way to enhance life quality for the elderly and their next of kin. The primary health care professionals felt it was of the utmost importance to create a climate of trust, safety and hope in society.

Public Responsibility

The common attitude among Swedes for the last decades have been that there are a public responsibility to take care of children at day care centers and to take public responsibility for care of elderly people. This attitude could also be found more or less explicit in both participant groups.

Typical for the discussion in the senior group was the underlying conviction that abuse is a social problem that should be dealt with at on the government level. It was seen as the society's duty to help the helpless. A recurrent theme was that of budget cuts, wrong priorities in state spending, and cutbacks in healthcare. One elder commented about elder abuse in institutions,

> *"Cutbacks in health care personnel everywhere! Those that are left must work themselves to death. They get stressed and do things they don't want to do but do anyway. I think we cut back in all the wrong areas."*

In the participant group of seniors it was agreed that volunteers should not replace personnel in organised healthcare. Paying taxes was considered to give citizens rights, which is the right to educated healthcare personnel.

> *"It should never become legitimate for the state to say, we are going to build eldercare and healthcare on volunteer organisations. We won't accept that. They have no right. As long as they demand that we pay taxes, we have rights too."*

They also wished for more public supervision of institutions. They saw a need for healthcare on the individual level, moving away from the idea of the standard patient. To increase respect for seniors, they suggested improvements in education, with a strong emphasis on the need for ethical discussions early on in children's schooling.

> *"Teach the children early what is right and what is wrong, what is good, what is evil. You sit there and watch TV and see only evil."*

Education for healthcare personnel and for perpetrators was also suggested.

Discussion

One of the findings from the interview with the group of seniors was that they feel elderly people don't have adequate knowledge of where to turn for help or to report elder abuse. This might be in line with Eriksson's (2001) results that 75% of the women and 40% of the men who had experienced abuse had never sought help. Eriksson also describes how there is no obvious authority for victims to turn to. She suggests that such an authority should be founded and that shelters for victims should be established for emergency situations. Eriksson further recommends that elder abuse should be made visible in crime statistics.

The discovery that the seniors and healthcare professionals interviewed alike are naive in their perceptions of elder abuse was one of the most important tendencies in this pilot-study. One example of this is that participants in both groups were in agreement that elder abuse is not commonplace. This is noteworthy when compared to the results of the recent study, which reported as many as 16% of older women and 13% of older men had experienced abuse sometime since turning 65 years (Eriksson, 2001). Another example is how the seniors could describe the perpetrator as a stranger, a robber, or a religious canvasser. Studies carried out in Sweden previously have ascertained that the typical perpetrator is a close relative (Saveman & Norberg, 1993, Saveman, Hallberg, Norberg, & Eriksson, 1993). Another very important notion was the uncovering of the belief held by the respondents in the group of seniors that interventions were expected to primarily be a public responsibility. Responsibility was never laid ultimately at the feet of the perpetrator or victim. In the Sweden it has been an attitude among people for several years that it is a public responsibility to take care of both children and disabled adults. The young and middle-aged families are not obligated to take care of their old relatives. However, the decrease of governmental finances for various public services has put heavier demands on families to take caring responsibilities of the elderly persons, and the amount of family caregiving of elderly persons today is.

If the tendencies from this pilot study are credible for more Swedish elderly people it is of ultimate importance to keep aware of this expectation and naiveté in the population when designing information material and intervention programs. This is perhaps the most pertinent

reason for doing more interviews and further developing this study. Current perceptions must be charted in order to plan the most effective offensive for elder abuse prevention.

There are very few studies focusing on elderly people's perception of elder abuse. Hudson and Beasley (1999) interviewed 944 American adults, half of them 65 years of age and older with various racial backgrounds about their knowledge of and experience of elder abuse (neglect excluded) in general and of their personal experiences of elder abuse. They conclude their study by focusing on the need for understandings of perceptions of elder abuse by further explore cultural and racial commonalities and differences that they found exist. The WHO/INPEA-study Global Response Against Elder Abuse is just the study to answer this request. Many interesting tendencies/results have been gleaned from these two Swedish interviews. It must be kept in mind, however, that this study and the findings thereof are to be considered as preliminary results. Sweden was invited to contribute to this global project at a rather late date and the study here is still in progress.

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