

Self-Neglect

Vulnerablility and Risk Factors
Associated with Self-Neglect of the Elderly

By

Sharon M. Beall, R.N., B.S., B.S.N.

The Masters Research Project

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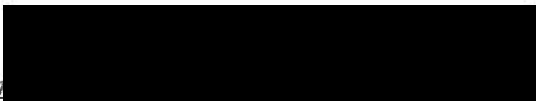
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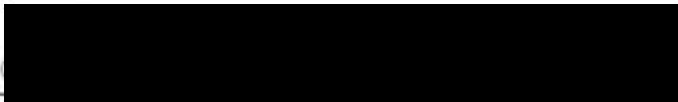
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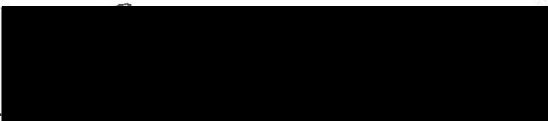
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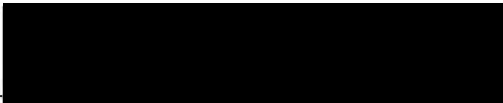
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APPROVED:


Patricia G. Archbold, R.N., D.N.Sc., Thesis Advisor


Jane M. Kirschling, R.N., D.N.Sc., First Reader


Virginia P. Tilden, R.N., D.N.Sc., Second Reader


Carol A. Lindeman, R.N., Ph.D., Dean, School of Nursing

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V. P. Tilden, R.N., D.N.Sc.

and

C. A. Tanner, R.N., Ph.D.

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Introduction

Self-neglect or the inability to care for oneself in a way that meets societal expectations was first identified in the literature during the early sixties.¹⁻³ Although the prevalence of self-neglect is unknown, estimates suggest that 7%-20% of persons 60 years of age and older need some assistance with activities of daily living.^{2,4-6} Assistance from the public sector, when provided to persons unable to care for themselves, is known as adult protective services.

Review of Literature. Isaacs⁹⁻¹⁰ was one of the first to describe a population of chronically ill geriatric patients who received "insufficient basic care" (defined as warmth, cleanliness, safety, and food). His patients were unable to provide adequate care for themselves at a level consistent with their needs. In the protective service literature, the "typical" case of self-neglect requiring protective services involved a female 75 years of age and over.^{3,6-9} She was Caucasian, widowed or single,⁶⁻¹⁰ and lived alone.^{1-3,6-10} Oftentimes defective decision-making resulted in an inability to recognize her own need for assistance and/or to manage personal affairs.⁶⁻¹⁰ As yet, empirically derived vulnerability and risk factors for self-neglect have not been identified.

Purpose. This study addresses this gap in the literature by identifying vulnerability and risk factors associated with a diagnosis of self-neglect. The conceptualization of

vulnerability and risk for this research is taken from Rose and Killien.¹¹ Vulnerability factors are defined as individual traits or characteristics of the older person that increase his/her likelihood of self-neglect. Risk factors are the interactions between the older person and other individuals and/or the environment that may result in self-neglect.

Although data were collected for a larger research project that focused on both elder abuse and self-neglect, this paper focuses exclusively on self-neglect among older persons. The following research questions guided this study. What are the differences in patterns of vulnerability and risk associated with a diagnosis of substantiated self-neglect and unsubstantiated self-neglect in persons 65 and over living in the community? What referral patterns are associated with caseworker determination of substantiated and unsubstantiated self-neglect?

Methods

The research questions were addressed by conducting a secondary analysis of data contained in state report forms used to record the self-neglect investigation. State administrative rules placed the self-neglectful individual in the state's "protective service" category for investigations. The self-neglectful person required investigation for protective services because he/she was "in danger of harm or neglect from self or other."¹² In the state in which data were collected,

psychological and financial abuse or neglect perpetrated by others were included in the protective service category with the self-neglect investigations, and therefore were included in this analysis.

The caseworker's investigation of reported self-neglect had several steps: (1) a self-neglect complaint was made, (2) a caseworker investigated the complaint, (3) a diagnosis was made, and (4) referrals were recommended. This study focused on reports in which a "substantiated" (the caseworker determined that self-neglect was evident) or an "unsubstantiated" (the caseworker determined that self-neglect was not evident) diagnosis was made. The report forms contained demographic information and narratives with subjective and objective observations written by the caseworker. These data were analyzed using content analysis procedures. 13-15

Sample. Two hundred report forms were randomly selected from 795 elder abuse and protective service cases investigated in a rural Western state during 1985. Of these 200 forms, 131 were reports of protective service investigations and 69 were elder abuse reports. Of the 131 protective service reports, 33 had a missing diagnosis and 20 had a questionable diagnosis. The final sample consisted of 78 report forms in which a clear diagnosis of substantiated (n=21) and unsubstantiated (n=57) self-neglect was present.

Persons identified in the 78 reports ranged in age from 65-95 years. The reports described 54 women and 24 men who had a variety of functional, physical, and mental disabilities. Most of the individuals lived alone (56%) but many received support with activities of daily living from families (68%), friends or neighbors (59%), and/or community agencies (50%).

Procedures. A coding sheet ¹³⁻¹⁵ containing lists of demographic characteristics, vulnerability factors, risk factors, indicators of self-neglect, and recommended referrals was developed in order to collect data systematically. The coding scheme was based on reviews of the literature, 20 report forms, three existing vulnerability instruments focusing on home care, ¹⁶⁻¹⁸ and upon suggestions of caseworkers. The coding sheet was reviewed by experts, pretested by reviewing 50 report forms, and revised for clarity. Discrete, independent, and mutually exclusive categories and subcategories of vulnerability and risk factors evolved which allowed the content of the reports to be separated for analysis. ¹³⁻¹⁵

Statistical Analysis. Following data collection, data were collapsed, then divided into two groups according to the substantiated and unsubstantiated diagnoses. The chi-square statistic was used to analyze the differences between the group diagnosed as substantiated in self-neglect and the group diagnosed as unsubstantiated in self-neglect on key vulnerability and risk factors, indicators of self-neglect, and

the caseworker referrals. A significance level of $p < .05$ was established.

Results

The results are reported in five subsections: demographics, vulnerability factors, risk factors, indicators of self-neglect, and referrals. The substantiated and unsubstantiated groups were compared on five demographic characteristics, eight vulnerability factors, six risk factors, four indicators of self-neglect, and six referrals (see Table 1).

Demographics. In this sample the mean age was 79.8 years; 68% were 75-89 years of age. Almost one third of the sample were men ($n=24$), three fourths lived in an urban region of the state, and one-third of the sample were veterans as indicated by billing status. No significant differences were found between the substantiated or unsubstantiated groups on the variables of age, gender, residence in an urban setting, or billing status (see Table 2).

Vulnerability Factors. Significant differences between the substantiated and unsubstantiated groups were found on four vulnerability factors as indicated in Table 3. Aspects of health status such as being weak or in poor health, having recent changes in health, being hospitalized, or experiencing recent falls were mentioned more frequently in the substantiated group than in the unsubstantiated group ($\chi^2=8.57$; $p < .01$). The groups also differed significantly in the

Table 1

Category and subcategory labels of self-neglect used for Chi-square analysis.

<u>Demographic Characteristics.</u>	
Age	Functional status
Gender	Billing status
Residence	
<u>Vulnerability Factors.</u>	
Medical diagnosis	Lifestyle
Health status	Problem with personal care
Cognitive impairment	Problem with nutrition
History of self-neglect	Problem with meal planning and preparation
<u>Risk Factors.</u>	
Family support	Living arrangement
Friends/neighbors support	Problem with home maintenance
Community services support	Unsafe environment
<u>Indicators of Self-Neglect.</u>	
Physical injury or problem	Indication of self-neglect
Psychological harm	Financial mismanagement
<u>Referral Patterns.</u>	
Referral recommended	Law enforcement agency
Health care services	Relocation
Referral to family	Legal services

Table 2

Demographic information in substantiated and unsubstantiated groups of self-neglect.

<u>Demographics</u>	<u>Substantiated</u> (n=21)		<u>Unsubstantiated</u> (n=57)		<u>df</u>	<u>χ^2</u>
	<u>N</u>	<u>(%)</u>	<u>N</u>	<u>(%)</u>		
<u>Age (n=71) ^a</u>						
65-69	1	(5)	4	(8)		
70-74	4	(22)	6	(11)		
75-79	5	(28)	13	(24)		
80-84	3	(17)	12	(23)		
85-89	5	(28)	10	(19)		
90-94	0	(0)	8	(15)	5	4.71
<u>Gender</u>						
Female	14	(67)	40	(70)		
Male	7	(33)	17	(30)	1	.00
<u>Residency ^b</u>						
Urban	16	(76)	42	(74)		
Rural	5	(24)	15	(26)	3	1.24
<u>Billing Status (n=66) ^c</u>						
VA	5	(29)	18	(37)		
Medicare	2	(12)	2	(4)		
Medicaid	2	(12)	3	(6)		
Private	8	(47)	26	(53)	3	2.04

a. 7 cases missing from the report forms.

b. Residency included two urban and two rural regions of the state.

c. 12 cases missing from report forms.

Table 3

Vulnerability factors in substantiated and unsubstantiated groups of self-neglect.

<u>Factors</u>	<u>Substantiated (n=21)</u>				<u>Unsubstantiated (n=57)</u>				<u>df</u>	<u>χ^2</u>
	<u>N</u>	<u>(%)</u>	<u>Not Mentioned</u>	<u>(%)</u>	<u>N</u>	<u>(%)</u>	<u>Mentioned</u>	<u>Not Mentioned</u>		
Health Status	17	(81)	4	(19)	23	(40)	34	(60)	1	8.57**
Cognitive Impairment	15	(71)	6	(29)	24	(42)	33	(58)	1	4.17*
History of Self-Neglect	7	(33)	14	(67)	3	(5)	54	(95)	1	8.45**
Problem with Personal Care	9	(43)	12	(57)	7	(12)	50	(88)	1	7.02**

*p<.05; **p<.01

vulnerability factor of cognitive impairment with factors of mental illness, mental retardation, confusion or delusions/hallucinations mentioned more frequently in the substantiated group than in the unsubstantiated group ($\chi^2=4.17$; $p<.05$).

The substantiated group was found to be significantly different from the unsubstantiated group on the vulnerability factors of history of self-neglect and problem with personal care ($\chi^2=8.45$; $p<.01$ and $\chi^2=7.02$; $p<.01$, respectively). These vulnerability factors were indicated less frequently in the substantiated group than in the unsubstantiated group. However, history of self-neglect was mentioned in 33% of the substantiated cases and a problem with personal care such as grooming, hygiene, or dressing was mentioned in 43% of the substantiated cases.

Risk Factors. Significant differences between the substantiated and unsubstantiated groups were apparent in the risk factors of problem with home maintenance and unsafe environment. A problem with home maintenance, such as marginal living conditions, cluttered or dirty, vermin or feces, or 'lives in only one room' was mentioned in 10 cases with a substantiated diagnosis and in 6 cases with an unsubstantiated diagnosis ($\chi^2=10.77$; $p<.01$) (see Table 4). Unsafe environment referred to inadequate utilities, hazardous conditions for fires or falls,

Table 4

Risk factors in substantiated and unsubstantiated groups of self-neglect.

<u>Risk Factors</u>	<u>Substantiated (n=21)</u>				<u>Unsubstantiated (n=57)</u>				<u>df</u>	<u>χ^2</u>	
	<u>Mentioned</u>		<u>Not Mentioned</u>		<u>Mentioned</u>		<u>Not Mentioned</u>				
	<u>N</u>	<u>(%)</u>	<u>N</u>	<u>(%)</u>	<u>N</u>	<u>(%)</u>	<u>N</u>	<u>(%)</u>			
<u>Problem with</u>											
Home Maintenance	10	(48)	11	(52)	6	(11)	51	(89)	1	10.77**	
<u>Unsafe</u>											
Environment	15	(71)	6	(29)	20	(35)	37	(65)	1	6.79**	

**p<.01

homicidal or suicidal threats. These factors were mentioned in 71% of the substantiated cases compared with 35% of the unsubstantiated cases ($\chi^2=6.79$; $p<.01$).

Indicators of Neglect. Indicators of Neglect was divided into the four subcategories of "physical injury or problem," "psychological harm," "self-neglect," and "financial mismanagement" to reflect the state's definition and administrative rules.¹² Table 5 shows that physical injury or problem was mentioned in 48% of the substantiated self-neglect group but in only 7% of the unsubstantiated group ($\chi^2=14.53$; $p<.01$). The substantiated group differed significantly from the unsubstantiated group on indication of self-neglect ($\chi^2=12.63$; $p<.01$). In 91% of the substantiated cases indication of self-neglect was evident when words, phrases, or themes indicating inadequacies in personal care, medical care, supervision, and/or home maintenance, and harm or threat of harm to self or other were identified by the researcher. There was no significant difference between substantiated and unsubstantiated groups on either indication of psychological harm or indication of financial mismanagement.

Referrals. The final subsection of results focuses on the referrals recommended by caseworkers after the investigation. A significant difference was found between the substantiated and

Table 5

Indicators of Neglect in substantiated and unsubstantiated groups of self-neglect.

<u>Indicators of Neglect</u>	<u>Substantiated (n=21)</u>			<u>Unsubstantiated (n=57)</u>			<u>df</u>	<u>χ^2</u>
	<u>Mentioned</u>	<u>N</u>	<u>(%)</u>	<u>Not Mentioned</u>	<u>N</u>	<u>(%)</u>		
Physical Injury								
or Problem	10	(48)	11	(52)	4	(7)	53	(93)
							1	14.53**
Indication of								
Self-Neglect	19	(91)	2	(9)	24	(42)	33	(58)
							1	12.63**

**p<.01

the unsubstantiated groups on relocation and legal services. Relocation was recommended for 62% of the substantiated group, but the unsubstantiated group was referred for relocation in only 28% of the reports ($\chi^2=10.87$; $p<.05$) (see Table 6). In addition, referrals for legal service were recommended in 43% of the substantiated cases and in 14% of the unsubstantiated cases of self-neglect ($\chi^2=5.88$; $p<.05$).

Discussion

This study was undertaken to compare substantiated and unsubstantiated report forms describing self-neglect on key vulnerability and risk factors, indicators of self-neglect, and referrals. Conceptual definitions of vulnerability factors, the inherent traits or characteristics that increase an older person's likelihood of self-neglect, and risk factors, the environmental interactions that increase the person's likelihood of self-neglect, were taken from Rose and Killien.¹¹ A secondary analysis of state report forms describing the self-neglect investigation was conducted using content analysis procedures. The chi-square statistic was then used to determine significant differences between the substantiated and unsubstantiated groups on the key factors.

Although significant differences in demographic data between the two groups were not found, this information was important in that it suggested independence of the personal characteristics of the older individual in relation to a substantiated or

Table 6

Referrals for substantiated and unsubstantiated groups of self-neglect.

	<u>Substantiated</u>		<u>Unsubstantiated</u>			
<u>Referrals</u>	(n=21)		(n=57)		<u>df</u>	<u>χ^2</u>
	<u>N</u>	<u>(%)</u>	<u>N</u>	<u>(%)</u>		
<u>Relocation</u>						
Family	1	(5)	2	(3)		
Sheltered						
Living	8	(38)	5	(9)		
Refused	4	(19)	9	(16)		
No Referral	8	(38)	41	(72)	3	10.87*
 <u>Legal Services</u>						
Recommended	9	(43)	8	(14)		
No Referral	12	(57)	49	(86)	1	5.88*

*p<.05

unsubstantiated diagnosis of self-neglect. In this sample, the demographic variables of age, gender, residency, and billing status did not increase the likelihood of being diagnosed for self-neglect.

In contrast to the literature which indicates a lack of, or insufficient assistance from, formal and/or informal support systems, ^{7,9,10,16} the majority of the subjects described in the report forms analyzed for this study were receiving support from family, friends, neighbors, and/or community agencies. This finding related to social support might suggest that the potential for self-neglect is not limited to the isolated older person, that support systems improve surveillance, and/or that the needs of the older person change and may exceed the capability of available social support systems. Additionally, the older person may have refused support or alienated supporters in the past. ^{9,10}

A majority of reports in this study indicated that the older individuals were frail. In the substantiated and unsubstantiated groups, one or more medical diagnoses were mentioned for 56% (n=44) of the sample investigated; at least one medical diagnosis was indicated in three quarters of the substantiated cases (n=16). This suggests a population that might require contact with health care professionals.

Although not significantly different, the analysis of the subcategory functional status indicated that three quarters of

the sample (n=52) were able to ambulate unassisted, with assistive devices or with another's assistance. After collapsing data, ambulatory referred to those individuals who ambulated unassisted which included those who wandered and became lost (walking or driving) or meandered across streets and along roads without concern for their personal safety. Although the frequency of wandering activity was minimal, the gravity of the wandering behavior makes this an important vulnerability factor because of the older person's lack of concern for personal safety. Therefore, wandering behaviors are important in the nursing assessment of older adults living in the community.

The vulnerability factors of health status and cognitive impairment, and the risk factor of unsafe environment have been identified in this study to be significant factors differentiating the substantiated group from the unsubstantiated group. These findings concur with the protective services literature which describes these as characteristics of the self-neglectful individual ^{1,2,4,6-8} and suggests that health status, cognitive impairment, and unsafe environment are critical aspects of substantiated self-neglect.

The vulnerability factors of history of self-neglect and problems with personal care and the risk factor of problem with home maintenance were mentioned in the substantiated group over 30% of the time. This may warrant the conclusion that these

factors are ones considered central by the caseworkers in their determination of a substantiated diagnosis of self-neglect. The fact that these vulnerability and risk factors are seldom mentioned by the caseworker in the unsubstantiated report narrative may be related to non-applicability to the case being investigated, an oversight in the assessment or documentation of the investigation, the general lack of evidence to substantiate the case, or to the personal values and beliefs of the caseworker which may influence the diagnosis of self-neglect.

The investigation and diagnosis of self-neglect requires an objective assessment and a non-judgmental attitude as professionals seek to practice with beneficence (doing good for others) while not inflicting harm (nonmaleficence). As stated by Gilbert,²¹ the older person's autonomy or self-determination must be maintained and weighed with the rights of the community. These three ethical principles result in dilemmas for health care and social service professionals when personal values, beliefs, and attitudes interfere with an objective assessment of the situation. While autonomy and nonmaleficence promote a safeguard against societal demands for conformity, beneficence requires that professionals protect the older person, as well as the community, from harm.

Indicators of Neglect was a category developed to summarize the caseworker narratives and to reflect the state administrative rules and definitions of protective services. The indications of physical injury or problem included decubiti

relocation, but the substantiated group received more frequent recommendations for relocation to sheltered living environments than the unsubstantiated group received. This might indicate that the substantiated group are more likely to require referrals for relocation to enhance their safety.

As one would expect, referrals for legal services were seldom recommended for the unsubstantiated group. However, referrals for conservatorship/guardianship/power-of-attorney proceedings, attorney services, or commitment did occur for 43% (n=9) of the substantiated group. This finding suggests that the self-neglectful individual may require more than supportive services and ongoing monitoring to continue living in their chosen environment.

Qualitative data from the narratives indicated that the principle of self-determination for the older person guided many referrals made by caseworkers. In some instances, acceptable, less restrictive referrals were necessary initially so that refusal of services would not occur. Attempts on the part of the caseworker to establish a trusting relationship and gain entree' to the residence were apparent in many narratives. The report forms indicated that the caseworkers attempted to provide appropriate services whenever possible; sometimes follow-up visits were the only acceptable alternative to the older person.

Interestingly, although a referral for relocation or commitment might suggest imminent danger, not every caseworker

recommending relocation or commitment diagnosed the case as substantiated for self-neglect. The phenomenon of self-neglect is complex as these data suggest and based on the number of self-neglect cases with questionable (n=20) or missing diagnoses (n=33).

Limitations. The results of this study must be viewed with caution due to several limitations. First, the sample size is small and generalizability is limited to the 1985 state report forms of one state. Second, the state definition of protective services provides a discretionary rule, not a mandatory law for reporting and investigating potential self-neglect cases. Unfortunately, one cannot assume that all potential self-neglectful older persons were reported or investigated. Additionally, the criteria for protective services includes activities by alleged perpetrators which are considered in other states to be elder abuse, not self-neglect. Third, the state report form is a non-systematic recording (a narrative) of the investigation with diagnoses based on expert judgments by caseworkers; therefore, consistency of data across narratives and consistency in diagnosis, given the same case information, may differ based on previously described caseworker differences, knowledge, and experience. In addition, the report form used by the state was not designed to answer the research questions as posed by this research project ¹⁹ and factors which were not identified in the coding sheet may have influenced the caseworker diagnosis.

Conclusion

Future research studies of the self-neglect phenomena are important as the number of frail elderly living in community settings continues to increase. Comparative data based on a diagnosis of self-neglect are needed in this area of research to determine the relationships among diagnoses and key variables such as health status, cognitive impairment, problem with home maintenance, problem with personal care, and unsafe environment. Using this study as a framework for continued research, clarification of the relationships between these and other key vulnerability and risk factors and the diagnosis of self-neglect may provide diagnostic cues for self-neglect.

A model describing the decision-making processes used by caseworkers and nurses when a potential self-neglect case is identified could also be developed. Such a decision-making model, similar to the model developed by Phillips and Rempusheski ²⁰ for diagnosing elder abuse, could provide more consistency in assessments, diagnoses, and referrals. With consistency in identification of self-neglect, a profile of the individual most susceptible might be determined and prevention of self-neglect could be addressed. Additionally, long-term planning for an aging population could focus more specifically on acceptable alternatives for the older person desiring independent living.

Nursing Implications. Nursing assessment of the elderly based on vulnerability and risk factors, as defined by Rose and Killien ¹¹ may assist in the detection and/or prevention of self-neglect. Because this assessment involves the individual and his/her environment, the person's health and social well-being can be monitored more holistically. Assessing availability and utilization of social support by the older person was not a specific focus of this study but could be addressed in future research to determine the effectiveness of interventions.

Nurses working in home health, emergency rooms, physician offices, clinics, and as discharge planners in acute care or skilled care facilities may identify the vulnerability and risk factors of self-neglect. The nurse-advocate who recognizes vulnerability and risk factors associated with self-neglect may successfully intervene with appropriate and acceptable services for the older individuals, thereby enhancing their health and resources in their environment.

In summary, self-neglect is a complex and emotionally charged issue that faces many elderly persons at some point in their lifetime. A comprehensive nursing assessment including vulnerability and risk factors is essential for the older person's continued health and well-being.

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Appendix A

Expanded Methods Section

The procedures for sampling, data collection, and the analysis will now be explained in more detail. This descriptive study used content analysis of secondary data to address the research problem. Specifically, a content analysis of the Oregon Elder Abuse/Neglect report forms (SSD 723 and SSD 723A) (see Appendix B) provided a medium for identification of vulnerability and risk factors associated with substantiated cases of self-neglect.

In order to use content analysis procedures, a consistent approach to the coding of data contained in caseworker narratives was necessary. These narratives, written by trained caseworkers, reflected their investigation of the self-neglect cases reported to the Senior Services Division. A structured data collection coding sheet minimized researcher bias and maximized reliability. Qualitative data were extracted from the narratives verbatim and recorded on the coding sheet (Budd, Thorp, & Donohew, 1967) for future analysis.

Sample. The data for this study was obtained from a random sample of 200 Oregon "Complaint Forms" (SSD 723) and "Complaint Investigation Reports" (SSD 723A) included in the 1985 statistics for the state. In addition to demographic data, the report forms contained two blank sections for narratives that described the problem (as reported by the complainant), and the investigative process. Caseworker diagnosis of the case and

their recommended referrals following the investigation were also available on the report forms.

The confidential information section on the Complaint Form was explicitly identified with words and solid lines. This section of the form contained demographic characteristics. Written permission was obtained from the Program Coordinator of the Senior Services Division to use specific non-identifying demographic information such as age, gender, medical status (see Appendix C for correspondence with the Senior Services Division).

The second area of the form identified the month and year of the report and was noted on the coding sheet to assure that the case was included in the 1985 statistics. The "Description of the Problem," which summarized the complainant's concerns was not used in this study; however, qualitative data were extracted from this section.

The second page included the "Narrative: Action taken and findings" which contained the caseworker's assessment of the older person and his/her environment. This was the major source of data for the study and the most complex section of the form. The accurate coding of data from this narrative was complicated for two reasons: the uniqueness of each case and the reporting style of each caseworker.

The "Actions and Findings" were found in one of two sections on the form. Some caseworkers included this

information at the end of the narrative, others indicated findings by using the check boxes below the narrative section. The final section of the form that was included on the coding sheet was the notification of law enforcement agencies.

Sampling Procedure. Due to investigator limitations of time and money, a random sample of 200 (25%) of the nearly 800 1985 reports was drawn for data collection and analysis.

Randomization was accomplished by using the random numbers table to select two numbers; these numbers, two and 14, were drawn with eyes closed. The number two determined a starting point in the first file drawer for the initial count; thereafter, every fourteenth report was content analyzed and replaced until 200 reports were selected.

Coding Sheet. A detailed category development of vulnerability and risk factors was derived from a review of the literature on elder abuse, self-neglect, the frail elderly living in community settings, and vulnerability assessment tools. Additionally, information was obtained through interviews with caseworkers, Senior Services Division staff, and through participation in the Multnomah Adult Protective Services Coalition. This information formed the basis of the coding sheet used for data collection (see Appendix D).

The coding sheet contained five major categories that were designed to be independent, discrete, and mutually exclusive. The major categories were the (1) case demographics (DEM),

(2) narrative vulnerability factors (NVF), (3) narrative risk factors (NRF), (4) indicators of abuse and neglect (IAN), and (5) referrals or outcome (OTC).

These five major categories were expanded to provide subcategories which defined specifically the data to be collected. Due to the nature and complexity of the symbolic communication that was studied, the subcategories were also discrete, independent, and mutually exclusive and were designed to reflect the circumstances of each case investigated. For example, the risk factor category included the following subcategories: social status, living situation, problems with home maintenance, and unsafe environment. Using this descending order for data categorization, the co-occurrence of the subcategories remained recognizable and data loss was minimal (Krippendorff, 1980). The level of specificity of the coding sheet enabled the researcher to record the caseworkers' investigations and assessments as accurately as possible.

The written message, contained on the two report forms described previously, was limited by the boundary of the physical forms; therefore, the boundary of the report forms defined the boundary of the data to be collected. However, because of the nature of the study (elder abuse and self-neglect), the circumstances of each investigation, and the need for inclusive subcategories, the absence of a subcategory from the narrative was not considered to be missing data.

Consequently, the coding sheet was devised to reflect that a subcategory was mentioned, suggested, not applicable, or not mentioned. Prior to data analysis the codes for mentioned and suggested were collapsed as were the codes for not mentioned and not applicable. These coding and data handling techniques minimized researcher inferences beyond the documentation of the caseworker and prevented the elimination of cases due to missing data (Krippendorff, 1980).

Recording. The coding sheet reflected subjective and objective observations of human experiences recorded by the caseworkers after their investigations. In order to analyze the data that appeared on the report forms, the data had to be identified and transcribed onto the coding sheet. The accurate collection of data was essential and became more systematic with the codebook and written procedures (Appendix D).

Research Procedures

A formal letter was mailed to the Elder Abuse and Protective Services Program Coordinator (see Appendix C). requesting permission to use the report forms for research purposes. After the research proposal was reviewed by the Human Subjects Committee at The Oregon Health Sciences University (Appendix E), a copy of the proposal and the coding sheet were mailed to the Program Coordinator and the Senior Services Division Administrator. The program coordinator reviewed the proposal and coordinated with the researcher the

time and dates for data collection. Data collection occurred at the Salem office for seven days in April 1986. A summary of the research findings will be forwarded to the agency upon completion of the study.

Data Collection

The 200 report forms were reviewed individually for demographic data, the presence or absence of each subcategory, and noteworthy qualitative data. As each form was reviewed four times, these data were recorded onto the coding sheet. The codebook was used as each report form was reviewed to ensure that the presence or absence of the subcategories was indicated accurately on the coding sheet.

Missing data were indicated only when the caseworker did not respond to a specific question on the report form. These specific questions included the demographic information, notification of a law enforcement agency, and the caseworker diagnosis. Unfortunately, the report forms without a diagnosis of elder abuse or self-neglect (n=46) and seven report forms that were reviewed unknowingly more than one time were later eliminated from the analysis.

Before the report form was replaced, verbatim comments of the complainant or the victim and statements indicating attitudes or values of the caseworker were recorded on the coding sheet. These statements and the person making the comment were written under "qualitative data" and are available for future analysis.

Reliability and Validity

Reliability and validity for this study was addressed in two ways. The first was the inclusion of significant categories and subcategories in the coding sheet, the second was the identification of relevant data during data collection. The systematic development of the coding sheet provided a means for consistently and accurately obtaining pertinent data. Stability, consistency, and accuracy during data collection were enhanced by researcher familiarity with the report forms, the caseworker syntax and semantics, the categories and subcategories, and the coding sheet procedures.

Appendix B

COMPLAINT FORM

INFORMATION IN THIS SECTION IS CONFIDENTIAL

COMPLAINANT NAME		ALLEGED PERPETRATOR(S)			
ADDRESS		WITNESS(ES)			
TELEPHONE	COMPLAINANT'S RELATIONSHIP TO RESIDENT				
COMPLAINANT TO ACCOMPANY: ☐ YES ☐ NO					
RESIDENT(S)/CLIENT(S) NAME		ROOM #	AGE	SEX	MEDICAL STATUS (AMBULATORY, ETC.)
BILLING STATUS: ☐ VA ☐ MEDICARE ☐ MEDICAID ☐ PRIVATE					

INFORMATION IN THIS SECTION IS NOT CONFIDENTIAL.

FACILITY NAME		DESIGNEE #	METHOD OF CONTACT
ADDRESS		DATE/TIME RECEIVED	RECEIVED BY:
DATE/TIME OF INCIDENT	REFERRED TO:	DATE INVESTIGATED	TIME REQUIRED FOR INVESTIGATION

DESCRIPTION OF PROBLEM: (who, what, when, where) DO NOT USE NAMES.

Circle category 1 2 3 4 5 6 7 8 9

LOG # 9352

COMPLAINT INVESTIGATION REPORT

Category: _____

Facility Name: _____

☐ Initial ☐ Follow-up

Narrative: Action taken and findings (include dates and times - do not use names)

FINDINGS: (Check appropriate box and provide comments if needed.)

- ☐ 01 Statute or rule violation evident _____
- ☐ 02 No statute or rule violation evident _____
- ☐ 03 Unable to determine if violation occurred _____

ACTION: (Check appropriate box(es).)

- ☐ 01 Revisit Date: _____ ☐ 05 Civil penalty
- ☐ 02 Referred to: _____ ☐ 06 Administrative conference
- ☐ 03 Decertification _____ DATE ☐ 07 Letter of reprimand
- ☐ 04 License revocation _____ ☐ 08 Date investigation closed: _____

FILED BY (Signature): _____

LEA NOTIFIED: ☐ YES DATE: _____ TIME: _____ ☐ NO

DISTRIBUTION: BRANCHES-KEEP LAST COPY AND SEND BALANCE TO SSD PROGRAM OPERATIONS

SSD PROGRAM OPERATIONS SEND COPIES TO: _____

SSD 723A

Self-Neglect

37

Appendix C

CONFIDENTIALITY CERTIFICATE

TO ALL EMPLOYEES AND REGISTERED VOLUNTEERS OF THE DIVISION:

For the purposes of this certificate the term "employee" will mean all paid employees and registered volunteers of the Division.

Oregon's laws contain provisions relating to confidentiality of records, lists and information about Welfare applicants/recipients and about State employees. These laws, and the penalties for violation of them, pertain to every employee of the Division, at all levels and in any capacity. As a condition of your continued employment or volunteer services with the Division you are required to complete the confidentiality training exercise and sign this certificate verifying that you understand the laws and are aware of the penalties for violation. If at some future date you have doubts about the legality of an action you may be about to take, ask your supervisor for an interpretation. You personally are legally responsible for any violation of the laws.

Adult and Family Services Division Volume XI-01-03 contains the Agency Policy on what information may be released and the appropriate circumstance for doing so.

Confidentiality of AFS Employee Information

ORS 192.500 The Public Records Act contains a number of exemptions for information maintained on State employees including a "personal privacy exemption" which states: "The following public records are exempt from disclosure... Information of a personal nature such as that kept in a personal, medical or similar file, if the public disclosure thereof would constitute an unreasonable invasion of privacy, unless the public interest by clear and convincing evidence requires disclosure in the particular instance. The party seeking disclosure shall have the burden of showing that public disclosure would not constitute an unreasonable invasion of privacy." (ORS 196.500 (2)(b))

Confidentiality of Welfare Applicants/Recipients Information

ORS 411.300 Regulations concerning use and custody of records. (1) The Division shall make and enforce reasonable rules and regulations governing the custody, use and preservation of the records, papers, files and communications of the Division. The use of such records, papers, files and communications by any other agency or department of government or person to which they may be furnished shall be limited to the purposes for which they are furnished and by the provisions of the law under which they may be furnished.

ORS 411.320 Disclosure and use of records limited; contents as a privileged communication. For the protection of applicants for and recipients of public assistance, the Adult and Family Services Division... shall not disclose or use the contents of any records, files, papers or communications for purposes other than those directly connected with the administration of the public assistance laws of Oregon, and these records, files, papers and communications are considered confidential subject to the rules and regulations of the Adult and Family Services Division, except as otherwise provided in ORS 411.325 to 411.335. In any judicial proceedings, except proceedings directly connected with the administration of public assistance laws, their contents are considered privileged communications. (Note: ORS 411.325 and 411.330 have been voided by court action.)

ORS 411.335 Prohibited use of lists or names. No person or agency shall solicit, disclose, receive, make use of, or authorize, knowingly permit, participate in or acquiesce in the use of, any lists or names for commercial or political purposes of any nature, or for any purpose not directly connected with the administration of public assistance laws. (Note: ORS 411.325 and 411.330 have been voided by court action.)

Penalties

ORS 411.990 Penalties (1) Violation of ORS 411.320 to 411.335 is punishable, upon conviction, by a fine of not more than \$1,000 or by imprisonment in the county jail for not more than 60 days, or by both. Violation of ORS 192.500 is cause for disciplinary action under ORS 240.555.

Instructions

Employee and supervisor will sign within 3 working days of employment. Return original to the AFS Personnel Services Unit attached to the appointment personnel action (PD 124). Retain yellow copy for the employee's file. Give pink copy to the employee.

JmSeall RR 7/16/85

7900 North Washburne
Portland, Oregon 97217
February 23, 1986

Aileen Kaye
Program Coordinator
Abuse and Protective Services
Senior Services Division
313 Public Service Building
Salem, Oregon 97310

Dear Aileen,

As a follow-up to our discussion in January, I am enclosing a timeline for my research project which was developed with my research committee members. This specific information should be helpful for you as the review of the state report forms (elder abuse and protective services) approaches. When the Oregon Health Sciences University Human Subject's Committee approves the research proposal, a copy will be sent to you and other state officials for your review prior to the content analysis of 200 randomly selected SSD 723 and SSD 723A forms.

At this time, I need written verification from you on several matters. They are as follows:

- 1) The names and titles of persons other than yourself who should be officially informed of the proposed research project and who should receive a copy of the approved proposal in April,
 - 2) Copies of the yearly elder abuse and protective services report statistics for as many years as you have data,
 - 3) Permission to collect non-identifying demographic information from the "confidential section" on SSD 723 i.e. sex, age, town/city, number of perpetrators and witnesses listed, and the medical status. (The only means of identifying reports on my data collection instrument will be by "log numbers," names will not be used.), and
 - 4) Permission for my research committee members to use the sample report forms (without confidential section) for evaluation of my data collection instrument. These forms are the ones obtained from you last summer during my instrument pretest.
- Your written verification to these four issues is to be included in the research proposal prior to Human Subject's Committee review.

Thank you for your continuing assistance in this research project. Receiving your support has been very encouraging for me, especially now as the project becomes a reality.

With appreciation,


Sharon M. Beall, RN, BSN.
503-283-3089



Department of Human Resources
SENIOR SERVICES DIVISION

313 PUBLIC SERVICE BUILDING, SALEM, OREGON 97310

March 7, 1986

Sharon M. Beall, RN, BSN
7900 North Washburne
Portland, OR 97217

Dear Ms. Beall:

Thank you for your letter regarding your proposed research project on elder abuse. The answers to your four questions are as follows:

1. Please inform:

Mr. Bob Zeigen, Section Manager
Program Assistance Section
Senior Services Division
313 Public Service Building
Salem, OR 97310

2. Enclosed are copies of the yearly elderly abuse and protective services statistics.
3. You are granted permission to collect nonidentifying demographic information from the "confidential section" of the SSD 723.
4. Your research committee members are granted permission to view the sample report forms (without the confidential section) for evaluation of your data collection instrument.

Please let us know when your plans are finalized. Your interest in elder abuse is most appreciated.

Sincerely,

[Redacted Signature]

Aileen P. Kaye, Program Coordinator
Program Assistance Section, SSD

APK:jj
0734L

Enclosures

cc: Bob Zeigen
Susan Dietsche

7900 North Washburne
Portland, OR 97217
April 21, 1986

Robert Zeigen, Section Manager
Program Assistance Section
Senior Services Division
313 Public Service Building
Salem, OR 97310

Dear Mr. Zeigen:

Aileen Kaye has kept you informed of my research proposal which focuses on the following research questions:

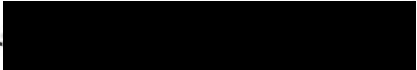
1. What are the patterns of vulnerability and risk factors associated with abuse or self-neglect of persons 65 and over living in a non-institutional community setting?
2. What referral patterns are associated with caseworker determination of substantiated, unsubstantiated, and questionable findings?

My plans are to randomly select 200 of the 1985 state report forms for this investigation of elder abuse and protective services. The forms are to be content analyzed.

I intend to submit the proposal to the Oregon Health Sciences University (OHSU) Human Subjects Review Committee next week. An exempt review will be requested because the research involves the study of existing data within records. Are there any State of Oregon policies or procedures that would pertain to this research project and dissemination of the findings? For example, will your Department accept the OHSU Human Subjects' Review, or must I submit the project to an SSD Review Board? I will mail a copy of the proposal and the Review to you as soon as possible. I would like to suggest a meeting with you the first week of May to discuss the proposal and answer any questions you might have.

I appreciate the continued interest and support of the Senior Services Division and the many individuals who have assisted me in the process.

Sincerely,



Sharon M. Beall, RN, BSN.

cc: Aileen Kaye
Susan Dietsche

Appendix D

Revised Coding Sheet for "Complaint Form" and
"Complaint Investigation Report" (SSD 723 and 723A)

Case Demographics (DEM)

ID Case number
DEM1 Log number
DEM2 1985 investigation
DEM3 Category circled
DEM4 Victim's age
DEM5 Victim's gender
DEM6 Victim's residence _____
DEM7 Number of alleged perpetrators
DEM8 Number of witnesses
DEM9 Medical status (Functional status)
DEM10 Billing status
DEM11 History of investigation

Narrative Vulnerability Factors (NVF)

NVF1 Medical Diagnosis
NVF2 Cancer dx
NVF3 Cardiac dx
NVF4 EENT
 auditory impairment
 speech impairment
 visual impairment
 other
NVF5 Endocrine dx
NVF6 Excretory dx
NVF7 Gastrointestinal dx
NVF8 Musculoskeletal dx
NVF9 Neurological dx
NVF10 Respiratory dx
NVF11A Other _____
NVF11B Other _____

NVF12A Health Status
NVF12B Problem mentioned
 fall/falls
 frail/weak/poor health
 other _____

NVF13A Impaired Mental Status
NVF13B Type Mentioned

NVF14A_____ Negative affect
NVF14B_____ Type Mentioned
 _____ angry/hostile
 _____ anxious/nervous
 _____ depression/withdrawal
 _____ fearful
 _____ other _____

NVF15_____ Negative behaviors toward caseworker
NVF16_____ Uncooperative/evasive
NVF17_____ Refuses entree' to caseworker
NVF18_____ Denies allegations
NVF19_____ Other _____

NVF20A_____ Negative behaviors toward alleged perpetrator
NVF20B_____ Type of Behavior
 _____ demanding/manipulative
 _____ verbally abusive
 _____ other _____

NVF21_____ Negative behaviors toward others
NVF22_____ Hostile
NVF23_____ Offensive
NVF24_____ Uncooperative
NVF25_____ Other _____

NVF26A_____ History of abuse
NVF26B_____ Abused by Whom
 _____ abused by others
 _____ abused others
 _____ abused self

NVF27_____ Lifestyle
NVF28_____ Substance abuse
NVF29_____ Non-compliance with medical care
NVF30_____ Non-compliance with social services
NVF31_____ Other _____

NVF32A_____ Harm/threat to self/others
NVF32B_____ Type of Harm/Threat
 _____ driving hazard
 _____ smoking hazard
 _____ other _____

NVF33_____ Medication management
NVF34A_____ Problem with medications
NVF34B_____ Type of Problem
 _____ improper meds
 _____ lack of meds
 _____ other _____

NVF35 _____ Management of personal care
 NVF36 _____ Problem with personal care
 _____ citizen complaints
 _____ other _____

 NVF37 _____ Management of toileting
 NVF38A _____ Problem with toileting
 NVF38B _____ Type of Problem
 _____ catheter
 _____ incontinence
 _____ other _____

 NVF39 _____ Management of nutrition
 NVF40A _____ Problem with nutrition
 NVF40B _____ Type of Problem
 _____ inadequate nutritional management
 _____ other _____

 NVF41 _____ Management of meal planning and prep.
 NVF42A _____ Problem with meal planning and prep.
 NVF42B _____ Type of Problem
 _____ meals-on-wheels
 _____ inadequate food supplies
 _____ spoiled foods
 _____ other _____

Narrative Risk Factors (NRF)

NRF1 _____ Social status
 NRF2 _____ Family support
 NRF3 _____ Friends/neighbors
 NRF4 _____ Community support
 NRF5 _____ Other _____

 NRF6 _____ Living situation
 NRF7 _____ Living arrangement

 NRF8 _____ Management of home maintenance
 NRF9A _____ Problem with home maintenance
 NRF9B _____ Type of Problem
 _____ cluttered/dirty
 _____ vermin/feces
 _____ other _____

 NRF10 _____ Unsafe environment
 NRF11 _____ Hazardous conditions for falls
 NRF12 _____ Hazardous conditions for fires

- NRF13__ __ Inadequate utilities
____ electricity
____ heat
____ phone
____ plumbing
____ water
____ other____
NRF14__ __ Other____
- NRF15__ __ Primary relationship of AP to
victim
- NRF16A__ __ Negative behaviors (A.P.) toward caseworker
NRF16B__ __ Type of Behavior
____ angry/agitated
____ evasive
____ denies allegations
____ refuses entree' for investigation
____ other____
- NRF17A__ __ Negative behaviors (A.P.) toward victim
NRF17B__ __ Type of Behavior

- NRF18A__ __ Negative behavior (A.P.) toward others
NRF18B__ __ Type of Behavior
____ distrusting
____ hostile/angry
____ other____
- NRF19__ __ Alleged perpetrator history
NRF20__ __ Physical health problems
NRF21__ __ Mental health problems
NRF22__ __ Family interactional problems
NRF23__ __ Employment concerns
NRF24__ __ Substance abuse
NRF25__ __ Insufficient income
NRF26__ __ Other____
- NRF27__ __ Alleged perpetrator in caregiver role
NRF28__ __ Provides personal care
NRF29__ __ Provides IADL assist
NRF30__ __ Uses community resources
NRF31__ __ Unaware of community services
NRF32__ __ Conservator, Guardian, Power-of-Attorney
NRF33__ __ Other____

Indications of Abuse or Neglect (IAN)

- IAN1 _____ Indications of physical injury/problems
IAN2 _____ Bruises/welts
IAN3 _____ Decubiti/ulcers
IAN4 _____ Dehydration/malnutrition
IAN5 _____ Laceration/cut/abrasion
IAN6 _____ Overmedicated/undermedicated
IAN7 _____ Possible head injury
IAN8 _____ Suspected fracture
IAN9 _____ Other _____
- IAN10 _____ Indications of psychological harm
IAN11 _____ Abandoned
IAN12 _____ Harrassed/intimidated
IAN13 _____ Restrained/confined
IAN14 _____ Verbally abused or threatened
IAN15 _____ Other _____
- IAN16 _____ Indications of Neglect
IAN17 _____ Inadequate personal care
IAN18 _____ Inadequate medical care
IAN19 _____ Inadequate supervision
IAN20 _____ Inadequate home maintenance
IAN21 _____ Harm/threat of harm to self
IAN22 _____ Harm/threat of harm to others
IAN23 _____ Other _____
- IAN24 _____ Indications of financial abuse
IAN25 _____ Theft money/property
IAN26 _____ Misuse money/property
IAN27 _____ Withholding finances
IAN28 _____ Inheritance pressures
IAN29 _____ Other _____
- DEM12 _____ Findings of the investigation

Outcome (OTC)

OTC1	_____	Outcome
OTC2	_____	Recommended referral
OTC3	_____	Relocation
OTC4	_____	Community services
OTC5	_____	SSD case management
OTC6	_____	Neighbor monitoring
OTC7	_____	Protective services
OTC8	_____	Risk intervention
OTC9	_____	Senior center management
OTC10	_____	Other _____
OTC11	_____	Health care services
OTC12	_____	Immediate medical care
OTC13	_____	M.D. consultation
OTC14	_____	R.N. consultation
OTC15	_____	ETOH treatment
OTC16	_____	Hospitalization
OTC17	_____	Other _____
OTC18	_____	Legal services
OTC19	_____	Arrest made
OTC20	_____	Criminal/DA referral
OTC21	_____	Attorney
OTC22	_____	Conservator/Guardian/Power of Attorney
OTC23	_____	Other _____
OTC24	_____	Refer to family
DEM13	_____	Law enforcement agency notified
QD	_____	Qualitative Data:

Codebook with Revisions
after Data Collection

<u>Var. Name</u>	<u>Var. Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
<u>Case Demographics (DEM)</u>				
ID	Case number	3	1-200	
DEM1	Log number	5	1-999999	
DEM2	1985 Investigation	1	1=1985 2=1984 3=1984 & 1985	9
DEM3	Category circled	1	1=elder abuse 2=protective services 3=both 8=other_____	9
DEM4	Victim's age	3	60-100+	999
DEM5	Victim's gender	1	1=female 2=male	9
DEM6	Victim's residence	2	1 to 34	9
DEM7	Number of alleged perpetrators	1	1-6 7=not applicable	9
DEM8	Number of witnesses	1	1-6 7=not applicable	9
DEM9	Functional status	2	1=ambulatory 2=ambulatory with aids 3=wheelchair/quad. 4=wandering 5=bedbound 6=housebound 8=_____ 9=_____ 10=1 or > medical dx 11=needs assit 12=non-ambulatory 13=old age 14=unknown	99

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
DEM10	Billing status	1	1=VA 2=Medicare 3=Medicaid 4=Private 5=2 or more	9
DEM11	History of Investigation	1	1=initial 2=follow-up 3=both	9

Narrative Vulnerability Factors (NVF)

NVF1	Medical Diagnosis	1	1=mentioned 2=not mentioned 3=suggested	
NVF2	Cancer dx	1	1=yes 2=no 7=NA	
NVF3	Cardiac dx	1	1=yes 2=no 7=NA	
NVF4	EENT	2	1=auditory 2=no 3=speech 4=visual 5=1 & 3 6=3 & 4 7=1 & 4 8=other combo 77=NA	
NVF5	Endocrine dx	1	1=yes 2=no 7=NA	
NVF6	Excretory dx	1	1=yes 2=no 7=NA	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NVF7	Gastrointestinal dx	1	1=yes 2=no 7=NA	
NVF8	Musculoskeletal dx	1	1=yes 2=no 7=NA	
NVF9	Neurological dx	1	1=yes 2=no 7=NA	
NVF10	Respiratory dx	1	1=yes 2=no 7=NA	
NVF11A	Other _____	2	1=weight loss 2=no 3=mental illness 4=recurrent dig. toxicity 5=recent triple bypass 6=retardation 7=FUO 8=terminally ill 9=Alzheimer's 10=integument 11=1 and 10 12=home health services 13=not specified 14=1 and 9 15=hypothermia and death 16=death 17=alcoholism 18=unresponsive 19=18 and 16 77=NA	
NVF11B	Other	1	1=not specified 2=no 7=NA	
NVF12A	Health Status	1	1=mentioned 2=not mentioned 3=suggested	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NVF12B	Problem mentioned	2	0=no problems 1=fall/falls/blackouts 2=frail/weak/poor health 3=hospitalized 4=recent changes 5=? survival 6=ER/mobile medical visit 7=other _____ 8=anxiety attacks 9=obesity 10=1 and 3 11=2 and 3 12=1,4,6 13=1 and 4 14=3 and 4 15=1 and 2 16=2 and 6 17=1,2,4 18=2 and 4 19=3 and 5 77=NA	
NVF13A	Impaired Mental Status	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
NVF13B	Type mentioned	2	1=cognitive impairment 2=delusions/hallucinations 3=suicidal/wish to die 4=bizarre behavior 5=mental illness/psych diag. 6= 1 and 2 7= _____ 8= 1 and 5 9= 4,5,2 10=2 and 3 11=MR/DD 12=impaired thought processes 77=NA	
NVF14A	Negative affect	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable/no visit	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NVF14B	Type mentioned	2	1=angry/hostile 2=anxious/nervous 3=depression/withdrawal 4=fearful 5=refuses relocation 6=grieving 7=homesick 8=speaks no English 9=1 and 2 10=2 and 4 11=2 and 3 12=4 and 5 13=2 and rapid pressured spch 14=1 and 5 15=3 and 6 16=3 and 7 17=1 and 3 77=not applicable	
NVF15	Negative behaviors toward caseworker	1	1=mentioned 2=not mentioned 3=suggested 7=NA/no visit	
NVF16	Uncooperative/evasive	1	1=yes 2=no 7=not applicable	
NVF17	Refuses entree' to caseworker	1	1=yes 2=no 7=not applicable	
NVF18	Denies allegations	1	1=yes 2=no 7=not applicable	
NVF19	Other _____	2	0=aware that services unavail. 1=second report same perp 2=no 3=result of investigation 4=telephone contact only 5=didn't interview 6=entree' with other 7=other _____ 8=admits and denies allegations 9=restrictive	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NVF20A	Negative behaviors toward alleged perpetrator	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
NVF20B	Type of Behavior	2	1=demanding/manipulative 2=verbally abusive 3=refuses to return to FH 4=striking out 5=protecting A. P. 6=wants caretaker constantly 7=other_____ 8=passive 9=2 and 4 10=2 and c/o serv. agency 11=fired 12=1 and 2 77=NA	
NVF21	Negative behaviors toward others	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
NVF22	Hostile	1	1=yes 2=no 7=not applicable	
NVF23	Offensive	1	1=yes 2=no 7=not applicable	
NVF24	Uncooperative	1	1=yes 2=no 7=not applicable	
NVF25	Other_____	2	2=no 3=annoying 4=combative 5=refuses home health services 6=agitated 7=worries others 8=isolation 9=left AFH 10=threat/abusive 11=left NH AMA 12=7 and 8 13= dissatisfied with placement 77=not applicable	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NVF26A	History of abuse	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
NVF26B	Abused by whom	1	1=abused by others 2=abused others 3=abused self 4=1 and 2 5= 7=not applicable	
NVF27	Lifestyle	1	1=mentioned 2=not mentioned 3=suggested	
NVF28	Substance abuse	1	1=yes 2=no 3=abstinent now 7=not applicable	
NVF29	Non-compliance with medical care	1	1=yes 2=no 7=not applicable	
NVF30	Non-compliance with social services	1	1=yes 2=no 7=not applicable	
NVF31	Other_____	2	0=not specified 2=no 3=wandering/lost 4=recent stove fire 5=forgetfulness re car 6=personality change 7=revolver for protection 8=religious beliefs=no MD 9=refuses relocation 10=manipulative 11=primitive living conditions 12=rmn/return hazardous envir. 13=disharmony in family 14=runs boarding home 15=friends move/dying 16=ineligible for \$ 17=isolation 18=financial crisis 77=NA	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NVF32A	Harm/threat to self/other	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
NVF32B	Type of harm/threat	2	0=not specified 1=driving hazard 2=smoking hazard 3=unable to care for self 4=fire as above 5=current illness 6=abusive/threatening others 7=other 8=independent/proud 9=driving and weapons 10=traffic when wanders 11=threatens others with weapon 12=3 and 8 13=2 and 8 77=not applicable	
NVF33	Medication management	1	1=independent 2=assist needed 3=dependent 7=not mentioned	
NVF34A	Problem with medications	1	1=yes 2=no 3=suggested 4=not if assisted 7=not applicable	
NVF34B	Type of Problem	1	1=improper meds 2=lack of meds 3=overmedicated 4=refuses to take 5=misuse by A.P. 6=IV tampering by A.P. 7=not applicable 8=MD adjusting 9=mismanagement	
NVF35	Management of personal care	1	1=independent 2=assist needed 3=dependent 7=not mentioned	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NVF36	Problems with personal care citizen complaints other_____	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
NVF37	Management of toileting	1	1=independent 2=assist needed 3=dependent 7=not mentioned	
NVF38A	Problems with toileting	1	1=yes 2=no 3=suggested 5=1 & 2 6=colostomy 7=not applicable	
NVF38B	Type of Problem	1	1=catheter 2=incontinence 3=diapers/depends 4=stress incontinence 5=1 and 2 6=colostomy 7=not applicable	
NVF39	Management of nutrition	1	1=independent 2=assist needed 3=dependent 7=not mentioned	
NVF40A	Problem with nutrition	1	1=yes 2=no 3=suggested 7=not applicable	
NVF40B	Type of Problem	1	0=starving self 1=inadequate nutrition 2=tube feedings 3=eye infctn, can't feed self 4=not specified 5=weight loss 6=1 and 5 7=not applicable 8=eats dog food	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NVF41	Management of meal planning and preparation	1	1=independent 2=assist needed 3=dependent 7=not mentioned	
NVF42A	Problem with meal plan. and prep.	1	1=yes 2=no 3=suggested 7=not applicable	
NVF42B	Type of Problem	2	0=not specified 1=meals-on-wheels 2=inadequate food supplies 3=spoiled foods noted 4=no food in house 5=no refrigerator 6=burning cookware 7=other 9=Sr. Center for meals 10=refuses services 11=no refrig, 2 and 3 12=M-O-W, only meal 13= no \$ for food 77=NA	

Narrative Risk Factors (NRF)

NRF1	Social status	1	1=mentioned 2=not mentioned 3=suggested (if 2, go to NRF6)	
NRF2	Family support	1	1=yes 2=no 3=unknown 4=poor 7=not applicable	
NRF3	Friends/neighbors support	1	1=yes 2=no 7=NA	
NRF4	Community support	1	1=yes 2=no 7=NA	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NRF5	Other_____	1	1=paid provider 2=no 3=FH/RCF placement 4=housekeeper/caregiver 5=Health care professional 6=4 and 5 7=NA	
NRF6	Living situation	1	1=mentioned 2=not mentioned 3=suggested	
NRF7	Living arrangement	2	1=lives alone 2=lives with spouse/partner 3=lives with relatives 4=lives with paid provider 5=whereabouts unknown 6=moving 7=NH/RCF/FH/B&B 8=2 and other relatives 9=with friends 10=visiting/visitor 11=other 12=van	
NRF8	Management of home maintenance	1	1=independent 2=assist needed 3=dependent 7=not mentioned	
NRF9A	Problem with home maintenance	1	1=yes 2=no 3=unknown 7=not applicable	
NRF9B	Type of Problem	1	1=cluttered/dirty 2=feces/vermin 3=reported, not noted 4=marginal 5=lives in one part of house 6=1 and 2 7=not applicable 8=1,2,5	
NRF10	Unsafe environment	1	1=mentioned 2=not mentioned 3=suggested 4=unknown 7=N/A	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NRF11	Hazardous conditions for falls	1	1=yes 2=no 7=N/A	
NRF12	Hazardous conditions for fires	1	1=yes 2=no 7=N/A	
NRF13	Inadequate utilities	2	0=unknown 1=no electricity 2=no problems 3=no phone 4=no plumbing 5=no water 6=no heat 7=1 and 3 10=1 and 5 11=1, 3, 4, 5 12=1, 3, 5, 6, 77=not applicable	
NRF14	Other_____	1	0=potential eviction 1=threat of murder/suicide 2=no 3=provider fear due to behavior 4=harm from another 5=inadequate support 6=intimidated by neighbors 7=N/A	
NRF15	Primary relationship of A.P. to victim	2	1=spouse 2=daughter 3=daughter-in-law 4=son 5=son-in-law 6=granddaughter 7=grandson 8=paid provider 10=2 and 5 11=friend 12=3 and 4 13=4 and 2 14=sibling 15=niece/nephew 16=unrelated 17=4 and 7 18=boarder 19=unknown 20=4 and 8 21=1 and 4 77=not applicable	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NRF16A	Negative behavior A. P. toward caseworker	1	1=mentioned 2=not mentioned 3=suggested 7=N/A	
NRF16B	Type of Behavior	2	0=not specified 1=angry/agitated 2=evasive 3=denies allegations 4=refuses entree' 5=not interviewed 6=threaten caseworker 7= 3 and 5 8=1 and 3 9=nervous and anxious 10=2 and 3 11=3 and poss expln of inf 12=2,3,4 13=1, 3,4 14=2 and 4 15=2 and 5 16=2 and suspicious 77=NA	
NRF17A	Negative behavior A.P. toward victim	1	1=mentioned 2=not mentioned 3=suggested 4=unknown 7=N/A	
NRF17B	Type of Behavior	2	0=not specified 1=unwanted 2=verbally abusive 3=reportedly hit/slap 4=depression 5=does not feed into dependence 6=denies services 7=rough handling 8=allowed envir. to deteriorate 9=exploit 10=beating 11=neglect 12=2 and3 13=threats 14=denies respon. for AV 15=confinement 16=disrespected verbally 17=1,2,3 18=2,3,9 77=N/A	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NRF18A	Negative behavior A. P. toward others	1	1=mentioned 2=not mentioned 3=suggested 4=unknown 7=N/A	
NRF18B	Type of Behavior	2	0=not specified 1=distrusting 2=hostile/angry 3=school counseling-?expulsion 4=private 5=withdrawn 6=refuses to allow visitors 7=history of theft 8=antisocial behavior 9=abuses children 10=2 and 3 11=1 and 4 12=1 and 2 13=three or more 14=1,2,9 15=1,2,8,9 77=N/A	
NRF19	Alleged perpetrator history	1	1=mentioned 2=not mentioned 3=suggested 7=N/A	
NRF20	Physical health problems	1	1=yes 2=no 7=N/A	
NRF21	Mental health problems	1	1=yes 2=no 7=N/A	
NRF22	Family interactional problems	1	1=yes 2=no 7=N/A	
NRF23	Employment concerns	1	1=yes 2=no 7=N/A	
NRF24	Substance abuse	1	1=yes 2=no 3=treatment program 7=N/A	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NRF25	Insufficient income	1	1=yes 2=no 7=N/A	
NRF26	Other_____	2	1=left area/moved 2=no 3=PPD for investigation theft 4=employment impossible 5=increase # in household 6=inappropriate decision-making 7=sleep/depression 8=? gambler 9=previous neglect 10=hates to cook 11=dependent on A. V. 12=3 and 1 13=stressed out 14=fearful of expulsion 15=numerous LEA investigations 16=Juvenile detention 17=MR/DD 18=probation 19=temper 20=weapon 77=N/A	
NRF27	Alleged Perpetrator in caregiver role	1	1=mentioned 2=not mentioned 3=suggested 4=unknown 7=N/A	
NRF28	Provides personal care	1	1=yes 2=no 7=N/A	
NRF29	Provides IADL assist	1	1=yes 2=no 7=N/A	
NRF30	Uses community resources	1	1=yes 2=no 7=N/A	
NRF31	Unaware of community services	1	1=yes 2=no 7=N/A	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
NRF32	Conservator, Guardian, Power-of-Attorney	1	1=yes 2=no 7=N/A	
NRF33	Other_____	2	1=refuses services 2=no 3=care manager 4=unscssfl attmpts to relocate 5=memory/knowledge deficits 6=placed against wishes 77=N/A 8=was, now placed	

Indications of Abuse or Neglect (INA)

IAN1	Indications of physical injury/problems	1	1=mentioned 2=not mentioned 3=suggested 4=no apparent inj/prob 5=unknown 7=not applicable	
IAN2	Bruises/welts	1	1=yes 2=no 7=NA	
IAN3	Decubiti/ulcers	1	1=yes 2=no 7=NA	
IAN4	Dehydration/malnutrition	1	1=yes 2=no 7=NA	
IAN5	Laceration/cut/abrasion	1	1=yes 2=no 7=NA	
IAN6	Overmedicated or undermedicated	1	1=yes 2=no 7=NA	
IAN7	Possible head injury	1	1=yes 2=no 7=NA	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
IAN8	Suspected fracture	1	1=yes 2=no 7=NA	
IAN9	Other_____	1	1=repeatd falls from W/C 2=no 3=inebriated 4=? rape 5=IV tampering 6=_____ 7=NA	
IAN10	Indications of psychological harm	1	1=mentioned 2=not mentioned 3=suggested 4=unknown 7=not applicable	
IAN11	Abandoned	1	1=yes 2=no 7=NA	
IAN12	Harrassed/intimidated	1	1=yes 2=no 7=NA	
IAN13	Restrained/confined	1	1=yes 2=no 7=NA	
IAN14	Verbally abused or threatened	1	1=yes 2=no 7=NA	
IAN15	Other	1	0=not specified 1=yes 2=no 3=more in household 7=NA	
IAN16	Indications of Neglect	1	1=mentioned 2=not mentioned 3=suggested 4=unknown 7=not applicable	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
IAN17	Inadequate personal care	1	1=yes 2=no 3=suggested 7=NA	
IAN18	Inadequate medical care	1	1=yes 2=no 3=suggested 7=NA	
IAN19	Inadequate supervision	1	1=yes 2=no 3=suggested 7=NA	
IAN20	Inadequate home maintenance	1	1=yes 2=no 7=NA	
IAN21	Harm/threat of harm to self	1	1=yes 2=no 7=not applicable	
IAN22	Harm/threat of harm to others	1	1=yes 2=no 7=not applicable	
IAN23	Other_____	1	2=no 3=1-3 hosp/yr. 4=removed AMA 7=NA	
IAN24	Indications of financial abuse/neglect	1	1=mentioned 2=not mentioned 3=suggested 4=unknown 7=not applicable	
IAN25	Theft money/property	1	1=yes 2=no 7=NA	
IAN26	Misuse money/property	1	1=yes 2=no 7=NA	

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<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
IAN27	Withholding finances	1	1=yes 2=no 7=NA	
IAN28	Inheritance pressures	1	1=yes 2=no 7=NA	
IAN29	Other_____	1	1=property settlement 2=no 3=unable to manage finances 4=withhold sps NH payment_ 5=? caregiver/friend 7=NA	

Findings (DEM)

DEM12	Findings of the investigation	2	0=I question the dx 1=questionable 2=substantiated 3=unable to investigate 4=unsubstantiated 5=substantiated then unsubstan. 6=subst. PS; questionable EA/N 7=subst. PS; unsubst. EA/N 8=committable 9=inappropriate case for PS 10=stable with home health care 11=D/C protective serv 12=1 and 9	99
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Outcome (OTC)

OTC1	Outcome	1	0=stable 1=no referral nec. 2 referral recommended 3=referral requested 4=unable to determine 5=witness will call if necess. 6=mediation by C.W. 7=NA 8=follow-up	9
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<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
OTC2	Recommended referral	1	0=follow-up 1=accepted 2=rejected 3=reject, then accept 4=accept, then reject 5=considering 7=NA	9
OTC3	Relocation	2	1=to family/friend 2=bed and board 3=foster home/RCF 4=nursing home 5=low income housing 6=unknown 7=not applicable 8=refused 10=Salvation Army	
OTC4	Community services	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
OTC5	SSD case management	1	1=yes 2=no 3=Salem SSD 4=ongoing 7=NA	
OTC6	Neighbor monitoring	1	1=yes 2=no 7=NA	
OTC7	Protective services	1	1=yes 2=no 7=NA	
OTC8	Risk intervention	1	1=yes 2=no 3=ongoing 7=NA	
OTC9	Senior center management	1	1=yes 2=no 3=ongoing 4=resume 7=NA	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
OTC10	Other	2	1=mental health services 2=no 3=outreach worker 4=children's services 5=meals-on-wheels 6=bank 7=OPI 8=photos 9=home health 10=respite 11=call PRN 12=SSD Dept 13=live-in help 14=C. W. from NH 15=Housing Authority 16=home health 17=NW Pilot Project 18=Home mntn volunteers 19=women's center 20=Alzh. support group 21=counseling 22=transportation 77=NA	
OTC11	Health care services	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
OTC12	Immediate medical care	1	1=yes 2=no 7=NA	
OTC13	M.D. consultation	1	1=yes 2=no 7=NA	
OTC14	R.N. consultation	1	1=yes 2=no 7=NA	
OTC15	ETOH treatment	1	1=yes 2=no 3=for care provider 7=NA	
OTC16	Hospitalization	1	1=yes 2=no 7=NA	

<u>Var. Name</u>	<u>Variable Label</u>	<u>Column Width</u>	<u>Possible Values</u>	<u>Missing Values</u>
OTC17	Other_____	1	2=no 3=MD/ER PRN 4=info re care 5=ongoing 6=autopsy 7=NA 8=home health care	
OTC18	Legal services	1	1=mentioned 2=not mentioned 3=suggested 7=not applicable	
OTC19	Arrest made	1	1=yes 2=no 7=NA	
OTC20	Criminal/DA referral	1	1=yes 2=no 7=NA	
OTC21	Attorney	1	1=yes 2=no 7=NA	
OTC22	Conservator/Guardian Power-of-Attorney	1	1=yes 2=no 7=NA	
OTC23	Other	1	1=fire department 2=no 3=committment 4=LEA PRN 5=refused 6=refused restraining order 7=NA	
OTC24	Refer to family	1	1=mentioned 2=not mentioned 3=suggested 4=unable, no info 7=not applicable	
DEM13	Law enforcement agency notified	1	1=yes 2=no 3=re investig other matter 4=LEA called SSD 5=called before SSD, not by SSD	9
QD	Qualitative data	1	1=yes 2=no	

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Appendix E

MEMO 

Date: April 24, 1986

To: Sharon M. Beall, RN, BS, BSN and
Patricia G. Archbold, RN, DNSc., FAAN
From: Donna Buker, Administrative Assistant
Committee on Human Research

EJH

Subject: Vulnerability and Risk factors Associated with elder Abuse and
Self Neglect

The above entitled study falls under category # 5 and is considered to be exempt from review by the Committee on Human Research. Therefore, I have put your study into our exempt files and you will receive no further communication from the Committee concerning this study.

If the involvement of human subjects in this study changes you should contact the Committee on Human Research to find out whether or not these changes should be reviewed.

If you have any questions regarding the status of this study, please contact Donna Buker at X7887.



IMPORTANT: Answers must be typed.

Date rec'd. _____

ORS I.D. No. _____

OREGON HEALTH SCIENCES UNIVERSITY
Committee on Human Research

PROTECTION OF HUMAN SUBJECTS
INITIAL REVIEW QUESTIONNAIRE

This information is needed to determine the human risks and potential benefits of the proposed research. The questionnaire is based on DHHS requirements for the protection of human subjects, OHSU policy, and legal considerations. All research involving humans, regardless of funding, must be reviewed. NOTE: Current DHHS regulations require that applications involving humans be reviewed by this institution within 60 days after the grant deadline. Please allow 6-8 weeks for the review process.

COMPLETE THIS QUESTIONNAIRE ONLY IF HUMAN SUBJECTS, INCLUDING HUMAN ORGANS, TISSUES, FLUIDS, OR OTHER MATERIALS, OR THE COLLECTION OF POTENTIALLY CONFIDENTIAL INFORMATION, ARE INVOLVED.

Principal Investigator (Last Name) Archbold (Advisor) Beall		(First Name) Patricia Sharon	(Initial) G. M.	Degree RN, DNSc., FAAN R.N., B.S., B.S.N.	
Department/Division Aging Family Aging Family	Rank/Academic Standing Professor Graduate Student	School Nursing Nursing	Telephone 225-8382 283-3089	Bldg./Room EJH	
RESEARCH PROJECT TITLE: Vulnerability and Risk Factors Associated with Elder Abuse and Self-Neglect					
Funding Source or Sponsor, if any * see below		I.D. No. Assigned by Funding Source			

1. Has the SAME project been reviewed before? NO.
If YES, give ORS I.D. No.: _____ Title of Project: (if different from above).

Principal Investigator: _____ Last Review Date: _____

Please note on separate attachment(s) any changes in the current protocol which differ from the previously approved protocol with regard to procedures involving human subjects (e.g., duration of study, age of subjects, study population, frequency of tests or visits, volume of blood, etc.). Federal and State regulations require that the Committee be informed of even minor changes. *If there are no changes in the current protocol, please sign here and date:*
(You need not complete the following pages.)

(Principal Investigator's Signature)

Date

- * Application submitted to Beta Psi Chapter Sigma Theta Tau for research funds.
Graduate studies funded partially by the Department of Health and Human Services
Public Health Service Grants #2A11 NU 00250-09 and #2A11 NU 00250-10.
The Office of Research Development and Utilization, School of Nursing, OHSU.

Initial Review Questionnaire

2. EXEMPTION CLAIMS:

If your study falls into one of the categories of studies exempt from IRB review, type in the exemption category number here and complete the rest of the form. (List of Exempt Categories is attached.)

Exemption claimed based upon 45 CFR 46.101 (b) # 5.

3. Study subjects will include (please check): ☐ Minors ☐ Fetuses
☐ Abortuses ☐ Prisoners ☐ Pregnant Women ☐ Mentally Retarded
☐ Mentally disabled ☒ None of the above.

4. If this study may involve any of the above special groups, check one:

☐ Use of such subjects is a necessary part of the research.

** ☒ Such subjects may be included incidentally as members of a more general population

- **It is expected that a portion of the group described as self-neglected will be mentally disabled.
5. Will this work be done if the project is not funded? ☒ Yes ☐ No.

Indicate date on which you expect to start this research:

Funding Date: _____ Other: May 1, 1986

6. Research will be conducted through or in collaboration with: PLEASE CHECK:

Clinical Research Center ☐ Primate Center ☐ VA Hospital ☐

Shriners Hospital ☐ Other Senior Services Division, Salem, OR Not Applicable ☐
(Insert name of organization)

If one of the above is checked, this questionnaire, copy of the protocol, supporting material and consent form should be submitted to the Human Research Committee of that organization, as well as the OHSU Committee on Human Research.

RADIATION:

7. Will subjects be exposed to radiation or radioisotope? ☐ Yes ☒ No.

IF YES, the investigator MUST contact the Radiation Safety Office. (The Committee on Human Research will withhold final approval until written approval by the Radiation Safety Committee has been received.)

Total Dosage in rads: _____

Date submitted to the Radiation Safety Committee: _____

8. CHARACTERISTICS OF STUDY SUBJECTS:

a. Patients ☐ Volunteers ☐

b. Age range: 65 and over

c. Estimated number to be studied: 200

d. Affiliation of source as subjects, e.g., OHSU hospital, OHSU outpatient clinics, general public, OHSU students, etc.: Senior Services Division Elder Abuse and Protective Services report forms for 1985.

9. Will the subjects be responsible for the costs incurred as a result of participation in the study. If no, explain: No, this study is a record review.

Statements of cost in the informed consent must not state or imply that charges for use of facilities, equipment, personnel or laboratory tests will be paid for or waived by the University Hospitals and Clinics unless approval has been granted by the Director of Hospital and Clinics.

Initial Review Questionnaire

10. DRUG USAGE

Will an investigational (unapproved) new drug be used? ____ Yes X No.

Will an approved drug be used for an unapproved indication? ____ Yes X No.

If YES, a) Name the drug(s) and uses:

b) Attach the data on previous human experiments, animal studies and lab tests.

c) Give the name of person/firm that hold IND and the date of IND filing:

Name: _____ Date _____

Address: _____

d) State in the consent form that records are subject to inspection by the Federal Drug Administration.

e) Sign the separate investigator's assurance below.

Obtain a copy of the Oregon State Board of Pharmacy requirements for investigational drugs. Information can be obtained from Donna Buker, X7887, MacHall 2160.

TO BE SIGNED ONLY IF SUBJECTS ARE TO RECEIVE FDA-REGULATED INVESTIGATIONAL NEW DRUGS OR DEVICES. I will obtain each subject's written informed consent incorporating the rules and requirements of the State Board of Pharmacy, filled in as approved by the institution's Committee on Human Research, maintain one copy of each completed and signed form in my files, and send additional copies to the State Board of Pharmacy as required by Oregon Law, and to the Pharmacy and Therapeutics Committee of the OHSU Hospital.

Principal Investigator _____

Date _____

11. CONFIDENTIALITY OF SUBJECT DATA:

a. If research records which identify subjects will be kept, describe measures to be taken to maintain confidentiality:

The research record (coding sheet) developed for this study identifies each state report form by its log number. Names, addresses, or other identifying information is not recorded and will not be available for this record review. The coding sheets and computer discs will be kept in a locked box

b. Will records which contain personal identification (i.e., name, address, Social Security number) of subject be transmitted outside this institution? ____ Yes ____ No. when not in use.

This information will not be transmitted outside the Salem Senior Services Division office where the report forms are kept.

Initial Review Questionnaire

12. RISKS TO SUBJECTS:

- a. Describe any physical, psychological, social, economic, or other risks to subjects, including discomfort or inconvenience:

<u>NATURE OF RISK</u>	<u>SERIOUSNESS</u>	<u>INCIDENCE/PROBABILITY</u>
None		

- b. Precautionary measures to be taken to eliminate or reduce the risks:

Not applicable

- c. Measures to be taken if complications occur:

Not applicable

13. Describe the benefits that may be reasonably expected from the proposed activity to:

- e older population:
- a. ~~The subjects:~~ provision of predictors and indicators of elder abuse and self-neglect. Improved surveillance, prevention, and/or identification of abuse and self-neglect of the older population.
- b. The advancement of scientific/medical knowledge: generate empirically the vulnerability factors and risk factors associated with elder abuse and self-neglect using substantiated cases.

14. If the study involves treatment, describe alternative treatment(s), including the benefits and risks: not applicable

15. Are you a physician or dentist? Yes X No.

If NO, attach written assurance from the physician or dentist who assumes medical responsibility for the subjects, if applicable.

not applicable

16. **REQUIRED ATTACHMENTS:** See Table of Contents

a. Protocol

- 1) **ABSTRACT:** Briefly outline objectives, methods and procedures.
- 2) **SUMMARY OF PREVIOUS RELATED WORK:** Include human and/or animal studies.
- 3) **METHODS AND PROCEDURES:** Describe in sufficient detail so that reviewers unfamiliar with the field may clearly understand what will be done with or to the subjects. If complete grant application is submitted, please list pages on which procedures involving human subjects are described.

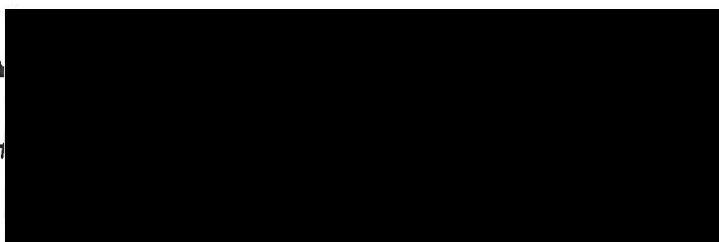
b. Informed consent form.

(The attached "Checklist of Required Information in the Consent Form" is offered as a guide in preparing an acceptable informed consent form. HHS and the Oregon Health Sciences University require that WRITTEN informed consent be obtained for ALL RESEARCH PROCEDURES INVOLVING HUMANS.)

c. Drug Brochure (for studies involving investigational new drug or approved drug for unapproved indication).

INVESTIGATOR'S ASSURANCES:

- a. I will promptly report proposed changes in the activity and any unanticipated problems involving risk to subjects, including adverse reactions, to the Committee on Human Research; and, in the case of DHHS-supported activities to the Department of Health and Human Services (through the respective granting office).
- b. I assure that documentary evidence of informed consent will be included in the medical files of the subjects after the proposed activity has been completed or discontinued.
- c. Since the Committee on Human Research is obligated to periodically review this activity, I will furnish it with relevant information when requested.
- d. I, the undersigned, will be responsible for the ethical conduct of this project, and for protecting the rights and welfare of the subjects.



Date April 22, 1986

OREGON HEALTH SCIENCES UNIVERSITY

Office of Research Services

STUDIES EXEMPT FROM FULL COMMITTEE ON HUMAN RESEARCH REVIEW

1. Research conducted in established or commonly accepted educational setting, involving normal educational practices, e.g.
 - (a) Research on regular and special education instructional strategies
 - (b) Research on the effectiveness of or the comparison among instructional techniques, curricula or classroom management methods
2. Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement
 - a. if information is recorded in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects
3. Research involving survey or interview procedures, except where all the following conditions exist:
 - a. Responses are recorded in such a way that the subjects can be identified directly or through identifiers linked to the subject;
 - b. The subject's responses, if they became known outside the research, could reasonably place the subject at risk of criminal or civil liability or be damaging to the subjects' financial standing or employability;
 - c. The research deals with sensitive aspects of subjects' behavior, such as illegal conduct, drug use, sexual behavior or use of alcohol.

All research involving survey or interview procedures is exempt, without exception, when the respondents are elected or public officials or candidates for public office.

4. Research involving the observation (including observation by participants) of public behavior, except, where all the following conditions exist:
 - a. Observations are recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subject;
 - b. The observations recorded about the individual, if they become known outside the research, could reasonably place the subject at risk of criminal or civil liability or be damaging to the subjects financial standing or employability;
 - c. The research deals with sensitive aspects of the subject's own behavior such as illegal conduct, drug use, sexual behavior or use of alcohol.

Exemption categories cont'd.

5. Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens,
 - a. if these sources are publicly available, or
 - b. if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

Even if the research is exempt from full committee review, the subjects must be informed in writing of the purpose of the study and that participation is voluntary. Some studies may not require any consent form.

When in doubt whether a study is exempt or not, please call the Chairman of the Committee on Human Research, X7743 or the Office of Research Services, X7784.

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Figure

Conceptual Model

Master's Research Project

The Oregon Health Sciences University

Sharon M. Beall

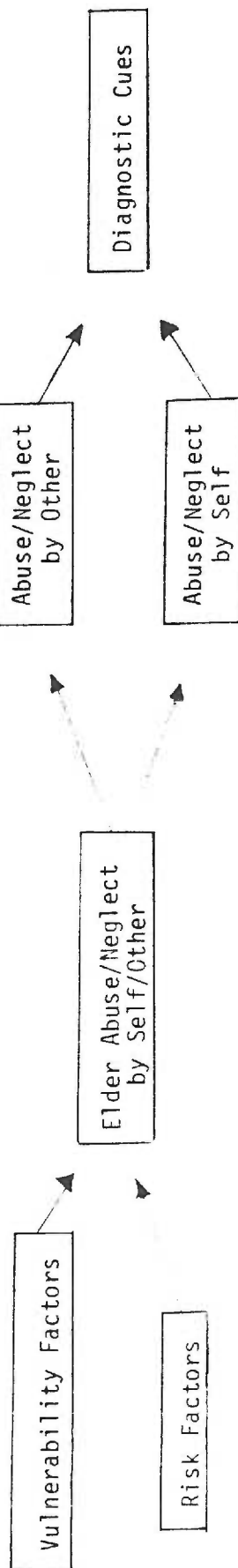
July 13, 1985

PREDICTORS

POTENTIAL

OUTCOME

INDICATORS



Abstract

Self-neglect, the inability to care for oneself in a manner that meets societal expectations, has been identified in the older population. A secondary analysis was conducted on 131 1985 state report forms which documented the self-neglect investigations. Content analysis procedures were used to collect data from caseworker narratives describing personal characteristics and environmental resources or hazards identified during the investigation. The coding sheet used in data collection differentiated these personal and environmental influences as vulnerability and risk factors. Vulnerability factors were defined conceptually as the inherent traits or characteristics of the individuals and risk factors were their interactions with the environment which increased the older person's likelihood of self-neglect (Rose & Killien, 1983). The Chi-square statistic was used to determine the differences between substantiated and unsubstantiated groups (n=78) and key vulnerability and risk factors, indicators of neglect, and referral patterns.

The findings indicate that significant differences exist between substantiated and unsubstantiated groups on the vulnerability factors of health status, cognitive impairment, history of self-neglect, and problem with personal care. Risk factors found to be significantly different based on caseworker

diagnosis of self-neglect included problem with home maintenance and unsafe environment. Differences between the substantiated and unsubstantiated groups were also noted on two indicators: physical injury or problem and indication of self-neglect; and on the referrals for relocation and legal services. Nursing assessments, which include the key variables identified in this study, are essential for the identification of older persons who are actually or potentially neglecting themselves.

Key words: Adult Protective Services, Content Analysis, Risk Factors, Self-Neglect, and Vulnerability Factors.