

## Family caregiving problems of suspected elderly neglect: A review of forensic autopsy cases in Japan

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### Abstract

**Background.** Elder abuse is a severe violation of human rights, and the most recent domestic violence issue to gain the attention of public and medical communities especially highly aged country like Japan.

**Methods.** To clarify family caregiving problems related to elder neglect in Japan, we reviewed 178 autopsies conducted between 2000 and 2003 at one centre.

**Results.** Of the 178 cases (134 males and 44 females), 53 involved people were 65 years old and over (30%). A careful investigation of these 53 autopsy reports (39 males and 14 females) allowed us to exclude obvious causes of death, such as traffic and other accidents, drowning, poisoning, alcoholism, and clear disease pathology. We were left with nine cases of suspected neglect (three males and six females). The mean age of victims was 82.1 years (range, 68–91). According to the autopsy reports, two were severely starved, two were putrefied or mummified, three had pressure sores, two had dementia and three would have had difficulty in performing the activities of daily living. Each victim had lived with one family member; their sons in five cases, and a grandson, brother, wife or husband in each case. The caregivers' ages ranged from 27 to 76 years, and five were unemployed; in three cases, the family incomes were very low. Of the caregivers, two were depressed, one was an alcoholic and one had dementia.

**Conclusions.** This investigation indicated that elderly parents living with their sons are a high-risk group for neglect. A family support system is needed to target male caregivers who are likely isolated from social services. Autopsy cases provide valuable information for public health to prevent similar cases in future.

**Keywords:** Elder abuse, Elder neglect, Male caregivers, Family caregiving, Autopsy records,

### 1. Introduction

Neglect is a serious clinical syndrome that can have a profound effect on the health and quality of life in the elderly, is the most common form of elder abuse. Elder abuse is a recently recognized internationally pervasive and growing problem, and is a serious social issue gaining attention of public and medical communities. According to the "World report on violence and health" by World Health Organization (WHO), elder abuse is being taken far more seriously now reflects the growing worldwide concern about human rights and gender equality, as well as about domestic violence and population aging<sup>1</sup>. Moreover, elder abuse is associated with distress and increased mortality in older people<sup>2</sup>. Indeed, the prevention of violence for elderly people, such as elder abuse and neglect, is a worldwide policy issue.

Several prevalence and incidence of elder abuse and neglect studies have been done throughout the world. The Boston survey revealed abuse in 3.2% of elders, including physical abuse in 2.2%, verbal abuse in 1.1%, and neglect in 0.4%<sup>3</sup>. A national random-sample survey of elderly people in Canada indicated that 4% reported experiencing maltreatment since the age of 65 years<sup>4</sup>. The same survey revealed material abuse in 1.9–3.3%, verbal abuse in 0.8–1.8%, physical abuse in 0.3–0.9% and neglect in 0.2–0.6%. Very similar rates of maltreatment were found in a epidemiologic studies carried out in Great Britain using similar methods and measures<sup>5</sup>. In other countries, a national telephone survey in Denmark and Sweden used a more inclusive definition and found elder abuse at 8%<sup>6</sup>. The incidence of elder abuse is estimated from cases reported to the states. Cases in Connecticut include neglect in 78%, physical and verbal abuse in 14%, financial exploitation in 7%, and abandonment in 1%<sup>7</sup>.

The geriatric populace in Japan is the fastest-growing age group, comprising 21.5% of the population in 2008 and possibly 25% by 2015<sup>8</sup>. For this reason, the Japanese government introduced public long-term care insurance (LTCI) in 2000 to share the burden of care for the elderly population that the traditional family system could no longer adequately support. The LTCI is the only major social insurance system that includes all Japanese residents aged 40 years and older, without exception, and that integrates the formal provision of community and institutional care services<sup>9</sup>.

Recently, there is increasing concern about elder abuse and neglect by informal family caregivers<sup>10</sup>. Social services have an important role in elder abuse and neglect assessment because they are accessible to local population; however, these resources may need adjusting to keep up with the rapidly increasing geriatric population. Even though the government provides informal service for elderly people and their families, family caregivers only can play family caregiver role in family members. In addition, there are few informal services for elderly people and their families provided in Japanese communities. In the family caregiver situation in Japan, Japanese culture has preserved the longstanding tradition that the wives, adult daughters and daughters-in-law are expected to be primary caregivers. Family caregiver must take care of impaired elderly in a small family, such as a nuclear family, women's participation in society. Moreover, although there are more female caregivers, the number of male caregivers has recently been increasing.

Various kinds of risk factors have been investigated regarding elder abuse and neglect. The preceding studies conducted so far on elder abuse have revealed the risk factors for caregivers to be stress pertaining to caregiving<sup>11</sup>, as well as economic dependence on the elderly by caregivers<sup>12</sup>, alcohol dependence<sup>13</sup>, and presence or absence of psychological disorder<sup>14</sup>. While it has been reported that difficulties of physical, mental health, and functional ability<sup>3</sup>, to perform activities of daily living (ADLs)<sup>7</sup> and dementia<sup>15</sup> are the risk factors for abused elderly, living arrangements<sup>16</sup> as well as social isolation<sup>17</sup> have been reported to concern both.

Since the late 1970s in the entire world, and the 1980s in Japan, rising public interest has initiated a large number of studies on elder abuse and neglect and suggested the actual situations and risk factors for elder abuse. Moreover, reports of elder abuse are increasing in the world; however, many barriers limit reporting of such cases. First, a blatant difficulty in elder abuse research is the disparity in the definition of 'elder abuse'. Elder abuse and neglect research has been criticized as being methodologically flawed and subject to bias. In previous studies, the subjects of elder abuse research have been mostly doctors and nurses in emergency departments; care managers, such as medical and social welfare workers, users, and family caregivers.

Neglect is the largest category of reported elder mistreatment and is the least understood.

Little is known about the actual situation of violence related to the elderly in Japan because it has not been well studied. The problem of elder abuse and neglect has been approached only recently. In previous studies, elder abuse and neglect in Japan are underreported in scientific literature. In particular, previous research has not focused much on elder neglect, and the actual situations are almost unknown. Therefore, the actual conditions of elder neglect are commonly underestimated. According to a previous report, neglect is an extremely dangerous syndrome, accounting for 60–70% of all elder mistreatment reports made annually to adult protective services (APS)<sup>18</sup>. According to the first national survey in Japan, elder neglect occurs in more forms than physical abuse<sup>19</sup>. Neglect is a serious clinical syndrome that can have a profound effect on elderly health and quality of life. However, the signs of neglect may mimic the symptoms of commonly found chronic medical conditions in elderly patients<sup>20</sup>. This mistreatment may be more difficult to identify than spouse or child abuse because of the lack of detection guidelines, lack of professional and public awareness, relative isolation of the victims, and reluctance to report an occurrence.

Due to this serious social problem, epidemiological studies by post mortem examination have been conducted in Germany to improve the quality of care, which contain clear available information related to abuse. For example, an epidemiological study used post mortem examination to investigate pressure sores<sup>21</sup>; however, such studies are rare in Japan<sup>22,23</sup>. The aim of this study was to clarify family caregiving problems related to elder neglect in Japan through autopsy cases. In particular, we focused on the effect of family caregiving.

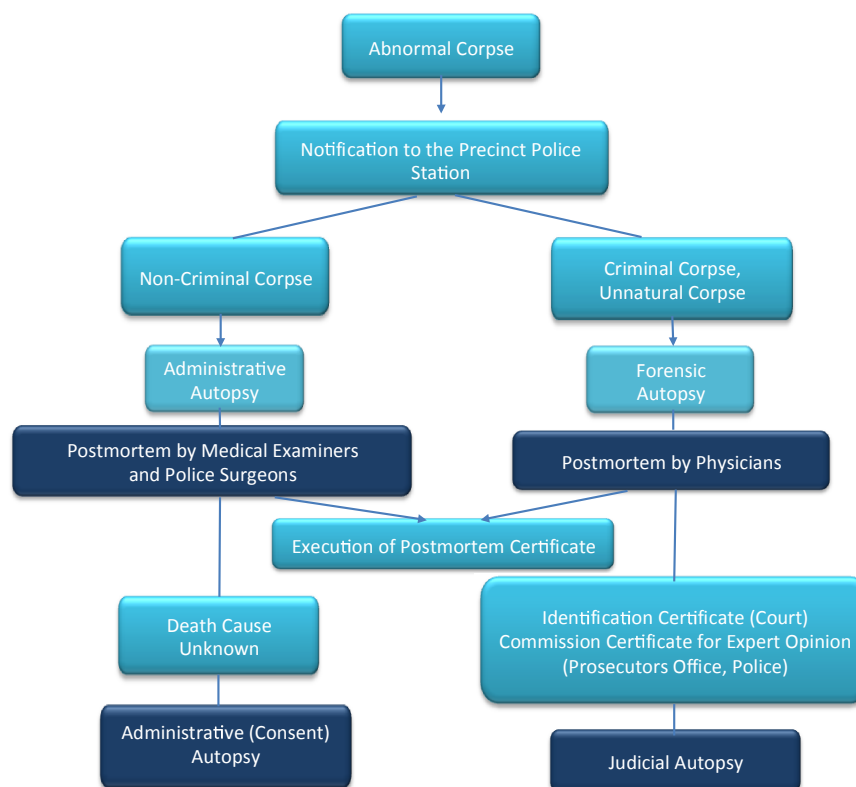
The growth of aged population is accelerated throughout the world, not only in developed countries, but also especially in developing countries. Understanding the situations of elder abuse in Japan where the leading aging society will become lessons for other nations when they will face similar situations.

## 2. RESEARCH METHOD

### 2.1. The systems of forensic autopsies in Japan

In the forensic autopsy system in Japan (Fig.1), except for the examiner's ward, forensic autopsies are initially separated into criminal and non-criminal cases. A criminal case is a legal autopsy case, whereas cases not associated with crimes are administrative autopsies.

Fig.1 System of Forensic Autopsies in Japan



### 2.2. Definition and autopsy sample selection and recruitment

Definitions and terminology for elder abuse vary considerably among studies and laws of different states. According to the definition by World Health Organization (WHO)<sup>1</sup>, such abuse is generally divided into the following categories.

- (1) Physical abuse—inflicting pain or injury, physical coercion, or physical or rug-induced restraint.
- (2) Psychological or emotional abuse—inflicting mental anguish.
- (3) Financial or material abuse—illegal or improper exploitation or use of funds or resources of an older person.
- (4) Sexual abuse—non-consensual sexual contact of any kind with an older person.
- (5) Neglect—refusal or failure to fulfil a caregiving obligation. This may or may not involve a conscious and intentional attempt to inflict physical or emotional distress on the older person.

For example, in the definition of neglect, a physical examination may reveal various types of abuse. Physical indicators of neglect are dehydration or malnutrition, poor hygiene, inappropriate clothing, unattended physical or medical needs, extensive bedsores, urine burns or excoriations and faecal impaction.

We reviewed all autopsies conducted at our institution between 2000 and 2003 at the Tsukuba Medical Examiner's office (n = 178). Persons aged 65 years and over were included in the study. Cases of death with

obvious causes or processes were excluded from the study and cases due to unnatural death, death from clear disease pathology or no family information, traffic accidents, drowning, suffocation, poisoning and alcoholism, other accidents, clear disease, pathology, and solitary living alone were included.

For the sample cases, we obtained the family caregiving information from the administration autopsy case records. We decided on the family caregiving information based on abuse-associated factors from previous studies. The investigative reports, autopsy findings, and all 178 cases were reviewed, and nine cases were classified as elder neglect.

### 2.3. Ethics

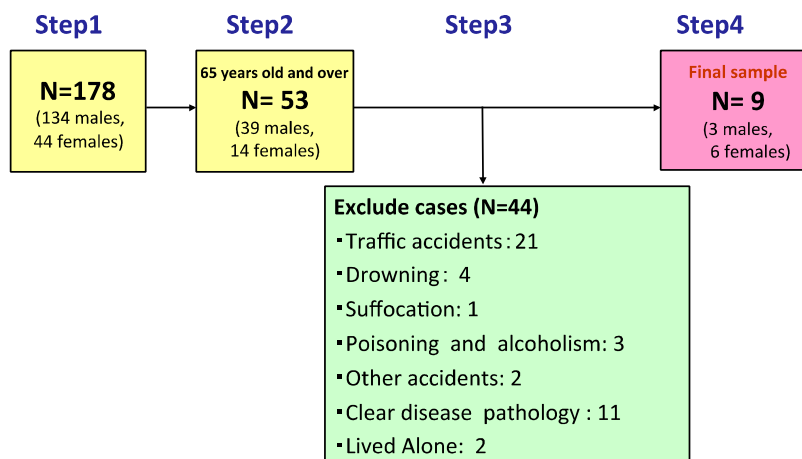
The study protocol was exempted from review by the institutional review board at the University of Tsukuba and Tsukuba Medical Examiner's office.

## 3 ANALYSIS AND RESULTS

### 3.1. Final samples

Our research revealed nine autopsy cases of suspected elder neglect. Of the 178 cases (134 males and 44 females), 53 involved people aged 65 years or older (30%). A careful investigation of these 53 autopsy reports (39 males and 14 females) allowed us to exclude the obvious causes of death and unsuspected abuse. Excluded cases were 44 cases of traffic accidents ( $n = 21$ ), drowning ( $n = 4$ ), suffocation ( $n = 1$ ), poisoning and alcoholism ( $n = 3$ ), other accidents ( $n = 2$ ), clear disease pathology ( $n = 1$ ), solitary living ( $n = 2$ ). The final sample of suspected neglect comprised of nine autopsy cases (three males and six females) (Fig.2).

**Fig.2 Autopsy sample selection and recruitment**



### 3.2. Elder's characteristics

The neglected victims' median age was 83 years (3 males and 6 females; range, 68–91 years). According to the autopsy reports, two cases were severely starved, two were putrefied or mummified, three had pressure sores, two had dementia, and three had difficulty performing the activities of daily living.

### 3.3. Family member's characteristics and family background

The age of caregivers' (8 males, 1 female) ranged in age from 27 to 76 years with a median age of 52 years. Each victim had lived with one family member: their sons in five cases, and a grandson, brother, wife or husband in one case each. The caregiver's health conditions were depression (n = 2), alcoholism (n = 1), dementia (n = 1) and chronic illness (n = 1). The caregiver's backgrounds were unemployed (n = 5) or the family incomes were very low (n = 3). All cases had two family members. Their economical situations were social security (n = 2) and unable to pay rent (n = 1) (Table. 1.2).

## 4. DISCUSSION

This report focused on the family background of the elderly who were neglected by family members acting as their caregivers. We found that people who neglected the elderly were almost always males, especially sons. Moreover, all cases had two family members. Some caregivers were depressed, alcoholic, and unemployed, whereas some elderly had dementia and pressure sores.

### 4.1. Risk factors of elderly neglect

Our study has indicated that, in many of the cases where neglect had been suspected, the elderly victims were living with their male family members, especially their sons. In the present study, all cases occurred in two-person households. According to the studies conducted so far in Japan, the majority of abusers have been presumed to be victims' spouses or daughters-in-law who are engaged in caregiving; however, this result seems to be influenced by the fact that the majority of these preceding studies conducted in Japan are based on small-scale samples. In addition, the bias pertinent to sampling problems may also have influenced the result. A Japanese nationwide survey implemented in 2004<sup>19</sup> on domestic abuse against the elderly revealed that 32.1%, i.e. the majority of the total cases of recognized elder abuse were perpetrated by victims' sons. The result obtained in the present study therefore has concurred with that of the nationwide survey with respect to the identity of the abusers.

**Table.1 Characteristics of suspected elderly neglect and family member (n = 9)**

Variable	Elderly people		Family member	
Median age (range)	83 years (68–91)		52 years (27–76)	
Sex	Male	3	Male	8
	Female	6	Female	1
Relationship to elderly people			Son	5
			Wife	1
			Husband	1
			Brother	1
			Grandson	1
Health status*	Bed ridden	3	Depression	2
	Dementia	2	Alcoholic	1
	Pressure sores	3	Mental retardation	1
	Severely starved	2	Chronic illness	1
	Putrefied Mummified	2		
Household	Two		9	
Financial status	Social security		2	
	Unemployed		5	

\*multipul answer

**Table.2 Characteristics of suspected elder neglect and family member of 9 cases**

Case	Elderly people									Family caregiver				Household		
	Age (years)	Sex	Cause of death	Previous illness	BMI	Dementia	Bed ridden	Pressure sore	Other	Caregiver	Age (years)	Job	Physical condition	Other	Family member	Financial condition
1	68	M	Suspected congestive heart failure	Depression		-	-	-	Putrefied	Brother	66		Depression		2	
2	75	M	Chronic alcohol liver disease	Liver disease	17.1	-	-	-	Severely starved	Son	42		Alcoholic		2	
3	78	F	Coronary thrombosis	High blood pressure		-	-	-		Husband		no			2	Social security
4	81	F	Suspected parkinson's disease	Parkinson's disease		-	+			Son		no	Depression	Committed suicide (by hanging)	2	
5	83	F	Congestive heart failure	Congestive heart failure	18.1	-	+	+	Bruises and scratches on the body, severely starved	Son	49		Mental retardation	No bathed in 10years	2	Social security
6	83	M	Unknown	Cerebrovascular accident		+	-	-	Mummified	Wife	76	no			2	Expulsion order
7	89	F	Pneumonia	No	13.4	-	+	+	Fractured rib	Son	52	no			2	
8	91	F	Coronary arteriosclerosis	Heart hypertrophy	18.6	+		+		Son	58	No	Chronic illness		2	
9	91	F	Fire	Unknown	15.4					Grandson	27			No communication	2	

We have postulated why the majority of suspected family abusers had been male caregivers, particularly victims' sons, to be as follows. The first would be the changing role of gender in the conventional Japanese perception in which family care was deemed to be particularly a task mainly for women. In general, male caregivers have had little experience in housework compared with their female counterparts<sup>24</sup>, thus probably feel more burdens from daily household chores than women do. Besides, it is highly likely that men are benefiting less from social support than women are. This is also evidenced by the aforementioned nationwide survey on domestic elder abuse. In terms of the caregiving environment for each relative, 25.7% of son caregivers, i.e. the highest, responded that they had "no one to cooperate or consult with regarding their caregiving". In addition, all of the cases in the present study occurred in two-person households, which indicates inferior care and exacerbates the risk of abuse by few human contacts.

Furthermore, the family members living with the elderly in the present study included cases of depression, alcoholism and mental retardation. Homer has reported that alcoholism of caregivers is the most palpable predictor of elder abuse<sup>25</sup>. According to Wolf<sup>14</sup>, 31% of alleged abusers have a previous history of mental disorder, whereas 43% have suffered from drug-related problems. As evidenced by the above, the results of the present study correspond to those of the preceding studies with regard to the risk factors from the perspective of caregivers. In addition, almost all of the subject family members living with the elderly in the present study were unemployed, hence signifying the possibility that they had been living under severe economic conditions with no sundry livelihood support such as welfare service. In other words, it appears highly likely that the subjects in the cases of the present study had been in a state of social isolation.

Change in family structure in recent years has resulted in an increasing number of male caregivers, and the trend is believed to be intensifying. According to a large-scale survey on caregiving for the elderly implemented by the National Alliance for Caregiving (US), male caregivers accounted for 27% of the total<sup>26</sup>. The figure in Japan was reported to be 28.1% in the National Livelihood Survey conducted in 2007<sup>27</sup>. In parallel with population strategy, it will be imperative to take active measures for such high-risk targets as identified in the present study, that is to say male caregivers who are engaged in caregiving under an environment where little or no support is available.

#### 4.2. The issues and provision of policy for elder abuse and neglect in Japan

In Japan, the first national survey of elder abuse in the home was conducted in 2003. Moreover, a provision for the prevention of abuse, neglect and exploitation was established in “The elder abuse prevention and caregiver support law” in 2004. However, this law imposes an obligation to notify authorities to those who discovered the abuse only when the elderly are in serious jeopardy. Besides, there are no punitive clauses specifying the penalty for neglecting this obligation with some clauses merely encouraging discoverers to make the effort to report. Nevertheless, the fact that such a law was enacted is of extreme significance as it clearly manifests a grave human rights violation stemming from elder abuse, which has been occurring behind closed doors. The law therefore has enlightenment value. It is also deemed to be the law intended to support caregivers, further epitomising its epoch-making nature. Nonetheless, the prevention and early detection of elder abuse through more effective enforcement of this law requires more active engagement in bureaucratic reduction, discovery effort, and reporting.

#### 4.3. Limitations and future research

The present study has a few limitations that need to be addressed. First, the data reported here might not be representative of elderly population in terms of at least autopsy cases. In previous studies pointed out that autopsy cases population were low social classes. Therefore, our sample of elderly and family may be possibility bias. Second, final sample size of the present study were small. Further research should be increased in data sample. Third, we were unable to examine by rural area.

Further research should explore other location, such as urban, semi-urban area.

On the other hands, despite these limitations, the present study has noted strength and will enhance the literature of elder abuse. In sum, the data of the present study has autopsy cases data, reliable by comparison with data in other studies that subject in investigation were family caregiver or public health nurse. This study, therefore, is considered to confirm an important aspect of the support for the family caregivers.

### 5 CONCLUSION

This investigation indicated that elderly parents living with their sons are a high-risk group for neglect. This survey of autopsy cases revealed that provision of family support, especially for the socially isolated cases are required. Autopsy cases provide valuable information for public health. We should use this information effectively for the prevention of autopsy cases in the future.

### ACKNOWLEDGEMENTS

The authors thank Dr.Ohashi, at the University of Teikyo Heisei (former Tsukuba Medical Examiner’s office) for his academic comments as a specialist of Forensic Medicine. This study was partially supported by the Grant-in-Aid for Scientific Research of the Ministry of Health, Labour and Welfare (H24-Chikyukibo-ippan-001) Challenges of global ageing without borders: Studies on the recommendations by an interdisciplinary network originating in Japan to support the sharing of experiences and mutual respect. And the authors thank members in Department of Health Service Research in Faculty of Medicine, University of Tsukuba, for their kind advice regarding the analyses and discussion.

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